#### UNIVERSITY OF THE WITWATERSRAND

# AFRICAN CENTRE FOR MIGRATION & SOCIETY (ACMS)



# TOWARDS UNDERSTANDING THE EXPERIENCES OF ACCESSING ANTIRETROVIRAL TREATMENT SERVICES AMONG CONGOLESE MEN AT CLINICS IN YEOVILLE, JOHANNESBURG

## THESIS FOR THE DEGREE OF MASTERS OF ARTS (MA)

## BY COURSEWORK AND RESEARCH REPORT

BY

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# Epigraph

For all the time I will be remembering your words: "Be blessed my children and keep on serving God. By the time, people will be running towards you for help be prepared to assist them..."

My father Daniel Swamba Omba: May 08<sup>th</sup>, 2001

# **Declaration**

I, Adrien BAZOLAKIO SWAMBA, do hereby declare that this research report titled: "*Towards understanding the experiences of accessing antiretroviral treatment services among Congolese men at clinics in Yeoville, Johannesburg*" is my own unaided work. It is submitted in partial fulfillment of the requirement for the degree of Master of Arts in Forced Migration at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination at any other university.

Adrien BAZOLAKIO SWAMBA

March 22<sup>nd</sup>, 2013

(Name of Candidate)

(Date of Submission)

# Dedication

To you **Miss Annekkie Duplessis**, your devotion and assistance towards the wellbeing of my family and I is immeasurable.

#### Abstract

Little is known about the experiences of Congolese men receiving antiretroviral therapy (ART) services in the urban areas of South Africa. Johannesburg is home to many non-citizens who left their home country because of political or human rights reasons and in search of better economic opportunities in South Africa. In South Africa, adult HIV prevalence is highest in urban areas: 9% in formal urban areas and 18% in informal urban (Shisana et al., 2005). South Africa has one of the highest rates of HIV infection and has the largest public sector antiretroviral programme with the health system enrolling a great number of people living with HIV for antiretroviral therapy (Boulle et al., 2008). Non-citizens have the same rights as South African citizens to access free ART services; however, challenges in access antiretroviral treatment for non-citizens have been documented (McCarthy et al., 2009).

This research project explores the following question: What are the treatment experiences of Congolese men who are currently well and receiving ART services at a government and at a non-government clinic in Yeoville Johannesburg? The study involves interviewing six Congolese men receiving antiretroviral therapy services and twelve healthcare providers at a government, the primary healthcare clinic and at a non-government clinic. Nazareth HIV clinic. Understanding the experiences of Congolese men and non-citizens is valuable to contribute to the literature on the role of male health seeking behaviour, access to healthcare, and treatment experiences in Johannesburg inner city. The primary objective of this study is to explore the treatment experiences of Congolese men receiving ART services at a government and at a non-government clinic in Yeoville. The study takes a qualitative approach and collects data in the Yeoville clinic (a government primary healthcare clinic) and in Nazareth House HIV clinic (a non-governmental clinic) in the Yeoville suburb of Johannesburg inner-city.

Findings from this research reveal different treatment experiences with respect to access - opening and closing hours, documentation, services available; other factors - including support networks, secrecy and stigma; and, survivalist livelihoods that affect access dimensions of Congolese men on ART at the two clinics.

Recommendations are made on access dimensions: Extending opening and closing hours of the clinic, giving the training to frontline healthcare providers on the rights of migrants on access to healthcare services including antiretroviral therapy services, and extending number of staff members. On other factors: Providing soup kitchen, shelters and extended campaigns on HIV related services to non-citizen patients on antiretroviral therapy services at the clinic, are ways to solve some challenges face by beneficiaries who access to antiretroviral therapy in both government clinic and non-government clinic in Yeoville, Johannesburg.

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In 2007, I first arrived in Johannesburg, South Africa leaving behind me my family despaired, later on my family rejoined me, together with many challenges surrounding the City of Johannesburg: My South African friend, Miss Annekkie Duplessis, lecture at South Africa University (UNISA) did not leave my family and I suffer, you did a lot to all my family to carry on in Johannesburg: May you find here my gratitude? To you my mother, Modiri-Onde Catherine your love to me is inestimable. To you my wife, Olga Kidima Mabanza what have I done without your love, companionship and patience? Your relationship to me is the God's will. To you my children: Exaucé Bazolakio, Karen Bazolakio and Emmanuella Bazolakio; I am grateful and sensitive for your fervent prayers for this study to be completed. To you my brothers and sisters: Mafoto Katerousse, Anna Wasolwa, José Walongo, Charlotte Sibazolakio, Mbokoso, Perpetie Nsele and Inde Swamba; I say many thanks to all of you on what you have done for me and my family. I would like to say many thanks to family: Kitutu's, Lakika's, Kandonda's, Tabala's, Kidima's, Koyundu's, Kikata's, Tayeye's, Muni's, Tshibanda's, Wutufwa's, Mavungu's and Makayabu's for all kinds of your supports to me. To you, Anna Mubobo and Willy Pangu who first received me in South Africa, find my gratitudes. To you my beloved father Daniel Swamba, brothers Samuel Omba and François Swamba; sister Louise Watuvanakio whom destine has taken you away early from the rest of members of the family you did not have time to see me completing this study; REST IN PEACE!!!

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# List of Acronyms /Abbreviations

| ART: Anti-Retroviral Therapy                               |
|--|
| COJ: City of Johannesburg                                  |
| CoRMSA: Consortium for Refugees & Migrants in South Africa |
| DRC: Democratic Republic of Congo                          |
| FOCAS: Forum of Congolese Organizations in South Africa    |
| HCT: HIV Counseling and Testing                            |
| HIV: Human Immuno-deficiency Virus                         |
| HRW: Human Rights Watch                                    |
| HR: Human Rights   |
| ID: Identity Document                                      |
| IOM: International Organization of Migrants                |
| JHB: Johannesburg  |
| MSF: Médecins Sans Frontière                               |
| NDOH: National Department of Health                        |
| NGO: Non-Governmental Organization                         |
| NH: Nazareth House   |
| PHC: Primary Healthcare Clinic                             |
| PEP: Post Exposure Prophylaxis                             |
| RSA: Republic of South Africa                              |
| STI: Sexually Transmitted Infections                       |
| TB: Tuberculosis   |
| UNAIDS: United Nations Programme on HIV/AIDS               |

UNHCR: United Nations High Commissioner for Refugees

# Chapter One: Introduction and background to the study

# **1.1 Introduction**

Since the end of apartheid and the onset of the democracy in 1994, South Africa has become a primary destination for many migrants from across the continent and beyond for several reasons. Some have come searching for protection and others have migrated for economic opportunities (Landau & Wa Kabwe-Segatti, 2009). In South Africa, the City of Johannesburg is the primary destination and home to many migrants some of whom are refugees and asylum seekers (Vearey, 2008). South Africa has an estimated overall HIV prevalence of 17,3% with about 5,600,000 million people living with HIV in 2011 (UNAIDS, 2012). Adult HIV prevalence is highest in urban areas: 9% in formal urban areas and 18% in informal urban areas (Shisana et al., 2005). South Africa has one of the highest rates of HIV infection and has the largest public sector antiretroviral programme in the world (Boulle et al., 2008). The programme has enrolled 1.79 million people which represents 80% of people whom are in need of antiretroviral therapy in South Africa (Johnson, 2012). Noncitizens have the same rights as South African citizens to access free ART services (McCarthy et al., 2009). However, challenges in accessing to antiretroviral therapy for noncitizens have been documented (CoRMSA, 2008; HRW, 2009; McCarthy et al., 2009; MSF, 2009; Vearey, 2008).

In-migration in South Africa is a livelihood-seeking strategy for many poor households (Vearey, 2011). Many migrants hope to have better economic opportunity for them and the rest of their family's members back home. In South Africa, the city of Johannesburg is an ideal place for many migrants to find a better livelihood opportunity. "The City of Johannesburg is the motor of national growth and roughly four million people live in it" (COJ, 2011:31). While most of migrants are attracted by better livelihood opportunities that the city of Johannesburg offers them, HIV prevalence remains higher than in rural areas (Vearey, 2008). Since early 1990s; South Africa became a preferred country of transit to Western Europe and North America for the Congolese middle class (Steinberg, 2005). With immigration policy of those regions tightening during 1980s that option could not work for many of Congolese to travel and use South Africa as a transit country (Steinberg, 2005).

By end of 2011, it was estimated that 16,970 Congolese migrants from the Democratic Republic of Congo were registered as asylum-seekers and refugees in South Africa (UNHCR, 2012). The socio-economic and political situation of Congolese has deteriorated since the fall of the former president Mobutu in 1997. After Mobutu, a series of wars in the Democratic Republic of Congo has led to political instability and economic crisis with consequences on the abuse of human rights that are causing many of Congolese to seek peace security and safety outside of the country's borders (Lakika, 2011). A substantial part of the Congolese community in Johannesburg is concentrated in Yeoville's suburbs (Vigneswaran, 2007). In South Africa, there are different categories of international migrants holding a range of temporary visitor permits including work and study permit; among them refugees and asylum seekers, and those without documents (Landau & A. Wa Kabwe-Segatti, 2009). All of them are referred in this study as non-citizens. The following section gives the research question and objectives.

### **1.2 Research question and objectives**

This study explores the treatment experiences of Congolese men on antiretroviral therapy at clinics in Yeoville, Johannesburg. This research project explores the following question:

What are the treatment experiences of Congolese men who are currently well and receiving ART services at a government and at a non-government clinic in Yeoville Johannesburg?

This question will be explored through the following objectives:

- To explore the experiences of Congolese men in accessing antiretroviral therapy (ART) services at a government and at a non-government clinic in Yeoville, Johannesburg.
- To determine whether there is a difference in acceptability, affordability and availability of access to ART services among Congolese men accessing treatment at a government and at a non-government clinic in Yeoville, Johannesburg.
- To gain insight into the role of social networks, livelihood activities, income, housing, and food security play in the treatment experiences of Congolese men accessing ART services at a government and at a non-government clinic in Yeoville, Johannesburg.

 To contribute to understanding the experiences of Congolese men accessing to ART services at the clinics in Yeoville, Johannesburg. The following section presents the justification of the study.

# 1.3 Justification of the study

Little attention is given to the experiences of non-citizen (Congolese) men who access antiretroviral therapy services in Johannesburg, South Africa. There is a large body of literature about women and children who access healthcare, HIV prevention, support or antiretroviral therapy services. Men do not have the same health seeking behavior as women who routinely access healthcare services (Galdas, Cheater, & Marshall, 2005). The Yeoville's suburbs in Johannesburg has two clinics; one is the public primary healthcare clinic known by most of members of the community as "Yeoville clinic" and the other is non-government clinic called "Nazareth House HIV clinic", known by the Yeoville community members as "Nazareth House". At Nazareth House HIV, McCarthy et al. (2009) conducted a clinical study whose findings revealed that cross-border migrants have better antiretroviral therapy outcomes than citizens.

Yeoville is an ideal place for most Congolese to live because of the social networks, affordable accommodation and a large cultural concentration. In addition, the majority of Congolese who live in Yeoville are men (Mavungu, 2007). Yeoville presents a lot of challenges to the Congolese community because living conditions are difficult and prevalence of HIV is higher (Lakika, 2011; Shisana et al., 2005). With this in my mind; I came to a decision to investigate the experiences of Congolese non-citizen men accessing antiretroviral therapy services at the clinics in Yeoville, Johannesburg. This allows me to highlight the cultural dimensions of Congolese non-citizen men accessing antiretroviral therapy services, despite the many challenges they are facing in Yeoville, Johannesburg. This research report aims to contribute to four key areas:

- 1. Understanding the experiences of Congolese non-citizen men receiving antiretroviral therapy services at a government and at a non-government clinic in Yeoville, Johannesburg.
- 2. Exploring the differences in access to ART services at a government and at a nongovernment clinic in Yeoville, Johannesburg.

- 3. Understanding the cultural dimensions of Congolese non-citizen men accessing antiretroviral therapy services at a government and at a non-government clinic in Yeoville, Johannesburg.
- 4. This understanding is useful to health practitioners, policy makers, and decision makers in developing and/or improving mechanisms of antiretroviral therapy services that take into account the different experiences of men, non-citizens and in rising future research in accessing antiretroviral therapy services. The following section presents organization of the study.

# **1.4 Organization of the study**

The present research report is structured into six chapters. The first chapter introduces the research report, gives the aims and the background of the study. The second chapter reviews the literature used to conceptualize the study; the third chapter highlights tools that guide this research report access dimensions theory and other factors, social constructionist theory; the fourth chapter presents the research methodology; the fifth chapter gives findings and discussions of the study and the sixth chapter provides the general conclusion and recommendations that ends the research report. The following section presents the literature review.

## **Chapter Two: Literature review**

# **2.1 Introduction**

This study situates itself within the literature on treatment experiences of Congolese noncitizen men in the context of South Africa which provides a rich framework for this study. A wide range of literature has been examined to frame this study and make sense of the findings. The chapter comprises eleven sections: The first section is the introduction that sets up the chapter; the second section provides the profile and the living conditions of Congolese in Johannesburg, South Africa; the third section presents migration and HIV history in South Africa; the fourth section describes migration in Johannesburg; the fifth section highlights access to healthcare services; the six section presents access to public healthcare services in South Africa; the seventh section focuses on access to documentation and treatment in South Africa; the eighth section underlines on access to housing in South Africa; the ninth section presents men and access to healthcare services; the tenth section focuses on HIV related stigma and discrimination; and the eleventh section that ends the sections describes the social support networks to access healthcare services. The following section provides the profile and the living conditions of Congolese in Johannesburg, South Africa.

# 2.2 Profile and the living conditions of Congolese in Johannesburg, South Africa

In the City of Johannesburg, Yeoville; Congolese community constitutes the largest portion of Congolese men (Mavungu, 2007). There is a saying among Congolese community living in Yeoville: "Oyo eza mboka ya bana na bana" meaning that "there are no fathers around us, the fathers are left at home"; is a popular saying among Congolese which shows that Yeoville constitutes of young men (Mavungu, 2007:18). Amisi and Ballard (2005:1) argue that Congolese's community in South Africa constitutes the largest group of refugees who have fled what has become known as "Africa war", that is the cause of deaths of around three million people".

In South Africa, there is way to identify Congolese community members with their traits. These traits include Congolese's languages, accent and poor English, clothing that is button up on their own style, appearance, hairstyles that are differently from citizens and way of walking (Amisi, 2006). Most Congolese community's members have high levels education but they struggle to find jobs corresponding to their qualifications, like some other noncitizens who struggle for their daily socio-economic living conditions (Lakika, 2011). In addition, many Congolese are found in informal activities that includes cutting hair and hairdressing in salons, trading and hawking, shoemaking and repairing, security industry and car guarding and the provision of transport services such as taxis, as well as productive activities like manufacturing (Lakika, 2011). In informal activities, many Congolese work under conditions that disregard the South African labour law in terms of contract and working conditions (Amisi, 2006). For this reason, both Congolese employed and employers have the benefit of not making complaint (Amisi, 2006). In formal activities Congolese's community face problem with documentation and they need like some non-citizens to conform to the South African's law that requires people to produce first proper documentation to access public services that many non-citizens struggle to get from the Department of Home Affairs in South Africa (Landau, 2005).

According to Lakika (2011), the Congolese community in Johannesburg lives in difficult conditions. They face the same suffering as other non-citizens in South Africa with limited livelihood opportunities, incapacity to access services such as health, poor provision of documentation from the Department of Home Affairs and everyday xenophobia experienced in institutions and public sectors (Amisi and Ballard, 2005). Like other non-citizens living in Johannesburg, Congolese's community experience everyday xenophobia. Crush and Tawodzera notice that in public healthcare sectors, healthcare providers need a patient to produce identification whenever she/he seeks healthcare. In this, they ask for identification, not in order to see the name or the address of the patient but with the purpose of knowing the patient's national origins, whether is eligible to the treatment or the patient has the legal right of staying in the country (Crush and Tawodzera, 2011). Despite, in the City of Johannesburg many Congolese prefer to access free healthcare in the public healthcare facilities as they cannot find money for the private's clinics that are expensive as they are living under harsh socio-economic conditions (Lakika, 2011). Many Congolese like other non-citizens rely on private's landlords for their accommodation as most have refugee's status or asylum seekers paper that are sometimes ignored in the public sectors, the Department of Housing (Greenburg and Polzer 2008). In the City of Johannesburg, many Congolese live in Yeoville where accommodation is affordable for many of them as they can share a flat or a room with their fellow Congolese. In addition, Congolese who come for the first time with less financial resources or without any resources at all can easily find themselves in security with their familiar community to kick start their new lives (Mavungu, 2007). The following section presents migration and HIV history in South Africa.

#### 2.3 Migration and HIV history in South Africa

About migration and HIV history, Anarti, (2005); MacPherson & Gushulak, (2001) state that migration is a central determinant of health. Lurie continues that in South Africa, the growing of HIV epidemic is associated with the role of the migration in the spread of HIV is that migrant men become infected away and return to infect their rural partner back home (Lurie, 2006). There is a number of different reasons are found on this growing of HIV epidemic in South Africa that include poverty (Peberdy and Dina, 2011). However, non-citizens are often blamed by citizens as being carriers of diseases, including HIV from home to their country of destination (Harper & Raman, 2008).

In addition, non-citizens are perceived by citizens as an additional burden for healthcare services in South Africa (Southern African HIV Clinicians Society and UNHCR, 2007 in Vearey, 2011). As a result, non-citizens may be denied healthcare, including antiretroviral therapy services in South Africa (CoRMSA, 2008; McCarthy et al., 2009). Yet, research conducted in the City of Johannesburg suggests that non-citizens leave to the country of destination healthy and no one comes in urban areas for healthcare seeking; they come for other reasons than health (Vearey, 2011). Also, 2008 findings from a cross-sectional household survey conducted in Johannesburg revealed that non-citizens prefer to go back home when they are too sick to be looked by their relatives and less than 5% of non-citizens would not prefer to bring a sick relative to join them in the city (Carrasco, Vearey, & Drimie, 2011). The following section describes migration in Johannesburg.

#### 2.4 Migration in Johannesburg

Migration in the City of Johannesburg, South Africa is "circular" or "oscillating" migration's between rural to urban areas or vice versa and the movement of across borders that is illustrated as seeking livelihood opportunity in the urban areas (Vearey, 2011). The City of Johannesburg is characterized as a reservoir for many non-citizens who are refugees and asylum seekers (Vearey, 2008). The City of Johannesburg has increased in urban poverty within the rise in unemployment since the post-apartheid period that poor survive through both economic and non-economic strategies (Beall et al. 2000). Many non-citizens have the skills and have the willingness to work in the City of Johannesburg but they are systematically excluded from the jobs and income generating opportunities in formal and informal mechanisms (Landau, 2007). With limited and exclusion job opportunities for many non-citizens; they accept jobs that are below the minimum wage or in inhumane conditions as some employers do not recognize their papers or their professionals' qualifications (Landau, 2007). Migration in the City of Johannesburg, South Africa is livelihood-seeking strategy for many poor households (Vearey, 2011) and access public healthcare services for non-citizens is limited by the lack of proper documentation from the Department of Home Affairs known as " one of the most corrupt Departments during the apartheid period under Minister Buthelezi (Landau 2007: 66). The following section introduces access to healthcare services.

#### 2.5 Access to healthcare services

The right to access the healthcare system for non- citizens are provided on a certain number of legislative guidelines and frameworks in South Africa. In South Africa, there are still considerable inequities in access to healthcare services (Harris et al., 2011). The concept of access to healthcare services is itself complex. Some authors refer to the concept of access to healthcare services as the entry point into or use of the healthcare system, while others believe that the concept of access to healthcare services describes factors influencing entry or use of the healthcare system (Penchansky & Thomas, 1981).

Within this, access to healthcare services is socially constructed, as people are surrounded within social, political, and economic systems that shape behaviours and access to resources necessary to maintain health (Israel et al. 1998). From the constructivist paradigm's view, there is multiple; socially constructed realities that are influenced by social, cultural, and historical contexts that individuals are connected in such a way that the findings are inseparable from their relationship (Israel et al. 1998).

The concept of access to healthcare services is a multidimensional concept (McIntyre, Thiede, & Birch, 2009); this refers to "the degree of fit between the clients and healthcare system" (Penchansky and Thomas 1981: 128). The concept of access to healthcare can be summarized into more specific areas of fit between the healthcare system and the clients (Penchansky & Thomas, 1981). These are what Penchansky and Thomas called the specific areas, dimensions of access that include availability, acceptability and affordability (Penchansky & Thomas, 1981). These three dimensions of access to healthcare are similar to the three points of the triangle that shapes the concept of access to healthcare services that McIntyre and colleagues called "A-frame" (McIntyre et al., 2009). Access to healthcare system and the individual perspective (McIntyre et al., 2009). Once the concept of access is understood in this way, access allows people to be in command of appropriate healthcare services that improve their health (Gulliford et al., 2002). The three dimensions of access to healthcare services that services have different meanings in the healthcare system.

Availability refers to as an appropriate healthcare service available in the right place and at the time that it is needed. In addition, healthcare system factors such as location of healthcare facilities, readiness to provide mobile services or carry out home visits to the clients' place, degree of fit between the hours of opening the clinics (McIntyre et al., 2009). In this study, availability refers to as opening and closing hours, documentation, services available and human resources at the two healthcare facilities – the government primary healthcare clinic and the non-government clinic. Availability means clients may have access to services (Gulliford et al., 2002).

Acceptability refers to as the reasons for provider choice, clients' satisfaction and health system perception (Penchansky & Thomas, 1981). This dimension of healthcare access looks at the relationships between the expectations of the healthcare providers and the clients at the clinics. The focus is placed on providers' expectations that the clients should have respect for their professional status and comply with their prescribed treatment (McIntyre et al, 2009). In return, the clients expectations that the healthcare providers should treat them with respect, listen to their symptom description carefully; and expectation that the clients should have access to receive the treatment needed (McIntyre et al., 2009). In this study, it looks at the healthcare providers and clients attitudes towards respect and expectations at the clinics.

Affordability refers to as the financial aspect of access to healthcare, whether the health service is properly charged to match the individual's capacity to pay for it (McIntyre et al., 2009). This dimension of access to healthcare looks at the degree of fit between the costs used at the clinics and the ability of the clients to pay (McIntyre et al., 2009). It looks at activities that require out of pocket money of the clients for their healthcare services (Harris et al., 2011). Affordability to healthcare system looks at the relationship of prices of services, income, and ability to pay the services (Penchansky & Thomas, 1981). In this study, affordability refers to the distance and the travel mode of the clients to the healthcare facilities and the duration of time spent at the clinic. The following section describes access to public healthcare system in South Africa.

#### 2.6 Access to public healthcare system in South Africa

South African's healthcare system has two challenges that overburden its public healthcare services. These are the massive shortages of healthcare staff and the struggle to deal with the HIV/AIDS epidemic (Cullinan, 2006). Massive shortages of healthcare staff still persevere within the public healthcare system (Coovadia, Jewkes, Barron, Sanders, & and McIntyre, 2009). All patients who are using the public healthcare system are now only able to access higher levels of care once they have assessed and referred upward by healthcare providers (Cullinan, 2006). At a lower level, the exemption is made to medical emergencies as it is the first point of entry for people who need to access public healthcare service in the primary healthcare facilities at the primary level treat what healthcare providers call ambulatory patients, or people who are to walk and do not need to be confined to bed (Cullinan, 2006). Cullinan states that since April 1996, access to public healthcare services at the first level is free of charge (Cullinan, 2006). It constitutes:

- A Clinic that is defined as a facility at and from which a range of Primary Health Care (PHC) services are provided, but that is normally open only 8 hours a day. Certain staff may, however, be required to sleep at or near the clinic so that they are available on call in case of emergency (Cullinan, 2006).
- A Community Health Centre that is defined as a facility that, in addition to a range of other PHC services, normally provides 24 hours maternity and accident and emergency services, and up to 30 beds where patients can be observed for a maximum of 48 hours. There are procedure rooms but not an operating theatre, patients are given general anesthetics, and they are admitted as inpatients in the community health centers (Cullinan, 2006).

According to Cullinan (2006), the primary level services are supposed to cover a comprehensive range of preventive, promotional, curative and rehabilitation services. Both clinics and health centres are to offer services such as mother and child care, immunization, family planning, treatment for sexually transmitted infection (STIs), minor trauma and care for those with chronic illnesses. In South Africa the Primary Health Care services are run by nurses, although doctors visit many clinics regularly.

When a more specialized level of care is needed, patients have to be referred to secondary level or hospital or by clinic staff (Cullinan, 2006). The following section presents access to the documentation and treatment in South Africa.

#### 2.7 Access to the documentation and treatment in South Africa

A lack of documentation constitutes an obstacle for non-citizens to access public services including healthcare services in South Africa (CoRMSA, 2009). Without proper documentation in public healthcare services, hospital or clinic staff members are not available to provide treatment to those who need it (Landau, 2005). This situation is not what the South African law says but a situation creates by the healthcare providers who do not respect legal legislations of access healthcare services in the public healthcare in South Africa. Yet, legal legislations in South Africa - including a memo from the Department of Health - provide the right to healthcare services and to antiretroviral therapy to everyone without producing South African documentation (DOH [South Africa], 2006). The South African Constitution provides on section 27(3)(RSA., 1996: 27(3)) that no one may be refused emergency medical treatment (South Africa Constitution, 1996). The National Health Act (2003) and the Constitution guarantees everyone in the country, without any discrimination, the right to health; The National Department of Health confirms that patient do not need South African ID, to access healthcare services and antiretroviral therapy (NDOH, 2006); the refugee act that gives the same right to healthcare to all migrants with refugee status in South Africa; the refugees Act (1998). While, rights to healthcare system in South Africa for non-citizens are developed and ensured, the practice on the ground does not follow (Vearey, 2011). Many non-citizens continue to face challenges in accessing the healthcare system, some healthcare facilities continue to request ID books for access to public healthcare; others refused to give antiretroviral therapy to non-citizens (McCarthy et al., 2009; Vearey, 2008). However, the South African's government fails to give to its policies effective protection as the practice on the ground, at clinic level, does not follow the legal legislations (Landau, 2006). In the public healthcare facilities, frontline healthcare providers make the own decisions regardless the legal policies handled down by the hierarchy to respect the legislative guidelines and frameworks (Moyo, 2010). In the private clinics or non-government clinics healthcare providers are not strict to documentation as they are interested to have money or to provide charitable healthcare services. The following section presents access to housing in South Africa.

#### 2.8 Access to housing in South Africa

In South Africa, the Department of Housing does not offer accommodation to non-citizens (CoRMSA 2009; Greenburg and Polzer 2008). Access to housing is one of the main concerns of many non-citizens (Landau, 2005). Many non-citizens live in conditions of overcrowding and share their accommodation with other family members (Mpedi & Smit, 2011). In addition, non-citizen migrants have a tendency to move from one accommodation to another (Mpedi & Smit, 2011). Most non-citizens cannot afford safe accommodation because they do not have good jobs and proper documentation to support them (Landau, 2005). They live in overcrowded accommodation that is a risk for many communicable diseases (Ahmed, Arabi, & Memish, 2006). In fact, there is epidemic of cholera in accommodation associated with crowded living conditions that limited sanitation (Zuckerman, Rombo, & Fisch, 2007). Despite, many non-citizens lack the ability to become self-sufficient to afford safe and secure accommodation with good conditions of sanitation (Landau, 2005). As a result, many renters rely on private landlords who overcharge them because of overcrowding people and taking opportunity of their inability to be landlords due to a lack of proper documentation (Landau, 2005). The following section describes men and access to healthcare services.

#### 2.9 Men and access to healthcare services

Traditionally, men and women access healthcare services differently (Galdas, Cheater, & Marshall, 2005). Within gender inequality in access to healthcare services, men are taking the risks by being unconcerned about their health (Galdas, Cheater, & Marshall, 2005). Men consider going to the healthcare services when their body can no longer hold out or when they are convinced that they are no longer in control of their health (Mavhu et al., 2010). Contrary to Banks who argues that men do care about their health issues but they often find it difficult to express their fears that are the cause for them to tend their healthcare services later than their counterpart women. In addition, this phenomenon is made worse by social class inequalities (Banks, 2001).

According to UNAIDS (2010), men have their socio-economic role as household providers and with their masculinity they do not want to leave to work for treatment out of fear of losing their job or income. In addition, they prefer to look for money first as their responsibility to the family is often perceived as connected with financial support instead of staying in the queue in the clinic for their own health problem. The following section highlights issue of HIV-related stigma and discrimination.

#### 2.10 HIV-related Stigma and discrimination

HIV-related stigma and discrimination limit people living with HIV/AIDS to access to HIV related services and to good adherence of antiretroviral therapy services (Skinner and Mfecane, 2005). People living with HIV/AIDS avoid rumors, social rejection and people to know that they access healthcare facilities; even if these healthcare facilities have other specialized services then HIV/AIDS services by the community members (Marinankunda, Loos, & Alou, 2009). Patients living with HIV/AIDS find themselves comfortable when they disclosed at least to one person whom they trust and they do not want to disclose to the larger members of their community that they belong (Daftary, Padayatchi, & Padilla, 2007). For example, married men insist to their spouses to keep confidential of their HIV positive to avoid discrimination (Daftary et al., 2007). They avoid potential social reactions of others when they talk about their HIV status in their community (Kalichman et al., 2007). Sometimes, people of the community have strong negative judgmental attitudes on people living with HIV (Cloete, Simbayi, Kalichman, Strebel, & Henda, 2008). With this, they are isolated as their family members or community members distance themselves from them because of their HIV status (Mitchell, Kelly, K.J.M., Potgieter, & Moon, 2007). They are themselves stigmatized because of other members of the community attitudes (Mbonu, Van den Borne, & De Vries, 2009). They are stigmatized to take their ARVs when they do not have anything in their stomach that affects their adherence to the treatment (Unge et al., 2008). The following last section underlines social support networks to access antiretroviral therapy services.

#### 2.11 Social support networks to access antiretroviral therapy services

Social support networks are generally seen as an enabling factor for engagement in healthcare services, including access to antiretroviral treatment services (Mkant, 2005). The sources and types of support are most effective in specific situations and most effective when offered by specific types of people for successful engagement in healthcare services (Gigliotti, 2002; Hamilton, Razzano, & Martin, 2007). There are two categories of sources of social support networks-formal and informal; the former consists of professional support systems (healthcare and social service providers) and the latter of family, friends, and other community organizations such as church (Waddell & Messeri, 2006). In managing most chronic diseases such as HIV/AIDS, informal social support networks, particularly relatives, are acknowledged as critical sources of social support (Berkman & T., 2000; Hamilton et al., 2007; Kaplan & Toshima, 1990). Availability of support from family members improves the probability of people living with HIV to access healthcare services; regardless of whether they were already receiving or not receiving support from supplementary HIV services (Waddell & Messeri, 2006). However, in the case of HIV treatment with patients who are non-citizens, such relationships often become more complex, and both relatives and nonrelatives may be part of the informal support systems involved in HIV/AIDS care giving (Johnston D, Stall R, & K., 1995; Knowlton, Hua W, & C., 2005). For example, a 2007 access study highlighted the role of the family members and friends in directing non-citizens to access antiretroviral therapy services in Johannesburg, South Africa (Vearey, 2008). The following section is chapter three that gives essential tools that guide the research report.

# **Chapter three: Theoretical framework: Access and other factors**

## **3.1 Introduction**

The review of the literature outlines substantial theoretical resources centered on the issue of access dimensions and other factors. The literature builds on the conceptual framework on access theory and the social constructionist theory.

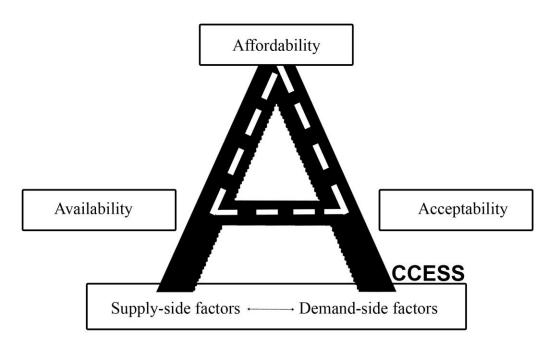
The access theory to healthcare provides three dimensions of access healthcare availability, acceptability and affordability (Schneider, McIntyre, Birch and Eyles, 2006) that form the key concept and discussion of this theoretical framework (see figure 1 below). Without these three dimensions to healthcare services, it is difficult to evaluate the perspective of individual who needs to access healthcare services (McIntyre et al., 2009). Availability of services in this study refers to as opening and closing hours, documentation, services available and human resources at the two healthcare facilities. Information on availability of services is a key issue when individual needs to access to healthcare services; individual's decision to go the clinic healthcare services depends on whether the services are available or not (McIntyre et al., 2009). Opening and closing hours refer to the time that the healthcare facilities and client are available to access healthcare services at the clinic. Documentation refers to as the documents which clients are required to possess or present in order to be seen for care.

Human resources refer to as different staff members available at the clinic who facilitate the client to access services needed. Acceptability of services refers to as respect and expectations between the healthcare providers at the clinic. McIntyre and colleagues indicate acceptability as attitudes of the healthcare providers towards the clients and the clients towards the healthcare provides (McIntyre et al., 2009). Respect looks at the considerations that healthcare providers give to the clients when they come to access healthcare services and clients' considerations to the healthcare providers. Expectations refer to as the way clients need to be receiving the treatment from the healthcare providers and the healthcare providers need the clients to comply with what the requirements of the treatment are. Affordability relates to as the mode of transport to the clinic and time spends at the clinic. Mode of transport refers to public or private vehicles that clients use to access to healthcare facilities.

Time spent at the clinic refers to as the duration that takes for a client to be assisted by the healthcare providers when s/he is at the healthcare facilities. These three dimensions form the concept of access relies on "the degree of fit between the clients and healthcare system" (Penchansky and Thomas 1981: 128) at the healthcare facilities.

#### Figure 3.1.1: Access dimensions to healthcare services in the healthcare

system



Conceptual framework on access to healthcare (Schneider, McIntyre, Birch and Eyles (2006:5)

The figure above shows how the healthcare system is accessible and illustrates the three dimensions that address the healthcare system and build individual confidence in the health system (McIntyre et al., 2009). With this conceptual framework on access to healthcare system, individuals with seeking behaviours are connected with multiple realities that are socially constructed and influenced by social, cultural, and historical contexts that the findings cannot be disconnted from their relationship (Israel et al. 1998).

The social constructionist theory perceives the discourse about the world not as a reflection of the world but as an object of mutual exchange. In Addition, Social Constructionist review is primarily about clarifying the processes by which people come to describe, explain, or otherwise account in the world they belong themselves (Gergen, 1985). An effective access healthcare services in the healthcare system is perceived by individual as a common exchange between access dimensions and other factors.

Other factors include support networks, secrecy and stigma; and survivalist livelihoods that form the understanding of the treatment experiences of Congolese men on the antiretroviral therapy services in the healthcare system. The support networks are important factors that affect people on antiretroviral therapy services within its role of engaging them in healthcare services (Mkant, 2005). Secrecy and stigma are factors that affect people on antiretroviral services with limitation and good adherence of antiretroviral therapy services (Skinner and Mfecane, 2005). The survivalist livelihoods that affect people on antiretroviral therapy services to cope with their daily living situation in the healthcare services for example, when they do not have anything in their stomach that affects their adherence to the treatment (Unge et al., 2008) or where there is an epidemic of cholera in accommodation associated with crowded living conditions that affects their sanitation (Zuckerman, Rombo, & Fisch, 2007). The following section concludes the chapter three.

#### **3.2 Conclusion**

The research report provides the literature on treatment experiences of non-citizen men on antiretroviral therapy servives in the healthcare system in the context of South Africa. To frame this study to make the sense of the findings, a range of literature selected provides this study with the rich theorical frameworks on access dimensions theory and social constructionist theory. Access dimensions theory looks at the three dimensions of access to healthcare availability, acceptability and affordability in the healthcare system (Schneider, McIntyre, Birch and Eyles, 2006). Social constructionist theory builds on other factors that affect people to access heathcare services. Social constructionist theory looks at the way people construct support networks, secrecy and stigma; and survivalist livelihoods in the healthcare system that form their confidence on effective access healthcare services in the healthcare system.

There is not a clear understanding of the experiences of Congolese men receiving antiretroviral therapy services at the clinic without these two theories access dimensions theory and other factors, social constructionist theory in South African healthcare services. The following section introduces chapter four, reseach methodology.

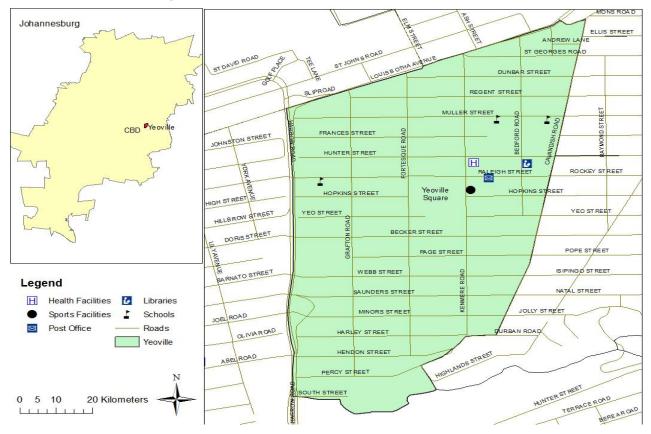
# **Chapter Four: Research methodology**

# **4.1 Introduction**

In this chapter, the methodology used to collect data from different participants to understand the experiences of Congolese men on antiretroviral therapy is discussed. Congolese men on antiretroviral therapy and healthcare providers were the target population for this study. The chapter comprises eleven sections. The first section introduces the chapter; the second section gives snapshot of the participants; the third second presents the sites of the study; the fourth gives the research design; the fifth describes the population, sample, choice of the participants and the scope of the study; the sixth section describes the language used during the interview process; the seventh section highlights interpretative thematic analysis and comparative analysis; the eighth section presents ethical considerations; the tenth section presents limitation of the study and the eleventh section is the conclusion and ends the chapter. The following section gives the sites of the study.

# 4.1 Sites of the study

#### 4.1.1 Yeoville Map



SOURCE: http://www.s4.brown.edu/southafrica/Reports/Johannesburg/Yeoville.pdf

This study takes in Yeoville, Johannesburg situates in the Central Johannesburg, South Africa. Yeoville is Central Business District (CBD) also called a central activities district. In Yeoville, there is a non-government clinic, the Nazareth House Clinic and a government Primary Healthcare Clinic (PHC), the Yeoville clinic where by the study takes place.

#### 4.1.1.1 Nazareth House HIV clinic

Nazareth House HIV clinic is a charity non-government clinic situates on corner Webb and Grafton in the suburbs of Yeoville. Nazareth House HIV clinic days and Hours are: Mondays to Fridays from 8:00 am to 5:00 pm. It provides antiretroviral therapy services and HIV counseling and Testing (HCT) for people who are in need of it. It has an Outreach Programme and hospice. The Outreach Programme provides food parcels, closing, and blankets and counseling to AIDS patients. The hospice provides healthcare to some patients on antiretroviral therapy who do not have their relatives in Johannesburg, South Africa. Since 1894, Nazareth House was established in Johannesburg, Gauteng with the first objective that was to care for orphans during the period of the 19<sup>th</sup> century rush. Over the time, Nazareth House has become clinic for HIV/AIDS patients that 80 per cent are non-South African (Nunez and Wheeler, 2012). The Southern African Catholic Bishops' Conference (SACBC) AIDS Office that began its ARV treatment programme in 2003 with the funding from CORDAID which laid the foundation for the PEPFAR funded programme begun in 2004 that ends its funded programme in May 2013. Over 45.000 patients have been initiated on treatment, with most of them now having been captivated by the clinics under the Department of Health (SACBS report, Dec. 2012).

#### 4.1.1.1.2 The Primary Healthcare Clinic (PHC): The Yeoville clinic

The Primary Healthcare Clinic, the Yeoville clinic is a government clinic in the Central Johannesburg, South Africa. It is one of the region F clinics in the city of Johannesburg. It is situated on corner Kenmere and Hoskins street in the suburbs of Yeoville. Yeoville Clinic days and hours are: Mondays to Fridays: 8:00 am to 4:00 pm. The clinic has a range of services: Family planning, Tuberculosis (TB), HIV Counselling and Testing (HCT), Health for men, Chronic services, Sexual Transmitted Infections (STI), Post exposure prophylaxis (PEP), Curative services, Trauma and Emergencies, Vitamin a supplement, Child health that includes immunisation, antenatal services, prevention of Mother to Child Transmission and Woman 'health. In the city of Johannesburg region F clinics; the Primary Healthcare Clinic is supported by nongovernment.

In the Yeoville clinic, there is a project called ANOVA that provides HIV related services for men. This project belongs to Health Institute that works with South African's Department of Health to extend free services for men who have sex with men (MSM), addresses the sexual health needs of men in general, gay, bisexual men and other men who have sex with men in South Africa; it also provides the STIs management and antiretroviral therapy to only patient men. The following section presents the research design of the study.

## 4.2 Research design

The research methodology used in this research is qualitative. Being qualitative in nature, this study sought to bring new insights on treatment experiences of Congolese men on ART services in South Africa's government and non-government clinics. Attitudes, interests, personal problems, mood, motivations, frustration, experiences are comparatively complex and therefore more difficult to capture quantitatively hence the study used a qualitative approach (Baumgartner & Clinton, 1998). The choice of qualitative approach is made because it permits to study in depth and details (Patton, 1987), the experiences of Congolese men who access antiretroviral therapy services. There are many challenges in accessing Congolese men on antiretroviral therapy services under this study. I predict some challenges that mat happen in accessing Congolese men on ART under this study. First, it is difficult to know when a Congolese man on ART comes at the clinic to collect his medication or see the healthcare providers as each patient on ART has his own date to collect the medication or consult with the healthcare providers. Second, it is difficult at the clinic to know who Congolese man is and who is not, although Congolese men have some traits (Amisi, 2006). Sometimes, it is confusing to approach a man who is not a fellow Congolese man like people may bear a resemblance to many ways. Third, it is difficult for a patient man to open up at the first contact with a stranger or a person he sees for the first time. Four, most men in general, Congolese men seem to be busy due to the responsibility they have in the households. They prefer to leave the clinic as soon as possible when they are done with the clinic. They can avoid somebody to delay their time for what they did not plan.

#### 4.2.1 Interviews

Face to face in-depth interviews with participants were used to explore their experiences regarding access to antiretroviral therapy services at a government and at a non-government clinic in Yeoville. Participants expressed themselves "in a way ordinary life rarely affords them" (Family Health International et al., 2005: 29). The questions were asked in following the order of the respondent's narratives with sufficient flexibility to enable the interviewer to probe responses where relevant. A semi-structured interview schedule was used during the month of November, 2012 and January, 2013 (see attached semi-structured interviews in the appendix). Open-ended questions were also utilized to investigate and encourage detailed response from participants instead of "Yes" or "no". Also, the open ended questions examined whether Congolese men experienced HIV/AIDS stigma. My first contact and the rest of the time of the view of the participants. All these variety of factors used in order to establish a good relationship with the participants. 18 in-depth interviews were conducted with the staff members and clients at the clinic settings, in a private room. The average duration of my interviews was 30 minutes.

#### 4.2.2 Observation

Observation is interested both in knowing what those diverse perspectives are and in exploring the interaction among them. "Observation is the empirical research method available because it allow us, first-hand, what people do, think, and believe, in their group" (Alder and alder, 2003:42). People in a group do not behave on the same way; they act and react differently (Family Health International, Mack, & Woodsong, 2005). I used observation in this study not as part of the methods of ethnographic, participant observation but as non-participant observation techniques. This non participant observation technique (Fabian, 2008; Hammersley & Atkinson, 2007) involves that researcher observes the participants without being involved in their activity. At clinics, I used to come before their opening time; I stood up near the gate as all patients who need access to services till they open then I entered and continued my observation. I observed at the clinics, the wearing of the hat was frequent for men in general, in particular Congolese men who come to collect drugs. Also, the throwing away of the package that contains the drugs in the dustbin before they leave the premises of the clinics.

#### 4.2.3 Field notes

The field notes are way to manuscript certain participant observations activities such as casual or unprompted interviews and observation; it is taken directly into the field notes book (Family Health International et al., 2005). Some informal conversations with some participants at the premises of the clinics are important for the researcher to get insight of the treatment experiences of Congolese men on ART under this study. Some informal observations activities were written in the field notes book in order to strengthen the research report. Family Health International et al., (2005), state that field notes are handwritten notes that later the researcher changes it into computer files. A field note is a diary of the research report. Being aware of the importance of the field notes on the research, I created the list of things that I focused on and what information was important to match the objectives of my study.

#### **4.3 SNAPSHOT OF PARTICIPANTS**

The snapshot of participants is presented in two tables below. The first table gives the profile of each staff at the two clinics and the second tables, the profile of each client, Congolese men on ART at the two clinics. To keep their identification protected, a pseudonym is allocated to each of the participants on this research report.

# Table 1: STAFF AT NAZARETH HOUSE AND AT THE YEOVILLE CLINIC

Staff members from different African countries women and men working at the two clinics participated in this study. Their profiles are given in this table below:

| Name              | Sex | Age | Origin  | <b>Reason/Migration</b> | Length              | Role at                      | Legal Status in     |  |  |
|-------------------|-----|-----|---------|-------------------------|---------------------|------------------------------|---------------------|--|--|
|                   |     |     | Country | in JHB,RSA              | of time             | the clinic                   | RSA                 |  |  |
|                   |     |     |         |                         | at                  |                              |                     |  |  |
|                   |     |     |         |                         | clinic              |                              |                     |  |  |
| Mpumi (NH)        | F   | 43  | Zambia  | Job                     | 9 years             | Nurse                        | Residence in<br>RSA |  |  |
| Helene (NH)       | F   | 45  | RSA     | Job                     | 8 years   Counselor |                              | South African       |  |  |
| Posha (NH)        | F   |     |         | Job                     | 6 years             |                              |                     |  |  |
| Henrietta<br>(NH) | F   | 39  | DRC     | War                     | 7 years             | Nurse                        | Refugee status      |  |  |
| Precious<br>(NH)  | F   | 36  | DRC     | Job                     | 3 years             | Facilitator<br>Support<br>gp | 5                   |  |  |
| Ngoyi (NH)        | M   | 46  | DRC     | Job                     | 4 years             | Doctor                       | Residence in<br>RSA |  |  |
| Lebo (PHC)        | F   | 40  | RSA     | Job                     | 7 years             | Nurse                        | South African       |  |  |
| Rita (PHC)        | F   | 38  | RSA     | Job                     | 4 years             | Counselor                    | South African       |  |  |
| Sipho (PHC)       | М   | 39  | RSA     | Job                     | 4 years             | Adm.<br>Ass                  | South African       |  |  |
| Kweto (PHC)       | М   | 36  | RSA     | Job                     | 1 year              | Doctor                       | South African       |  |  |
| Maria (PHC)       | F   | 45  | RSA     | Job                     | 3 years             | Counselor                    | South African       |  |  |
| Justice (PHC)     | М   | 25  | RSA     | Job                     | 1 year              | Clerk                        |                     |  |  |

#### Source: Fieldwork

The table 1 above reveals that there are twelve staff who participated in this study at the two clinics, six at a non-government clinic, Nazareth House and six at a government clinic, the primary healthcare clinic, the Yeoville clinic. The oldest staff member was 45 years and the youngest was 25 years old though, one staff member did not want to reveal her age. She had the right to refuse to respond on this question as it was written on participant information sheet that "participation in the study is voluntary, the participant has the right to refuse to respond to the question that she/he feels uncomfortable". However, she did not look to be less than 18 years old. The findings reveal that all participants in this study fit to the exclusion and inclusion criteria fixed under the study that says: "Only a staff member/or client at the clinic over 18 years who is allowed to participate in this study".

The table 1 shows that at the two clinics, staff members who work at the two clinics in Johannesburg come from different African countries. Findings support the argument that migration in the City of Johannesburg, South Africa is "circular" or "oscillating" migration's between rural to urban areas or vice versa and the movement of across borders that is illustrated as seeking livelihood opportunity in the urban areas (Vearey, 2011).

The reasons of migration in the City of Johannesburg the table reveals, that all staff members at the two clinics stated that they have migrated in Johannesburg for job opportunities, except one staff member from the Democratic Republic of Congo stated that she came in Johannesburg for another reason than Job. Findings support the argument that in-migration in South Africa is a livelihood-seeking strategy for many poor households (Vearey, 2011).

Concerning the length of time working at the clinic, the longest length of time working at the two clinics was nine years and the shortest was one year. None of the participants was less than 3 months by the time this study was conducting. Findings support the argument this study fixed for selecting participants: "Only a staff member who has been at the clinic for more than 3 months was eligible to participate in this study".

The table 1 also reveals that between the two clinics, at the government clinic all staff are South Africans compared to Nazareth House, there are different staff members from other African countries who are working. Findings reveal that in South Africa, there are limited and exclusion job opportunities for many non-citizens in public sectors that many noncitizens accept jobs in informal sectors whereby their professionals' qualifications are taken in considerations by the employers (Landau, 2007).

# Table 2: CONGOLESE MEN AT NAZARETH HOUSE AND AT THE YEOVILLE

#### **CLINIC**

Some Congolese men on antiretroviral therapy services who are living in Yeoville, Johannesburg accepted to participate in this study. Their characteristics are provided in this table below.

| Name            | Age | Origin | Reason of<br>Migration<br>into South<br>Africa | Year<br>of<br>arrival<br>in<br>RSA | When<br>found<br>HIV<br>positive | Where<br>tested for<br>HIV for<br>the first<br>time | Reason<br>for HIV<br>testing | How<br>long<br>on<br>ART | Legal<br>status in<br>RSA |
|-----------------|-----|--------|--|------------------------------------|----------------------------------|---|------------------------------|--------------------------|---------------------------|
| Antoine<br>(NH) | 32  | DRC    | Job  | 2008                               | 2008                             | RSA/NH  | Rash                         | 4<br>years               | Asylum                    |
| Paul<br>(NH)    | 48  | DRC    | War  | 2003                               | 2008                             | RSA/JHB   | ТВ                           | 4<br>years               | Refuge                    |
| Jeremy<br>(NH)  | 42  | DRC    | Human right                                    | 2001                               | 2009                             | RSA/NH  | Weight<br>loss               | 3<br>years               | Refuge                    |
| Marcel<br>(NH)  | 38  | DRC    | Job  | 2007                               | 2010                             | RSA/NH  | Hepatitis                    | 2<br>years               | Undo.                     |
| Eric            | 49  | DRC    | Job  | 2006                               | 2010                             | RSA/PHC   | ТВ                           | 2                        | Refuge                    |

| (PHC) |    |     |    |      |      |         |    | years |        |
|-------|----|-----|----|------|------|---------|----|-------|--------|
|       |    |     |    |      |      |         |    |       |        |
| Edo   | 31 | DRC | HR | 2007 | 2010 | RSA/PHC | TB | 2     | Refuge |
| (PHC) |    |     |    |      |      |         |    | years |        |
|       |    |     |    |      |      |         |    |       |        |

Source: Fieldwork

The above table 2 reveals that there are six Congolese men who participated in this study at the two clinics, four at a non-government clinic, Nazareth House and two at a government clinic, the primary healthcare clinic, the Yeoville clinic. This study targets only client men from the Democratic Republic of Congo (DRC) receiving antiretroviral therapy services and living in Yeoville, Johannesburg at these two clinics. The study wants to understand the cultural dimensions of Congolese non-citizen men accessing antiretroviral therapy services at the two clinics. As the literature informs that men do not have the same health seeking behavior as women - who routinely access healthcare services (Galdas, Cheater, & Marshall, 2005). The oldest Congolese man was 49 years and the youngest was 31 years old. Findings support the criteria of the study that says: "Only a Congolese man on antiretroviral therapy living in Yeoville and receiving ART services at the clinic over 18 years who is allowed to participate in this study".

There are some reasons that some Congolese men under this study fled their countries and come to South Africa. Some Congolese men said they fled their country to South Africa because of searching for jobs opportunities, others said for searching protection as they run war and human right abused. Findings support argument that some migrants in South Africa have come searching for protection and others have migrated for economic opportunities (Landau & Wa Kabwe-Segatti, 2009). Also, a largest group of Congolese who have fled their country is because of what has become known as "Africa war", that is the cause of deaths of around three million people" (Amisi and Ballard 2005:1).

Many Congolese men in this study have come to South Africa between 2001 and 2008. Findings reveal that in-migration of Congolese in South Africa has started for a long time as South Africa has become for a long time a preferred country of transit to Western Europe and North America for some Congolese middle class (Steinberg, 2005). To the question to find out when, where and for what reason Congolese men on ART under this study found that they are HIV positive? The table shows that Congolese men under this study found that they are HIV positive between 2008 and 2010 that falls between two and four years, before this study to be conducted. Findings reveal that Congolese men on ART found out that they are HIV positive when they are in South Africa and they tested for different reasons when they were sick with TB (Tuberculosis), weight loss, rash, and hepatitis. No Congolese man tested before outside of South Africa, they know that they are HIV positive when they are in South Africa like many non-citizens who do not test at home they test when they come in South Africa (Vearey, 2008). Congolese men on ART, like other men sick come to access healthcare services when it is late and while they are already sick (Banks, 2001). Congolese men like other men come to access healthcare services when their body can no longer hold out or when they are convinced that they are no longer in control of their health (Mavhu et al., 2010).

To the question to legal status in South Africa, many Congolese men reported holding refugee status, asylum seeker and some Congolese men reported being undocumented. Findings support the argument that South Africa has different categories of migrants (Landau & A. Wa Kabwe-Segatti, 2009). Also, the table shows that none Congolese man interviewed reported having South African's residence permit while some Congolese men interviewed have been in South Africa for more than eight years. Findings support the argument that the challenge to get South African's residence permit or proper documentation comes from the Department of Home Affairs known as " one of the most corrupt departments during the apartheid period under Minister Buthelezi (Landau 2007: 66). The following section gives the population, sample, choice of the participants and scope of the study.

# 4.4 Population, sample, choice of the participants and scope of the study

The focus on Congolese men aimed at contributing to the literature on non-citizen men and their experiences of access antiretroviral therapy services in urban areas, in Johannesburg inner city. The choice of Congolese men on ART and the suburbs of Yeoville in this study were based on some reasons. First, Congolese men are taken as a case study of non-citizen men in South Africa whom treatment sometimes are denied in public sectors. Second, most Congolese who have migrated into South Africa are men and a large number of them live in Yeoville, Johannesburg (Mavungu, 2007; Steinberg, 2005).

Third, Yeoville, in Johannesburg is where adult HIV prevalence is highest in urban areas: 9% in formal urban areas and 18% in informal urban(Shisana et al., 2005). Fourth, Congolese men who live Yeoville and are in antiretroviral therapy services have two alternatives to access healthcare services; either Nazareth House HIV Clinic or the Yeoville Primary Healthcare Clinic that are located in Yeoville.

Fifth, McCarthy and colleagues who conducted a clinical study among South African and non-citizens on antiretroviral therapy used a non-government clinic: Nazareth House HIV Clinic that is located in Yeoville (McCarthy et al., 2009).

I intended to interview at the clinics 10 Congolese men on antiretroviral therapy services (5 Congolese men in Nazareth House and 5 Congolese men in Yeoville primary health care), it was difficult to access them. I interviewed 6 Congolese men (2 Congolese men at the Yeoville clinic and 4 Congolese men at Nazareth House).

In order to know more on the experiences of Congolese men who access antiretroviral therapy at the clinics; I interviewed 12 healthcare providers (6 healthcare providers at Nazareth House and 6 healthcare providers at the Yeoville clinic). Exclusion and inclusion criteria for all the participants under the study were that, only Congolese men or staff at the clinic over 18 years who has been receiving/providing antiretroviral therapy for more than 3 months was eligible to participate in the research study. The research participants were recruited using purposive and snowball sampling methods as I knew the population that fits the criteria of my study was difficult find (Penrod, Preston, Cain, & Starks, 2003). I had the first contact with the staff in order to establish a good relationship. I had help from the staff in the clinic to identify and to be introduced to the first patients. The stigma surrounding HIV sometimes makes difficult for people to come out openly and declare their status to people they are meeting for the first time. Participants, who are identified using purposive sampling at first contact, were requested to identify others who fit into research criteria. At this point, it was sometimes difficult for the participants identified at the first contact to introduce me to their colleagues as each of participants has his day of the appointment at the clinics and comes on his time that the first participants ignored. At all the time it happened, I stood up in queue and I was attempting to approach kindly all men till I find a man who suited to the criteria of the study and I invited him to voluntary in-depth interviews. There is a need to indicate that the result from the current study cannot be generalized due to the small size of this sample.

However, the results of this study contribute and add to others to understand the experiences of men who access to antiretroviral therapy services in the urban space. The following section presents the languages used during the interviews process.

# 4.5 Language used during the interviews process

English is recommended and is an official language that is used in all public sectors in South Africa. Interviews were conducted in three languages English, French and Lingala that is a vernacular language spoken by majority of provinces in Democratic Republic of Congo (DRC). English was used for staff members who do not speak French and Lingala. At Nazareth House, some of the staff members are from DR Congo interviews were in French and Lingala. At home, the two languages are often mixed for those of the Congolese community members who speak them. In South Africa, majority of Congolese mix English, French and Lingala when they are speaking among fellow's Congolese. It was a privilege for me to meet some of the staff members who speaks Lingala at Nazareth House.

It allowed me to collect rich data as Congolese staff members master Lingala. Congolese men preferred French and Lingala during the interviews as they could feel comfortable with the two languages. Some of Congolese men could speak in English since they are living in South Africa but the flow of the words could not follow as in their home languages. After interviews, of those in French and Lingala were transcribed within 24 hours into English. Some of the direct quotations are left in French and Lingala but explained in English for the better understandings of the readers who do not have a background in French or Lingala. I would like to indicate that some Congolese community members mixed French, Lingala and English in the same sentence during the interviews. With my background in the three languages, I can capture what is important for the study. The following section describes the interpretative thematic analysis and comparative analysis.

# 4.6 Interpretative thematic analysis and comparative analysis

Interviews were analyzed by the means of interpretative thematic analysis (Vicsek, 2007). Themes from interviews were analyzed to shed light on experiences of access ART services of Congolese men at the clinics. Given that different individuals during interviews contributed differently, analysis included a valuation of the comparative inputs that different participants made to the overall responses and the social changes likely impacted upon levels of the participation (Parker & Tritter, 2006). Resemblances and differences on the participants' responses were identified at the courses of interviews. Through which key themes were identified.

Evaluation of resemblances and differences of the experiences of participants were analyzed and compared regarding interpretative thematic analysis and comparative analysis. First, responses from the participants were gathered and secondly, divided into different key themes that emerged. The unit of analysis was the individual as the study's primary focus was to explore the treatment experiences of Congolese men on antiretroviral therapy services. Each of the staff members and the clients owned particularities through the interview that other participants did not have. The following section gives the roles of the researcher in the study.

# 4.7 Reflexivity: Roles of the researcher

Being outsider and insider in the study is complex and difficult to manage. I looked at myself as a member of Yeoville's community, Congolese, man, non-citizen, facilitator of a big Congolese community organization in South Africa: Forum of Congolese Organization in South Africa (FOCAS) and researcher.

My different roles in the research could change the way data was collected. According to Gray (2009: 498), "reflexivity involves the realization that the researcher is not a neutral observer, and is implicated in the constructed of the knowledge".

In this regard, what to do and not do during all the process of the research report was carefully explored.

Being a member of Yeoville's community, I was aware of the living conditions of Congolese in this community. The networks among Congolese in Yeoville are very strong, the more participants stay in this community, the most the networks are developed and expanded. Information share in the Yeoville's community does not take long to be shared among other Congolese community's members. It is easy to find a next-of-kin, a relative from Congo who comes to stay in this community. In Yeoville, most Congolese share rooms or dwellings. In this case, English is not fluently spoken among Congolese who are sharing the same accommodation. Those of Congolese, who stay with only Congolese in this community, face a lot of difficult to communicate with other members of the community who do not share the home language spoken in Congo.

Being a Congolese in this community, most of the Congolese were curious to see me at the clinics. Participants wanted to know the reason of my presence in the clinics. Some of the Congolese on antiretroviral therapy wanted to know about my presence at the clinic I explained to those Congolese who approached me the reason of my presence of being at the clinics, of the researcher. Many of women who were under treatment seem to be curious on the nature of the research, some Congolese men came themselves to be interviewed. But the criteria did not allow to some of them to participate to the research. Some of the women promised me to be introduced to their husbands who were also under antiretroviral therapy. For my first time at the clinic, few patients were men and none of the patient men was a Congolese. I wondered where to get patient men from Congo in this study.

Being a man and non-citizen, I was affected by participants' experiences on the antiretroviral therapy. Congolese men have to take ARVs for the rest of their life, in host country; it is difficult for them. However, I could only contain my feelings and emotions to continue with the process of collecting data.

Being a facilitator of a big Congolese community organization in South Africa, I was attempting to construct participants' experiences on antiretroviral therapy as everlasting pains away from their home.

As a researcher, I have trusted scientific, researchers and scholars in the domain of health; they all could help participants to cope with their status of HIV positive and to continue to live their normal lives through the improvement of the science. All these different roles taken in the study, could affect the data collected in this study. Nevertheless, these weaknesses are insignificant and cannot challenge the validity of the findings of this study because the study aimed to give new insights on the experiences of access antiretroviral therapy of Congolese men on antiretroviral therapy services at the clinics in Yeoville, Johannesburg. The following section presents the ethical considerations of this study.

# **4.8 Ethical considerations**

The study received an ethical clearance from the University of Witwatersrand Medical Ethics Research Committee (HREC-Medical), this in order to comply with the university's requirements. Firstly, the application to the Human Research Ethics Committee (HREC-Medical) was submitted and the Ethical approval was obtained from the University of Witwatersrand Medical Ethics Research Committee (protocol M120849, see attached in appendix). Secondly, the researcher obtained the permission from the City of Johannesburg and Gauteng province to conduct the research at the Yeoville Primary Health Care (see attached in the appendix) and also, permission has been obtained from Nazareth House (see attached in appendix). It was important that the rights of the participants are respected. I took the following ethical issues into consideration:

# 4.8.1 Confidentiality and anonymity of participants

Confidentiality and anonymity of the participants were guaranteed to individuals who participate in the study. All activities done during all the process of data collection at the clinics remained secret between me and the participants who completed interviews.

At less, I recognized that it difficult to assure the guarantee of individuals in group settings for example, in the case of focus group discussions.

But for this study, only one-on-one interviews were conducted in a private location. This private space was given to me by the staff members in charge of the room at the clinic.

There were not a lot of rooms at the clinics, anytime that I had a Congolese man who accepts to complete the interview I asked the permission to use one of the rooms at the clinic that was not occupied. In the private room, I could assure the confidentiality and anonymity for individuals who completed the interviews.

A pseudonym was assigned to each of the participants during the interviews. I asked the participants to state their pseudonym if possible each time that they responded to the interviews. This is in order to protect them against potential harm action at the clinic. This aspect of ethics was made clear in the information sheet and consent form as attached in the appendix of this study.

#### 4.8.2 Informed consent

Within the informed consent, all the participants understood what participating in this research meant for them. Participants decided in a conscious, deliberate way whether they wanted to participate. Informed consent was used as a tool in order to ensure respect to all the participants during the process of the research (Family Health International et al., 2005). I ensured that for face-to-face interviews with the participants, each participant obtained (written or verbal) consent to ensure that their participation was of a voluntary nature. The written consent form was transcribed from English to Lingala and French languages spoken for all Congolese staff member and Congolese men. At home Congolese do not speak English; most of them find it a difficult language. This way, I ensured that their participation was voluntary. Then, the researcher requested permission to record interviews. Separate consent for recording was obtained from participants. All was written on the information sheet that participants kept with them. Information such as: the tapes will be kept for 2 years after the publication is done or for 6 years if no publication results are available. Some people could not read and write what was on the consent form. The informal (verbal) consent from the participants was obtained to ensure that their participation in the study was of a voluntary nature.

By October 2012, I received my Ethical approval from the University of Witwatersrand Medical Ethics Research Committee and I started my data collection in November because I was waiting permission from the two healthcare facilities before I start my field work.

The time I started, I was using informal (verbal) consent to the participants to ensure that their participation in the study was of a voluntary nature. There was not a problem while I was using this verbal consent form to the participants.

In November, one month after starting my field work; the Medical Ethics Research Committee required me to use logged verbal consent to all participants and to stop with the informal (verbal) consent. On the logged verbal consent form introduced by the Medical Ethics Research Committee, it was mentioned that two witnesses have to sign to valid that a participant has accepted to complete the interview. This new logged verbal consent form was not accepted by the participants; most Congolese men rejected this new form and they simply preferred to walk out of the room that was available for the interview.

Yet, many Congolese men were willing to participate in this study after introducing myself to them, they gave their informal consent but discouraged by the logged verbal consent. Most Congolese men if not all, were not favorable to see two persons to sign on their form for them to participate in interview. This is how a Congolese man rejected logged form consent:

"When you explain to me that you are doing your research about Congolese men in ART I accepted to participate to because I am one of Congolese men on ART in this clinic [The Yeoville Clinic] I always come alone; People around do not know that I am HIV positive and I am on ART; Why do you plan to expose me to people who do not know my HIV status and respect me? [He stood up and shut the door...] (Field notes of Thursday 8<sup>th</sup> November, 2012).

The findings illustrate the difficulties that I was going through all the time that a participant accepts to complete the interview and refuses to see other people to sign on his form for him to participate in interview. Most Congolese men did not want more than two people in the room that was allocated for the interview. Some Congolese men interrupted their conversation when they feel that a staff member wants to get into the room for other purpose than to hear what was going on in the private room.

The logged consent form delayed my time of data collection at the clinics and confused most Congolese men who were contacted at the clinic.

During this time of refusal of logged consent form by most Congolese men at the clinics; my supervisor, Dr. Joanna Vearey was informed time to time on what was going on the fieldwork and she was promising me to find the solution for it. It seemed to me that the University of Witwatersrand Medical Ethics Research Committee (HREC-Medical) kept on pushing researchers to use logged consent form, as it took some times for this situation be solved.

With informed consent form, participants were informed of the objectives of the study; no one was remunerated in any manner to participate in the research. Participants were free to withdraw at any stage of the research or to refuse to answer a specific question. It is important to mention that all Congolese men with whom I approached for interviews were received of R30. This money came from the African Initiative Award of GIGI, Canada that funded this research report. This reimbursement is recognized that I have taken of their time while they could be doing something else; it is not "payment" or "incentive" (Family Health International et al., 2005: 36).

The reimbursement was given to 3 Congolese men who chose not to complete the interviews; two Congolese men who decided to withdraw the interviews before or after they had completed the interview and even to Congolese men who turned out because they did not have knowledge about the interview topic or they heard about logged consent form.

In the course of the research, prevention of any harmful act and protection was considered. After the research report is completed and the degree is awarded, the copies of interview will be stored in a locked file cabinet. Also, digital voice recorder files data will be stored on a computer and protected with a password known only by researcher. The completed report will be placed in the library for the community use. In case, participants may have potential health problems such as symptoms of psychological distress that will be referred to relevant service providers for therapeutic interventions. I had a list of referrals to free health and psycho-social support services that could be offered to all participants needing them. This is also in line with ensuring no harm and protection principles agreed with participants at the beginning of the interviews as mentioned on the information sheet. The following section presents the limitations of the study.

# 4.9 Limitation of the study

I would have conducted interviews with more than six Congolese men on antiretroviral therapy services at Nazareth House and the Yeoville clinic. It was not possible because of the logged consent form introduced by University of Witwatersrand Medical Ethics Research Committee (HREC-Medical), majority of Congolese men refused to accept to see two witnesses signed their logged consent form before they complete the interviews. HIV/AIDS is stigmatized diseases; majority of Congolese men did not want to see more than two people in the room that interviews were taking place; they seem to feel uncomfortable. Logged consent was disincentive to participants.

HIV/AIDS is a sensitive issue, surrounded with stigma. Some of the Congolese men could not trust me due to this stigma around HIV when it comes to disclosure, accessing them it was difficult. Many Congolese in Johannesburg, South Africa are undocumented for one reason or other; they feared to be arrested by South African authorities. They could avoid to divulgate any information about their legal status to the individual they meet for the first time. So this means, finding them and opening up for interviews could be difficult.

To manage this situation, I used my nationality status as Congolese to approach and build rapport with the selected participants. Also, I used other existing Congolese networks such as the name of the well-known Congolese Organization (FOCAS) to approach the selected Congolese men.

In this research report, I have looked at a small number of Congolese men who access to antiretroviral therapy services at the clinics in Yeoville; to generalize these results to all Congolese men will require other researchers to elaborate on a larger sample of Congolese men who access antiretroviral therapy services at the clinics. Also, by looking only at Congolese men could be a limitation to the results as their counterpart Congolese women access to antiretroviral therapy services at the two clinics in Yeoville. The fact that I did not compare Congolese men with other nationalities or with South African could be a limitation to the results. The following section concludes this chapter.

# 4.10 Conclusion

This chapter has presented the different methods used to collect data at the field work; I made a choice of in-depth interviews to collect data at the field work. In –depth interviews was the unique qualitative method instrument used to collect data from participants in this research report. The research report targets Congolese men on antiretroviral therapy and healthcare providers at the government and at a non-government clinic. Three languages were used English, French and Lingala for data collection at the field work. Interpretative thematic analysis and comparative analysis were used.

Reflexivity as the role of the researcher at the field work was difficult to manage with different challenges that Congolese men on antiretroviral face at the clinics could affect data collection of this research. Ethical consideration, logged consent form was a discouragement to participants to complete interviews as it requires two witnesses to sign on the consent of Congolese man who is willing to participate but does not want to sign. This was one of the limitations that affected this research report more and causes this study to have the small sample size. The following section presents the findings and discussions of the research report.

# **Chapter Five: Findings and discussions**

# **5.1 Introduction**

This chapter presents and discusses the findings from my fieldwork; it describes largely the date from in-depth interviews conducted at a government clinic: Primary healthcare clinic (PHC), the Yeoville clinic and at a non-government clinic: Nazareth House HIV Clinic. To reveal the respondents' arguments, their quotations are cited word for word but their identities are protected by the use of pseudonyms to ensure their confidentiality and respect. All questions asked on treatment experiences of Congolese men on antiretroviral therapy services at the two healthcare facilities are discussed in this chapter. The chapter comprises seven sections.

The first section is the introduction, the second section is a table with access dimensions and other factors of Congolese men on ART; the third section presents the participants; the fourth section presents access dimensions to healthcare services; the fifth section gives additional factors affecting Congolese men on ART at the clinics; the sixth section presents Nazareth House compared to the Yeoville clinic and the seventh section is conclusion of the chapter. The following section presents access dimensions and other factors of Congolese men on ART services at the clinics.

# 5.2 ACCESS DIMENSIONS AND OTHER FACTORS OF CONGOLESE MEN ON ART SERVICES AT THE CLINICS

In this table 2 below, there are two key themes access dimensions and other factors that outline this study to understand the treatment experiences of Congolese men on antiretroviral therapy services at the two healthcare facilities in Yeoville, Johannesburg. Some example of quotes selected from participants interviews serve to reveal how participants experience the treatment of Congolese men on ART at the two healthcare services. PHC means primary healthcare clinic that is the Yeoville clinic, a government clinic and NH means Nazareth House, a non-government clinic that provides ARVs on patients as an act of charity in Yeoville, Johannesburg.

|  | ACCESS DIMENSIONS AND OTHER FA  | CTORS  |
|--|---|--|
| ACCESS<br>DIMENSIONS                             | There are three dimensions of access to<br>healthcare services: Availability,<br>acceptability and affordability<br>(McIntyre et al., 2009)   | EXAMPLE OF QUOTES  |
| Availability                                     | Availability refers to as opening and closing<br>hours, documentation, services available and<br>human resources at the two healthcare facilities<br>– the government primary healthcare clinic and<br>the non-governmental clinic. |  |
| Opening and<br>closing hours of the<br>clinic    | This dimension of access to healthcare services<br>is experienced differently by Congolese men<br>and healthcare providers at the two healthcare<br>facilities.   | Staff: "at 4:00pm patients are<br>coming with excuses while we are<br>closing"(PHC)<br>Client: "at 4:00 pm I am still at my<br>work I cannot see the<br>doctor"(PHC)   |
| Documentation                                    |   | Staff: "for the first time at the clinic<br>a patient need to have SA's valid<br>permit, proof of address, cell number<br>or referral letter"(PHC)<br>Client: "I showed them my status of<br>refugee when I came for the first time<br>at the clinic"(PHC)<br>Staff: "no document is requested<br>from the patient"(NH)<br>Client: "I am undocumented my visa<br>from Congo expired when I" (NH) |
| Services available<br>Human resources            |   | Staff: "patients with TB are<br>referred"(NH)<br>Client: "firstI had HIV and<br>TB"(PHC)<br>Staff: "patients are too many I am   |
| Acceptability                                    | Acceptability refers to as respect and<br>expectations between the healthcare providers<br>and Congolese men at the two healthcare<br>providers.  | alone" (PHC)   |
| Respect  | This dimension of access to healthcare services<br>between the healthcare providers and<br>Congolese men is experienced the same at the   | Staff: "I observe PATO<br>PELEmeaning people first"<br>(PHC)   |
| Expectations                                     | two healthcare facilities.  | Sttaff:: "Congolese men comply<br>with ARVs" (PHC)   |
| Affordability                                    | Affordability was found to relate to the mode<br>of transport to the clinic and time spends at the<br>clinic at the two healthcare facilities.  |  |
| <i>Mode of transport</i><br><i>to the clinic</i> | This dimension of access to healthcare services<br>is not experienced the same by Congolese men<br>on the aspect of time spends at the clinic.  | Client: "I always walk to the<br>clinic(PHC)<br>Client: "I do not use transport, I live<br>here"(NH)   |

| <i>Time spends at the clinic</i>                                     |   | Client: "this clinic take me all my<br>time"(PHC)  |
|--|---|--|
| OTHER<br>FACTORS   | There are factors that affect the three<br>dimensions of access to healthcare services of<br>Congolese men at the two healthcare facilities.  |  |
| Support networks   | Support networks are referred to as different<br>people who help the Congolese men receiving<br>ART. This includes family members in<br>Johannesburg, co-workers and friends in<br>Johannesburg; at the clinic in accessing to<br>healthcare services at the two healthcare<br>facilities |  |
| Family members in<br>Johannesburg                                    | This factor is different at the level of the two<br>healthcare facilities. At the government clinic,<br>Congolese men are not connected to the clinic<br>when the leave. They do not have support   | Client: "wife, brother,<br>sister"(NH)<br>Client: "co-worker, boss, church<br>mate"(PHC)   |
| People in JHB: Co-<br>workers, church<br>mates, Congolese<br>friends | networks from the clinic at their home place<br>unlike at the nongovernment clinic  |  |
| At the clinic  |   | Client: "clerk, counselor, doctor,<br>"(NH)  |
| Back home: Family<br>and Friends                                     |   | Client: "brother, friends,<br>mother"(NH)<br>Client: "my parents, brothes and<br>sisters, friends"(PHC)                            |
| Secrecy and stigma   | Secrecy and Stigma are referred to as (lack of)<br>disclosure of HIV status and keeping ARVs a<br>secret for clients at the two healthcare facilities   |  |
| Disclosure   | This factor negatively affects the Congolese<br>men in accessing healthcare services at the two<br>healthcare facilities. Congolese men take ARVs<br>in solitude and do not disclose to their relative  | Client: "I do not tell them about my<br>ARVs"(NH)<br>Client: "they will say naza na<br>nyamameaning I am HIV"(PHC)                 |
| ARVs are secret  | that they are in ARVs services at the clinic.   | Client: "I take my ARVs in the<br>bathroom where I am alone(NH)<br>Client: "at 5:00 am and 5 pm when<br>my phone alarm rings"(PHC) |
| Survivalist<br>livelihoods   | A survivalist livelihood refers to as struggles in<br>accessing jobs and an income, accommodation<br>and food security for clients at the two<br>healthcare facilities.   |  |
| Job and income   | This factor impacts negatively on Congolese<br>men who access healthcare services at the two  | Client: "at home I was a nurse but I<br>become a haircutter"(NH)   |
| Accommodation  | healthcare facilities. The living conditions for<br>Congolese men on ART services are difficult.  | Client: "I share a room with five<br>other Congolese men"(NH)  |
| Food security  | Congolese men work hard and earn a little<br>income that they cannot provide food for full<br>month to help them take the ARVs and sleep<br>safely without living in overcrowd conditions.  | Client: "when I take my ARVs<br>without eating all my body is<br>shaking"(NH)  |

#### Source: Fieldwork data

The table 2 above presents access dimensions and other factors that are key themes this study focuses on to understand the experiences of Congolese men on antiretroviral therapy services. Access dimensions include availability, acceptability and affordability of healthcare services at the clinics (McIntyre et al., 2009). Each three dimension aspects has its meaning availability refers to as opening and closing hours, documentation, services available and human resources at the two healthcare facilities; acceptability refers to as respect and expectation between the healthcare providers and Congolese men on ART at the two clinics; affordability refers as mode of transport to the clinic and time spent at the two healthcare facilities.

Other factors are aspects that affect the three access dimensions of Congolese men on ART services. They are support group networks that refer to as different people who help Congolese men on ART services receive antiretroviral therapy family members in Johannesburg, people in Johannesburg, family member's back home and people at the clinics; secrecy and stigma refer to as lack of disclosure of HIV status and keeping ARVs a secret for Congolese men on ART; survivalist livelihoods refers to struggles in accessing jobs and an income, accommodation and food security for Congolese men on ART services at the two healthcare facilities.

The general view of the table shows that without these two key themes in the healthcare system the treatment experiences of Congolese men on ART cannot be understood at the two clinics in Yeoville, Johannesburg. The following section presents the participants in this study.

# **5.3 PRESENTATION OF THE PARTICIPANTS**

Healthcare providers and Congolese men on antiretroviral therapy services at a government and at a nongovernment clinic are presented in the following sections. Each of the participants gave an input that was different or similar to others. The following section presents participants at a government clinic, the Yeoville clinic.

# 5.3.1 GOVERNMENT CLINIC IN YEOVILLE: THE PRIMARY HEALTHCARE CLINIC: The Yeoville Clinic 5.3.1.1 CLIENTS

# <u>EDO</u>

Edo is 31 years old. He came from Kinshasa in the Democratic Republic of Congo. Edo is not married. Edo arrived in South Africa in 2007 and he reported holding status of refugee. He is a painter in a private company in Johannesburg. He shares a room with some other Congolese men in Yeoville. In 2007, Edo came in South Africa with the aim of to travel to France. He got arrested with improper travel documents by the immigration services at Or Tambo airport in Johannesburg and he was deported to Lindela<sup>1</sup> for one year. In 2008, he was discharged from Lindela and he soon got his first asylum seeker that later on he received a status of refugee. In 2010, he was not feeling well. He was weak, coughing, having diarrhea and losing weight. With diarrhea he could not go to his work. His uncle told him to see the doctor at the Yeoville clinic. In 2010, at the Yeoville Clinic he diagnosed HIV positive and he was also found with TB. Edo has been on antiretroviral therapy services for one year and six months after first completing TB treatment for six months at the Yeoville Clinic. Edo has lived in South Africa for 3 years before he became sick and diagnosed with TB and HIV.

#### ERIC

Eric is 49 years old. He came from Lubumbashi in the province of Katanga, in the Democratic Republic of Congo. Eric is married and has lived in Johannesburg with his three children (Son of 10 years old, two daughters of 8 years old and 6 years old). Eric came to South Africa in 2006; he is a French teacher in a private school in Johannesburg. He shares a room in a flat. Eric left the Democratic Republic of Congo because of the abuse of human rights. At Lubumbashi he worked for a long time as a principal in the public school. He was arrested and persecuted for leading a protest march against bad conditions of teachers in Katanga, DRC in 2005. He passed two years in jail in DRC with some of the teachers. When they discharged them; he lost his position of a principal and became a simple French teacher at the same school because his salary was not respectable anymore and the overcrowded conditions of pupils in his classroom.

<sup>&</sup>lt;sup>1</sup> Lindela repatriation centre : Is a detention centre for illegal foreigners in South Africa

In 2006, he came to South Africa alone leaving behind him his family which joined him in 2008. Eric shares a room in a flat in Yeoville and Eric's family is well known because his wife is an interpreter of Swahili and English in one of the Courts in Johannesburg and many of pupils' parents where Eric is teaching live around Yeoville. In 2010, Eric was coughing and vomiting blood. He decided to go to the Yeoville Clinic where he tested for his first time. Eric was found with HIV and TB. Eric has been on antiretroviral therapy services for one year and six months after first completing TB treatment for six months at the Yeoville Clinic. Eric has been in South Africa for 4 years before getting, tested for TB and HIV positive.

#### **5.3.1.2 STAFF MEMBERS**

#### <u>KWETO</u>

Kweto is 36 years old. He is South African from Gauteng province. He is doctor employed by ANOVA at the Primary Healthcare Clinic's buildings. Kweto has been practicing as a doctor since he graduated in 2010 from the University of the Witwatersrand. He worked at the public institutions hospital like Johannesburg hospital, Baragwanath hospital, and in some rural hospital and clinic. Kweto has worked for one year as a clinic manager in a programme called Health4 Men that is a project of ANOVA Health Institute. Health 4 men works with South African's Department of Health to extend free services for men who have sex with men (MSM). ANOVA<sup>2</sup> Health Institute addresses the sexual health needs of men in general, gay, bisexual men and other men who have sex with men in South Africa; it also provides the STIs management and antiretroviral therapy to only patient men.

#### <u>SIPHO</u>

Sipho is 39 years old. He is a South African from Limpopo province. He is an Administrator Assistant. He has worked at the Yeoville primary healthcare clinic for 4 years. Sipho has been working at clinics and hospitals of the region F in the city of Johannesburg for a long time where he learnt many things from patients of different countries.

He can greet some of Congolese patients who access healthcare services at the Yeoville clinic in their home language Lingala and French because of his experiences at the clinic.

<sup>&</sup>lt;sup>2</sup> ANOVA is a project of Health Institute that provides HIV related services for men.

#### JUSTICE

Justice is 25 years old. He is a South African from Gauteng province. He is a clerk. He has worked at the Yeoville clinic on his learner-ship for one year. Justice works at the entrance point of the primary healthcare clinic at the help desk. Justice reported to have some difficult with some patients who cannot speak or understand English as some patients at the Yeoville clinic are not South Africans; they are patients from other parts of African countries. He said at the Yeoville primary healthcare clinic; they used to have interpreters who helped staff members to understand the need of the clients at the time they are at the clinic.

## MARIA

Maria is 45 years. She is South African from Gauteng. She is a HIV counsellor. She has worked at the Yeoville clinic for 3 years with contract of six months all the time. She is employed at the Yeoville primary healthcare under a nongovernment organization that she did not want to reveal the name of the organisation which she was working with. She reported having some Congolese patients in her room for HIV counselling; some Congolese patients do not want to accept their HIV positive result when announced to them.

#### <u>LEBO</u>

Lebo is 40 years old. She is South African from Gauteng province. She is a nurse. She has worked at the primary healthcare clinic for 7 years. She is in charge of providing antiretroviral therapy services to patients since 2009. She reported that in the past years, she was proving antiretroviral therapy services to Congolese men on antiretroviral therapy services. Since there is a men health services at the clinic, all men who found with HIV and need to access to antiretroviral therapy services are referred to ANOVA. However, Congolese men can start TB treatment at the primary healthcare clinic.

## <u>RITA</u>

Rita is 38 years old. She is a South African from Limpopo. She is a HIV counsellor. She has worked at the Yeoville primary healthcare clinic for 4 years. She worked with other public healthcare services in the rural areas before she comes at the Yeoville clinic.

She reported that Congolese patients who found HIV positive can understand and speak English; they often do not want interpreters to assist them as many other patients from other countries who diagnosed HIV positive at the Yeoville primary healthcare clinic. She reported that at the Yeoville clinic, there are more Congolese women who are diagnosed HIV positive than Congolese men. The following section presents participants on a non-government clinic, Nazareth House.

# 5.3.2 NON-GOVERNMENT CLINIC IN YEOVILLE: NAZARETH HOUSE HIV CLINIC

#### **5.3.2.1 CLIENTS**

# **ANTOINE**

Antoine is 32 years old. He is from Kinshasa, in the Democratic Republic of Congo. He is not married. He came to South Africa in June 2008. He reported using South African's asylum seeker. He is unemployed. He shares a room with some fellow's Congolese. In June 2008, he came to South Africa via Lubumbashi, Zambia and Zimbabwe. In South Africa, before he became unemployed, Antoine was working as car guard security at East Gate Mall in Johannesburg. He lost that job when he became sick. Since he was in Kinshasa he was suffering from his skin complications.

Many people told him that it was a rash. Periodically, his skin had some lesions that did not allow him to sleep as he often scratched all body at night. He did not know what the reason his skin complications were. All the family's members at home said to him that it was witchcraft. Antoine came to South Africa without solving the problem of his illness. At the flat where he is sharing with others, a South African woman told him about Nazareth House if he wants to know about his skin complications. In December 2008; Antoine went at Nazareth House after severe skin complications and after a HIV test, Antoine diagnosed HIV positive. Antoine reported that despite all the skin complications, in DRC he did not test for HIV.

# PAUL

Paul is 48 years old. He is from Goma in the province of Kivu in the Democratic Republic of Congo. He is married and lives with his two children (10 years and 8 years) in Yeoville, Johannesburg.

Paul came to South Africa in 2003 and reported that he holds the status of refugee. He works as a security guard in Johannesburg. He rents a cottage on the 5<sup>th</sup> floor of a building in Yeoville.

In Goma, he was a soldier in the national army. He left DRC when he resigned from the national army. In 2007, Paul became sick with his glands that were swollen in his neck. He thought that it was simple infection and it will pass. For three days he was not going to work and his situation was becoming worse and worse. Some of his colleagues from where he was working advised him to see the doctor, but Paul preferred to drink hot water mixed with salt and lemons. After one week, Paul could not speak properly due to his glands that were swollen. Finally, he decided to see the doctor at Johannesburg Hospital because he knew that doctors at Johannesburg Hospital are more permanent than in the clinics. At the help desk in Johannesburg; the lady asked him a referral letter from the clinic. The lady at the help desk asked him why he did not go to Hillbrow clinic where he could first start his services. Paul kept quiet he made her a sign to show her the neck that was swollen. He gave the lady at the help desk his refugee status and his brother's proof address that he took one day before he visited the Hospital. The doctor took his blood and his saliva; the doctor prescribed some medications for him and fixed him another appointment after one week. On the day of his appointment with the doctor; Paul was told by the doctor that he was HIV positive and he had TB. He completed his TB treatment after six months at the Johannesburg Hospital. Paul knew about Nazareth House that provides patients with antiretroviral therapy as he has been living in Yeoville for 9 years. From Johannesburg Hospital he was aware of his HIV positive status but he was afraid to tell his wife about it. Paul managed to ask his wife to see him off at Nazareth House for TB checkup. At Nazareth House they told them about HIV test instead of TB checkup. After a session of HIV counseling, they both accepted to come to collect their HIV result after one week. On the day of the appointment they told them that they were HIV positive; Paul knew his HIV status since Johannesburg Hospital but he could not tell his wife. He wanted the healthcare providers at the clinic to tell her reason why he wanted his wife to see him off at the clinic. Paul came in South Africa in 2003; he started to access to antiretroviral therapy in 2008 at Nazareth House.

#### **JEREMY**

Jeremy is 42 years old. He is from Goma in the Democratic Republic of Congo. He is a widower and lives with his daughter of 16 years old. Jeremy came in South Africa in 2001. He worked as nurse at home in the DRC.

In South Africa, Jeremy reported that he holds a status of refugee. Jeremy is haircutter in his own barbershop in Berea, Johannesburg. He shares a room in a flat where he stays with his daughter in Yeoville. In August 1996; Jeremy's wife was kidnapped by Mavi-Mavi<sup>3</sup> soldiers in a village called Hombo in South Kivu. After these Mayi-Mayi soldiers failed to occupy the village of Hombo; they kidnapped girls and women of that village. Jeremy's wife was one of the women kidnapped among other women. Since August 1996; Jeremy did not have any news about his wife. He left DRC to South Africa in 2001 without any hope to see his loved wife. In 2009, Jeremy noticed that he was losing weight and he was feeling very weak. By the time went on, he was unable to eat. He had thrush and oral herpes which were sore. Some of his cousins, friends and colleagues told him to see the doctor about his health. The Yeoville clinic is two streets from his place and it takes him less than 15 minutes' walk. But the problem with the Yeoville clinic for him is that people are in queue along the street where everybody who lives Yeoville can pass and see him in the queue. He did not have enough energy to be early at Yeoville clinic's in queue. He walked to Nazareth House that is about 20 minutes from his place; they told him about HIV and Jeremy was found with HIV positive. He has lived in South Africa for 11 years before became sick and diagnosed with HIV positive.

#### MARCEL

Marcel is 38 years old. He is from Matadi town in the province of Bas Congo in the Democratic Republic of Congo. He is not married. He came in South Africa in 2007. He is unemployed. Marcel lives under his cousin's place who shares with some Congolese men in Yeoville. At home, Marcel was a professional football player.

In 2007; his club came to Durban, South Africa for football competition versus some of the South African's clubs. The duration of the competition was one month. All the Congolese team members had a visa permit of South Africa for three months. After one month the competition was over, Congolese's club members were preparing to go back home.

Marcel left the Hotel where the entire club's members were living he went to hide to one of his relatives at place called Umlazi<sup>4</sup> in Durban where his cousin had married a South African woman.

<sup>&</sup>lt;sup>3</sup> Mayi-Mayi: Malicious group in the Easter part of the Democratic Republic of Congo

<sup>&</sup>lt;sup>4</sup> Umlazi is a township on the East coast of KwaZulu-Natal in South Africa

Marcel's visa permit was expired in that township. Before his visa expired, he spoke to his cousin that he wanted to join Johannesburg in order to look for money to renew his visa. Marcel came to Yeoville where he has some of his relatives. In Umlazi in Durban; Marcel could make good sentences in Zulu and he is better in Zulu than in English. Since the time he was living in Umlazi the color of his eyes changed, people were telling him that it was hepatitis. Marcel could not go to the clinic because he was afraid as he did not have South Africa legal status of staying in the country. He was all the time indoors vomiting and lack of appetite for several months. In 2010; in Yeoville, Johannesburg he met one lady from Kwazulu Natal, South African by the shop. He spoke to her with his Zulu that he learnt when he was in Umlazi and he told her that he was from Congo DRC. She could not believe it and she was curious to know how Marcel knows Zulu. She told her that his Zulu was good. Marcel got used to see her and speak Zulu with her whenever they meet. The South African's lady became his girlfriend. One day Marcel told her that he was not feeling well and he was afraid to go to the clinic because he did not have South Africa paper. The lady told him about Nazareth House where he can know about his health and at Nazareth House they do not ask paper. In February 2010; Marcel's girlfriend took him to Nazareth House for checkup. He was diagnosed HIV positive and started to access antiretroviral therapy. The girlfriend knew the place because she was HIV positive but she did not tell Marcel; only later on she told him the entire story of her HIV positive.

# 5.3.2.2 Staff

#### <u>MPUMI</u>

Mpumi is 43 years old. She is from Zambia. She is a nurse in charge at Nazareth House HIV clinic. She has worked for 9 years at Nazareth House HIV clinic. She worked at Nazareth House's hospice before they transferred her to Nazareth House HIV clinic. She can speak some of the South African languages. She reported holding resident South African permit and has come to South Africa because of job opportunity. Since she has been working at Nazareth House HIV clinic; she reported that many patients who come to access to healthcare services are not South African and there are more women than men. She said that Nazareth House HIV clinic has 22 staff members who speak most of the languages that patients at Nazareth House HIV clinic speak. About Congolese men, she reported that Congolese men are very secretive when they come to access to healthcare services at the clinic and there are more Congolese women than men.

# HELENE

Helene is 45 years old. She is South African from Cape Town. She is a counsellor. She worked in Zimbabwe for three years before. She speaks some languages of other countries such as Shona, Ndebele and Nyanja. She has worked for 9 years at Nazareth House HIV clinic. Helene reported that many Congolese men come for HIV counselling session when sick. Often when they come to collect their HIV test result, many Congolese men diagnosed HIV positive. The problem with Congolese men they do not accept the HIV positive result when announced to them.

# PRECIOUS

Precious is 36 years old. She is from Kinshasa in DRC. She is a support group facilitator. Precious speaks English, French and Lingala. She has worked at Nazareth House for 3 years. She reported that she holds South African's asylum seeker permit.

She assists many Congolese who come at Nazareth House HIV clinic's support group. She reported that many Congolese patients have problem to communicate with other patients in the support group because of English that is used as a language of communication for all patients. Among Congolese patients, few Congolese men come on Fridays at Nazareth House HIV clinic's support group to share their experiences. Many Congolese men who work do not regularly come for support group's meetings.

#### **HENRIETTA**

Henrietta is 39 years old. She is from Bukavu in the eastern part of the DRC. She is a HIV counselor but sometimes she provides also ARVs to the patients with French background. She reported that she is holds a South African's refugee status. She has worked for 7 years at Nazareth House HIV clinic. She speaks several languages of Congo Lingala, French, Swahili and Kikongo. She came in South Africa because of the political situation in the Eastern part of DRC. She reported that Congolese men who access to healthcare services at Nazareth House HIV clinic avoid other people who are not Nazareth House HIV clinic's staff members to know that they are on antiretroviral therapy. On the street, many Congolese men on treatment ignore them completely.

#### NGOYI

Ngoyi is 46 years old. He is from Katanga in DRC. He is a doctor. He has worked for 4 years at Nazareth House HIV clinic. He speaks most of the Congolese languages from home Lingala, Swahili and French. He reported that in South Africa he holds South African's residence permit. He reported that he can make some good sentences in some of the South African's languages such as Zulu and Xhosa because he worked in some of public clinics and hospitals in the rural areas of South Africa. He reported that most Congolese men do jobs that require them a lot energy, when they come for consultation some ask for their treatment's regime to change They prefer to have one dose a day instead of two times a day.

#### **POSHA**

Posha refused to give her age, country of origin and profession at Nazareth House HIV clinic. She mentioned that she is a staff at Nazareth House. She speaks some of the South African's languages Zulu, Xhosa and Tshwadi. She has worked for 6 years at Nazareth House. She reported that there are many challenges for men in general who access to healthcare at Nazareth House. Some men are ignoring and shouting on healthcare providers during home visit. Many men come sick at the clinic, the time they start taking their treatment they become healthy they forget that they have to take their ARVs for the rest of their life. Some men default because as they do not continue to take their medication because they look healthy. It is in this particular time that healthcare providers' team who visit patients at home face challenges on address and cell phone numbers given by the patients that are not correct. She said that it is more difficult to work with patient men than women for most of the time. The following section presents access dimensions to healthcare services.

# **5.4 ACCESS DIMENSIONS TO HEALTHCARE SERVICES**

In order to understand the treatment experiences of Congolese men on antiretroviral therapy services at a non-government clinic and at a government clinic, there is a need to understand how participants perceive availability, acceptability and affordability that build individual confidence in the healthcare system (McIntyre et al., 2009).

In another way, how participants experience opening and closing hours, documentation, services available and human resources at the clinics. The following findings and discussions on access dimensions to healthcare services give the light on treatment experiences of Congolese men at a non-government clinic and at a government clinic in Yeoville, Johannesburg.

## **5.4.1 AVAILABILITY**

Availability of services is referred to as opening and closing hours, documentation, services available and human resources at the two healthcare facilities – the government primary healthcare clinic and the non-governmental clinic. This dimension is found to be a key issue when exploring the treatment experiences of Congolese men on ART services at the two healthcare facilities.

#### 5.4.1.1 Opening and closing hours of the clinic

- Staff: "...the Yeoville clinic hours: 7:30 am to 4 pm Mondays to Fridays-some of the patients are coming with excuses while we are closing at 4:00 ..." (PHC)
- Client: "... at 4:00 pm I am still at my work I cannot see the doctor because the clinic is closed..." (PHC)
- Client "...for my first visit I came at 5:00 am when you come at 7:30 am the queue is too long on the street you cannot see who the last patient is..." (PHC)
- Staff: "...at Nazareth House HIV clinic we open from Mondays to Fridays; at 8:00 am to 5:00 pm-patients are welcome at 5pm ..." (NH)
- Client: "...at 8:00 am I can collect my ARVs when I will work night shift and at 5:00 pm I can pass by the clinic before I go to my work..." (NH)

The quotes above illustrate that the opening and the closing time at the two healthcare services facilities are experienced differently by Congolese men on ART and healthcare providers and the challenges on hours of the clinics are not the same between Congolese men on ART at Yeoville and Congolese men at Nazareth house. Officially, the opening at the two clinics is the same time but they do not close at the same time.

Findings on opening and closing time of clinic at the Yeoville primary healthcare supports the argument that official working hours of the public clinics in South Africa are 8 hours a day from 8:00 am to 4:00 pm from Mondays to Fridays (Cullinan, 2006); Nazareth House HIV clinic is a non-government clinic that depends on their funders rules and regulations, its longer opening hours offer greater access and convenience to clients to have access to healthcare services (Huff Rouselle & Pickering, 2001).

#### 5.4.1.2 Documentation

- Staff: "...I know that patients with ARVs have to access to healthcare services without South African's ID but how should I know?-patients on ARVs do not tell anyone about their HIV status..." (PHC)
- Staff: "...for the first time at the clinic a patient needs to have South African's valid permit, proof of address, cell phone number or a referral letter if he/she is referred to us..."(PHC)
- Client: "...I showed them my status of refugee when I came for the first time at the clinic ..." (PHC)
- Staff: "...no document is requested from a patient to access to healthcare here we only need them to accept our conditions on ARVs to respond to all appointments dates of the clinic..."(NH)
- Client: "...I am undocumented my visa from Congolese expired when I was at Umlazi in Durban..." (NH)

The quotes above illustrate that documentation to access healthcare services is experienced differently by healthcare providers and Congolese men on antiretroviral therapy services at the two healthcare facilities. Findings from the Yeoville clinic show that with inappropriate identification documents, it is difficult for Congolese men to access healthcare services, antiretroviral treatment. The findings oppose what is legally known by the South African laws that documents should not be required at the public healthcare clinic to everyone who needs to access to healthcare services (NDOH, 2006).

The quotes support what Crush and Tawodzera state that staff members in the public healthcare services are strict to all of those people who need to have access to treatment to produce the documentation before the access to healthcare services (Crush & Tawodzera, 2011). At Nazareth House HIV clinic, documentation is not important to whomever needs to access to healthcare services at their clinic. The Nazareth House HIV clinic is non-government clinic staff members are not strict as they provide charitable healthcare services to everyone who needs to access healthcare services.

#### 5.4.1.3 Services available

The two healthcare services have different services that they offer to Yeoville's community. There are a range of services at the government clinic, the Yeoville clinic including *Family* planning, Tuberculosis (TB), HIV Counselling and Testing (HCT), Health for men, Chronic services, Sexual Transmitted Infections (STI), Post exposure prophylaxis (PEP), Curative services, Trauma and Emergencies, Vitamin a supplement, Child health that includes immunisation, antenatal services, prevention of Mother to Child Transmission and Woman 'health. Nazareth House HIV clinic offers few services on HIV patients including antiretroviral therapy services and HIV counseling and Testing (HCT) and Outreach Programme that provides food parcels, clothes and blankets. (Field notes of Tuesday 6<sup>th</sup> November, 2012).

- Staff: "...all our patients with TB are referred to other clinics or hospitals because we only have specific service on HIV that is ARVs service..." (NH)
- Client: "... I knew that Nazareth House is only for HIV people but I trusted the service to help me to know about my rash after a check-up..." (NH)
- Client: "...I was coughing too much and vomiting blood and I decided to come here at the clinic. They found me with TB and HIV I was told to start with TB treatment I am now on ARVs at health for men service..." (PHC)
- Staff: "...I am assisting only men on ART services in this room. Many patient men are referred to me from some services here[the Yeoville clinic] or other patient men come outside the Yeoville clinic......" (PHC)

As the quotes above illustrate that different services are offered at two healthcare facilities and they are experienced differently by Congolese men and staff. At the Yeoville clinic, there are a range of services on HIV related diseases that Congolese men benefit from. One of the staff members at the Yeoville primary healthcare clinic acknowledged that there is a specific service for men that the clinic has; health for men. One Congolese man came to the clinic because he was coughing and vomiting blood; at the clinic he was found with HIV and TB. He started with TB treatment first before he could be accepted to access to ART services at the clinic. Finding from the Yeoville clinic supports the argument that the public clinics in South Africa have a range of services for many ambulatory patients who need more services available for the community that they belong (Cullinan, 2006).

Findings from Nazareth House show that the clinic offers few services to Yeoville's community members. Services offered by Nazareth House HIV clinic are specific to patients with HIV. As a staff member indicated that patients with TB treatment are referred to other clinics because of the lack of the service. The findings above illustrate the argument that the availability of services concerns with whether the services need by the client is appropriate at the right place and at the right time (McIntyre et al., 2009).

#### 5.4.1.4 Human resources

- Staff: "... we are only two and we overwork every day because there are many patients in the queue I book some of the patients for the next day..."(PHC)
- Staff: "... I work every day 8 hours alone with a short time of break I advise patients to come on their day of appointment..." (PHC)
- Client: "...the doctor assists all of us but the problem is that he is alone and it takes us a lot of time as we are received one after one..." (PHC)
- Staff: "... we are all comfortable because we have 22 staff members who come every day

to assist the patients..." (NH)

Staff: "...healthcare provides come to help after a short time I am at the clinic ... "(NH)

The quotes above show that Congolese men on ART services and healthcare providers experienced differently the human resources at the clinics. Finding from the Yeoville clinic indicates that there is a shortage of human resources at the clinic. Staff members overwork because they are a lot of patients but there is a few number of staff members who assist.

Congolese men have to wait for too long before they can be assisted because there is one healthcare provider for all the patients at the clinic. This finding from the Yeoville clinic supports the argument that there is still massive shortage of healthcare staff members at the public healthcare system sector in South Africa (Coovadia et al. 2009). This situation is what the post-apartheid government of South Africa inherited at public healthcare system (Benatar, 2004).

Findings from Nazareth House indicate that there are a lot of staff members at the clinic that Congolese men on ART benefit from. This supports the argument that shortage of staff members is the result of long waiting of patients at the public healthcare compare to nongovernment organization (Nuwaha, 2006). My own experience, the Yeoville clinic is closer to me and where my family and I access healthcare services; it happens sometimes that healthcare providers take a longtime talking about their private issues during the lunch-time, they can stay talking longer than the time set for them to take lunch.

# **5.4.2 ACCEPTABILITY**

Acceptability refers to respect and expectations between the healthcare providers and Congolese men at the two healthcare providers. This dimension of access to healthcare services between the healthcare providers and Congolese men is experienced between Congolese men and healthcare providers at the two healthcare facilities.

#### 5.4.2.1 Respect

- Staff: "... I respect all the patients the same I observe PATO PELE ...meaning people first..."(PHC)
- Client: "... when I see the first day came for the first time and now I respect them too much, they know what they are doing to us [patients on ARVs] ..."(PHC)
- Client: "....there I respect. I am attracted when doctor greets me in French or Lingala before he gives me ARVs ..." (NH)
- Staff: "...patients on ARVs are human beings they did not apply to be HIV we all do not know who will be the next patient on ARVs? Our respect is mutual ..." (NH)
- Client: "...but the problem with the Yeoville clinic for me is that people are in queue along the street where everybody who lives Yeoville can pass and see me in the queue. It is disrespect to me..." (NH)

The above quotes illustrate that respect is not experienced the same by healthcare providers and Congolese men on ART at the two healthcare facilities. At the Yeoville primary healthcare clinic, some Congolese men found that by the fact that they are in queue on the street waiting to access to healthcare services it not respect for them.

Findings reveal that respect is not about the staff talk to them but the way they treat them at the clinic. This joins what McIntyre and colleagues state, respect concerns the relationship between the attitudes and the expectation of the patients towards the healthcare providers (McIntyre et al., 2009). However, Congolese men on ART services indicated respect when they compare their first day at the clinic and their current situation that they find a change on their health; they consider the profession of their healthcare providers. Healthcare providers consider patients in observing the principle of PATO PELE meaning people first when Congolese men are coming for the treatment. Nazareth House, Congolese men on ART services are attracted by the healthcare providers as they can greet them with their home language; it is a respect for some of them.

#### 5.4.2.2 Expectations

- Staff "...Congolese men comply with ARVs; they are willing to hear when I explain them after their complaints..." (PHC)
- Client: "...I would like to take every days my ARVs to live a normal life as other people as I am still not married [laughed] ... "(PHC)
- Staff: "...Congolese men come and collect their ARVs on the days of appointment; they do not stress as other patients who do not come for many days..."(NH)
- Client: "...my doctor listens to me carefully all the time that I have my appointment here [Nazareth House] ... "(NH)

The quotes above show different expectations between Congolese men and healthcare providers at the two healthcare facilities. At the Yeoville primary healthcare clinic and Nazareth House HIV clinic, the expectations of Congolese men on ART services are to take ARVs with the aim to live normal life while healthcare providers expect Congolese men comply with the medication.

There are some good reasons that Congolese men on ART services at the two healthcare facilities do well on antiretroviral therapy services, quotes such as follow explain their decision on antiretroviral therapy:

Client: "...I did not come sick to South Africa and my family in DRC does not know that I am now HIV positive...all I can do for my current situation is to take seriously my medication to live as everybody in here... [Johannesburg, South Africa] (PHC)

Client: "...I do not want to miss to take my medication any single day; I live with my family *here* [Johannesburg, South Africa] *without any relative who can support my family when I die here*..." [Johannesburg, South Africa] ... (NH)

At the two healthcare facilities, Congolese men on ART services want to conform first on their treatment prescribed by the healthcare providers. This determination of taking care of themselves is the expectation of their healthcare providers since they have been on the antiretroviral treatment at the clinics. The findings support the argument that there are expectations when the patients get what they expected from the healthcare providers and when healthcare providers see that patients respect what they want from them (McIntyre et al., 2009). However, this finding challenges the argument that men do not take care of their health because of the socio-economic role of men in the household (UNAIDS, 2010).

## **5.4.3 AFFORDABILITY**

Affordability was found to relate to the mode of transport to the clinic and time spent at the clinic at the two healthcare facilities.

#### 5.4.3.1 Mode of transport to the clinic

- Client: "...for all my appointments to the clinic; I always walk because I live two streets from *here* [The Yeoville clinic] ... "(PHC)
- Staff: "... many of the patients at the Yeoville clinic live around Yeoville..."(PHC)
- Staff: "...to visit some of the patients; we walk to their place because many live in Yeoville..." (NH)
- Client: "....I really do not need a transport; J'habite juste ici... meaning French....I live just here [ in Yeoville]..."(NH)

The quotes above illustrate that the mode of transportation to the clinic is experienced the same for Congolese men on ART services at the two healthcare facilities. The findings support the argument that the two healthcare services are located in Yeoville where they are large number of Congolese who are men and share flat or rooms (Mavungu, 2007).

My non participant observation, on Friday 9<sup>th</sup> November, 2012 one of the Congolese men who participated on this research report was called on the phone by a Congolese healthcare provider to contribute on this study. It did not take time for that Congolese man to access the premises of the clinic (Nazareth House HIV clinic) and see me. This could be difficult for me if this fellow Congolese could live where he could pay for transportation to come to the clinic to participate on this research report.

#### 5.4.3.2 Time spends at the clinic

- Staff: "...the Yeoville clinic opens at 7:30; some patients are still at the clinic till 4 pm; we wait for them to go out before we close...."(PHC)
- Client:: "...at 5:00 am I am at the clinic I am not sure at what time I will go out of the clinic when the queue is too long in the morning..."(PHC) on the street you cannot see who the last patient is..." (PHC)
- Client: "...at 8:00 am I can collect my ARV; I am done after 30-40 minutes when I do not see the doctor for my personal complaints..." (NH)
- Staff: "...we open from Mondays to Fridays at 8:00 am to 5:00 pm. At 5:00 many patents are gone; we wait patients who come late..." (NH)

The quotes above illustrate that time spent at the clinic is not experienced the same by Congolese men and healthcare at the two healthcare facilities. At the Yeoville clinic Congolese men on ART services spent more time at the clinic compared to Congolese men on ART services at Nazareth House.

The findings support the argument that there is a different between government and nongovernment clinics with shortage of staff members and long waiting hours, patients spend more time at a government clinic than at a non-government clinic. This impacts to the lack of opportunity to patients on convenience access (Huff Rousselle & Pickering, 2001). The following section looks at the additional factors affecting Congolese men on ART services at the clinics. The following section presents additional factors affecting Congolese men on ART services at the clinics.

# **5.5 ADDITIONAL FACTORS AFFECTING CONGOLESE MEN ON ART SERVICES AT THE CLINICS**

There are three additional factors that have an effect on Congolese men on ART services at the two healthcare services facilities: Support networks, secrecy and stigma; and survivalist livelihoods.

#### 5.5.1 SUPPORT NETWORKS

Support networks are referred to as different people who help the Congolese men receiving ART. This includes include social support networks from family members in Johannesburg, people in Johannesburg, family member's back home and people at the clinics. The following quote from a client at Nazareth House HIV clinic illustrates how some Congolese men on ART services experienced the support networks:

Client: "....wherever I stand up for my first time is my place and whoever kindly approaches me for help is my brother or my sister because we are all foreigners in the world and I have got the same ancestors ...."(NH)

The quote illustrates that some Congolese men on ART services at the clinics trust on a wide range of people who can contribute to their access to healthcare services, antiretroviral therapy services. They trust people who voluntary come closer to them for assistance. The findings support the argument that in accessing healthcare services, antiretroviral treatment the two categories of social support networks formal and informal help patients to access healthcare services, antiretroviral therapy, the former consists of professional support systems (healthcare and social service providers) and the latter of family, friends, and other community organizations such as church (Waddell & Messeri, 2006).

Though, in most chronic diseases such as HIV/AIDS, informal social support networks, particularly relatives, are acknowledged as critical sources of social support (Berkman & T., 2000; Hamilton et al., 2007; Kaplan & Toshima, 1990). Between the two categories of social support networks formal and informal there is not one that can be neglected as both of them play an important role of enabling patients on ART services to access their treatment.

#### 5.5.1.1 Family members in South Africa

Client: "...wife, brother, sister, sisters in law & children advised me for a check-up..."(PHC);

Staff: "... brothers, sisters, mothers let's me say their relatives come to book the place in queue for them because they cannot walk, stand or come early at 5:00 am because they are sick as we open at 7:30; the queue is too long ..." (PHC)

Staff: "...some patients come with their brothers, sisters and children who accompany them here [Nazareth House] ... " (NH)

Client: "...uncle, aunt & cousins provide me with foods..." (NH)

The quotes above illustrate that different relatives come to assist Congolese men on ART services at the clinics; each of the members of the family plays a role to help Congolese men on ART services. The findings support the argument that the family members enable people on ART services to be engaged in accessing healthcare services (Mkant, 2005).

At the Yeoville clinic, staff members recognized the role of the family members who come to help patients who cannot come early at the clinic at 5:00 am because they are sick. Brothers, sisters and other members of the family who care for the patients come at the clinic to book the place for the patients to access to the services at the correct time. Otherwise, the patients will have access to healthcare services late because the queue is too long. The same kind of support is observed at Nazareth House; some Congolese men on ART services come to see their relatives off at the clinic.

#### 5.5.1.2 People in Johannesburg

Client: "...here [In Johannesburg], you hear all the time people saying "I am busy", even your own brothers or sisters of the family-my next door friend is from Zimbabwe sometimes he helps me on the dates of consultation with the doctor when I cannot walk and when he is available at his place..."(NH)

Client: "...my co-workers at the school, boss, church mates, neighbours..." (PHC)

Client: "...my girlfriend, church mates, fellow' Congolese in Johannesburg..." (NH)

The above quotes show how different people who are not directly members of the family sometimes helps Congolese men on ART services to access antiretroviral services at the healthcare facilities. The findings support the argument that regardless of the support people living with HIV have, the availability of support from other networks improves their probability to access healthcare services (Waddell and Messeri, 2006). To illustrate the above quotes, comments from some Congolese men such as:

Client: "...my church's mates visit me when they do not see me at the church for a monththey sometimes come with money or foods..." (NH)

Client: "... I did not work for the all month of December, 2010 but my boss helped me pay the rent with my full salary..." (PHC)

The above quotes illustrate how people from outside of Congolese men's family in Johannesburg contribute as a social network to help them access healthcare services. To access healthcare services in Johannesburg, Congolese men on ART services are connected with different social networks that support them to access antiretroviral therapy services at the two healthcare facilities.

#### 5.5.1.3 At the clinic

At the level of the two clinics, the experiences of healthcare providers and Congolese men on ART services are different. To the question to know who helps Congolese men at the clinic to access to ART services and how do they get help? The following quotes illustrate their experiences at the clinics:

Client "...clerks, counsellors, doctor, interpreters..." (PHC)
Staff: "...we do not have a social worker here [the Yeoville clinic] and we do not follow patients on ART services at their home..." (PHC)
Client: "...doctors, nurses, counsellors, social workers, security officers..." (NH)

Staff: "...with home base team & support group patients remain on ART; we visit all patients within 14 days of absence at the clinic..." (NH)

The quotes above illustrate that this factor is differently experienced by Congolese men on ART services and healthcare providers at the two clinics. At the government clinic, the Yeoville clinic Congolese men on ART services get the help of the interpreters who facilitate the communication between the healthcare providers and the Congolese men on ART services at the clinic. As all the healthcare providers at the Yeoville's clinic are from South Africa. Contrary, at Nazareth House, Congolese men on ART services do not need interpreters because some of the healthcare providers are from the Democratic Republic of Congo and they speak some of the home language of Congolese men on ART services. The findings support the argument that communication in healthcare is tool for a good adherence to healthcare services (Crush & Tawodzera, 2011). The quotes also show that at the government clinic, the Yeoville clinic Congolese men on ART services do not benefit from the services of the healthcare providers when they leave the clinic's premises.

A staff member at the clinic recognized that Yeoville clinic does not have a social worker available for patients on ART services who can liaise with patients when they are outside of the clinic. Yet, at Nazareth House Congolese men on ART services benefit from the healthcare providers outside of the clinic's premises, there is a follow up of patients on ART services. The clinic has home base team and support group that look at the patients on ART. All patients within 14 days of absence at the clinic are followed up at their place by members of home base team and support group.

The findings from the two healthcare services support the argument that patients on HIV face challenges to have their family members to support them but formal support that consists of professional support systems (healthcare and social service providers) encourage patients to access to healthcare (Waddell and Messeri, 2006) and also, these findings support the argument that there is successful engagement in healthcare services when the support networks in given by a specific type of people at the healthcare facilities (Hamilton et al., 2007). The lack of services outside of the clinic at the Yeoville clinic for Congolese men on ART services impacts a lot on their access to healthcare services, antiretroviral therapy services at this clinic.

Client: "...when I was not working because I was very sick my brothers and sisters helped me sell some items that I was sending back home..." (NH)

Client: "...often on the phone my family was telling me to keep on going to the treatment of

flu as I did not tell them the truth that I am HIV positive here [South Africa]..." (PHC)

The above quotes reveal that this factor is differently experienced by Congolese men on ART services as the lealthcare providers at the two clinics. Some Congolese men on ART services at the Nazareth House HIV clinic get the support from their family back home through remittances of some items that members of the family back home sell for them. Other Congolese men on ART services at the Yeoville clinic get supports from their family members back home from the connection that they often have on the phone that allows them to access healthcare services.

#### 5.5.2 SECRECY AND STIGMA

Secrecy and Stigma are referred to as (lack of) disclosure of HIV status and keeping ARVs a secret for clients at the two healthcare facilities. This factor negatively affects the Congolese men in accessing healthcare services at the two healthcare facilities. Congolese men take ARVs in solitude and do not disclose to their relative that they are in ARVs services at the clinic. The following quote from a patient from the Yeoville clinic shows in which level Congolese men on ART services fear community's members to know that they are HIV positive and on ART services:

Client: "...gossiping when I am walking on the streets of Yeoville I do not like; it is better not

to disclose my HIV status and I discipline myself to keep quite on my medication..." (PHC) The quote above illustrates how some Congolese men on ART services experience secrecy and stigma in their community, Yeoville. Some Congolese men on ART services prefer to keep quite on the way they are HIV positive and access ART.

The findings support the argument that patients on ART services avoid potential social reactions of others when they talk about their HIV status in their community (Kalichman et al., 2007). As in their community people have strong negative judgmental attitudes on them (Cloete, Simbayi, Kalichman, Strebel, & Henda, 2008). With this, they are isolated (Mitchell, Kelly, K.J.M., Potgieter, & Moon, 2007).

#### 5.5.2.1 Disclosure

- Client: "...I will not tell fellow Congolese otherwise they will be saying everywhere: "na na nyama"...meaning "...I am HIV..." (NH)
- Staff: "...Congolese men do not disclose their HIV status because at home [DRC] speaking about HIV in the public place or in the family is taboo and disrespect to other people who are around..." (NH)
- Staff: "... it is difficult for Congolese to disclose their HIV status here in South Africa; since home [DRC] when people know that you are HIV positive they will point you fingers saying: "; akota ndako meaning in English "She/he is indoors"; afandeli pot meaning in English " She/he is sitting on toilet..."(PHC)
- Staff: "...I only disclosed to my HIV status to my wife and she knows all about my ARTs at the clinic; I told her to keep it very secret for her..."(PHC)
- Client: "...it is better for me to keep quiet to make sure that I am safe with my ARVs in the room ..."(PHC)

The quotes above at the two healthcare facilities indicate that Congolese men on ART services do not disclose their HIV status to the people whom they do not trust as they avoid other people to show them fingers on the street. The findings support the argument that people living with HIV/AIDS avoids rumours, social rejection and other people of the community to know that they are living with HIV (Manirankunda et al. 2009). There is contrast among Congolese men on ART services, some Congolese men who are married indicated that they disclosed to their wives that they are HIV positive and they are on ARVs programme.

This supports what Daftary et colleagues said that married men who are living with HIV/AIDS disclose their HIV status to their wives and insist to their wives to keep the confidentiality between them to avoid discrimination among other members of the community they belong (Daftary et al., 2007). Other Congolese men who are not married indicated that it is better for them to keep quiet about their HIV status. They do not disclose even to their brothers whom they are sharing the same room.

#### 5.5.2.2 ARVs are secret

Client: "...I take my ARVs at 5:00 am and 5:00 pm when my phone alarm rings..." (PHC)
Staff: "...they pull out ARVs from the wrapper that they leave in dustbin here [the Yeoville clinic] they put ARVs in their pockets before they leave..." (PHC)
Client: "...I take my ARVs in the bathroom where I am alone..." (NH);

The quotes indicate Congolese men on ART are secretive when they are taking their ARVs. They avoid their relatives to know that they are on ART. The findings support the argument that the community within people living with HIV live has strong negative judgmental attitudes on them that affect their adherence to access healthcare (Cloete et al., 2008). Congolese men on ART services take their ARVs in solitude that people cannot understand that they are on ARVs. Some Congolese prefer to take their ARVs at the bathroom where they feel safe and alone. Others when their cell phone alarm rings they know that it is time for them to access their ARVs. The findings support the argument that because of the stigma that patients on ARVs have, they have developed ways to take their medication (Mbonu, Van den Borne, & De Vries, 2009). The following section presents survivalist livelihoods among Congolese men in Yeoville, Johannesburg.

#### 5.5.3 SURVIVALIST LIVELIHOODS

A survivalist livelihood refers to as struggles in accessing jobs and an income, accommodation and food security for clients at the two healthcare facilities (Vearey, 2008). This factor impacts negatively on Congolese men who access healthcare services at the two healthcare facilities. The living conditions for Congolese men on ART services are difficult. Congolese men work hard and earn a little income that they cannot provide food for full month to help them take the ARVs and sleep safely without overcrowd conditions.

Client: "...there is not a situation as difficult as living with HIV and family in foreign country and in the place like Yeoville with fellow Congolese ..." (PHC).

This quote above illustrates how Congolese men on ART services struggle to live with HIV in South Africa. The finding support the argument that the living conditions of Congolese in South Africa is difficult (Lakika, 2011).

5.5.3.1. Jobs and income

Client: "...there are not jobs for us foreigners in this country [South Africa] and money is

difficult to find ... " (NH)

The above quotation from a Congolese man at Nazareth House shows how Congolese men on ART services struggle for their living conditions in the country that they belong. This supports what Amisi argued that Congolese have challenge with social and economic conditions in their host country where they are foreigners with poor conditions of life (Amisi, 2006). The following quotes show how Congolese experience survivalist livelihoods in Johannesburg:

- Client: "...at home I was a nurse but here [South Africa] I become a haircutter; my income from my salon is too little to feed me and my daughter..." (NH)
- Client: "...when I work night shift I suffer more as I do not have time to sleep because my boss is behind me with a little money monthly..."(NH)
- Staff: "...security guards, car wash guards are hard jobs for them they complain too much when they come to their appointment but in support group there are small jobs for patients on ARVs..."(PHC)
- Client: "… I am on duty every day from Monday to Sunday; I am changing only shifts. I am paid by shift I cannot buy food for a full month because my wife does not Work and I have children..." (PHC)

The quotes show that Congolese men on ART services at the two healthcare facilities in South Africa struggle for jobs that most of them do not match to their qualifications or what they have done in DRC (Lakika, 2010). Some of the Congolese men do not have off-days as they can work every day in a roster that only shifts change with small earning that they cannot provide food for a full month. There are some projects that support patients on ART services at Nazareth House HIV clinic in support group as a staff at Nazareth House mentioned. These are only projects, patients on ART services can take opportunities but projects do not guaranty for a full living conditions for them in Johannesburg.

Findings indicate that jobs and income negatively affect the Congolese men on ART services at the two healthcare facilities as some of them are employed in informal sectors and others are working in conditions works that are unlawfully This supports what Vearey argued that in Johannesburg, most migrants struggle to find the jobs they are found in informal sectors (Vearey, 2008), some non-citizens in South Africa have unreliable sources of income in their households (Mpedi & Smit, 2011).

The support group at Nazareth House HIV clinic is a structure that was created by one of the patients on ART services at this clinic. This structure operates independently of Nazareth House HIV clinic with staff members who all access antiretroviral services at Nazareth House HIV clinic. Some projects of the support group come from Europe, especially from Holland. One of the projects that often come from Holland is making designs on beats. Patients who enter this project get paid monthly and they can support themselves to pay the rent, buy clothes or foods (Field notes: Prompt conversation with the coordinator of support group, on Friday 7<sup>th</sup> December, 2012).

#### 5.5.3. Accommodation

- Client: "...I share a room with five other Congolese men; it is not easy to take my ARVs...." (NH);
- Staff: "...there is accommodation for patients on ART who do not have family members here [Johannesburg] or who cannot work because they are seriously sick..."(NH)
- Client: "...I live in a cottage on the 5<sup>th</sup> floor with all my family in Yeoville it is not safe for my health and my children who are still small but I cannot afford another cottage now ..." (NH)
- Client: "...I share a bed with my uncle and another Congolese man; my sleeping conditions

#### are difficult..."(NH)

Staff: "...not having good conditions of sleeping make patients on ARVs suffer more..." (PHC) Client: "I rent a room in a flat with my family; it is difficult for my privacy ..." (PHC)

The quotes above illustrate that accommodation negatively affects the Congolese men on ART services at the two healthcare facilities. Some Congolese men on ART services sleep in overcrowded conditions that affect the way they access antiretroviral therapy, others with bad conditions of sleeping. This supports the argument that overcrowded conditions is a risk for other many communicable diseases (Ahmed et al., 2006).

Congolese men on ART services at the two healthcare services suffer of the conditions of sleeping are not fine. As a Congolese man indicated that they sleep three people on the same bed. This support what one of the staff members at the clinic said that lack of good sleep for patients on ARVs make them suffer more. Taking ARVs without a good sleep or bad conditions of accommodation is difficult for some Congolese men on ART services. Accommodation is a problem for patients on ART services who are seriously sick and cannot work, Nazareth House HIV clinic provides for such category of patients a place to sleep for patients who do not have relatives in Johannesburg as one of the staff members noticed it.

#### 5.5.3 Food security

- Client: "...when I take my ARVs without eating all my body is shaking; I suffer more and stress..." (NH)
- Staff: "... we give foods to patients on ART services with scant..." (NH)
- Client: "...food is a problem because it is difficult for me to put food in the fridge for two months as I do not have enough money I am sometimes stressed ..." (NH)
- Client: "...not all the time that I have money but for my ARVs to be taken I have to make sure that my two apples are in my bag when I am going to my work (PHC)

The quotes above illustrate that lack of food negatively affects the Congolese men on ART services to access antiretroviral therapy services at the two healthcare facilities. The food security is experienced differently between the two healthcare facilities by Congolese on ART services. At Nazareth House, Congolese men benefit from parcels of food that the clinic offers to patients on ART services.

At the Yeoville clinic, Congolese men on ART services do not have this privilege of having food at the clinic. An availability of food for patients, non-citizens on ART services is important as most non-citizens do not have enough foods on their households in South Africa (Mpedi. & Smit, 2011).

My non participant observations: In the morning on their day of appointment at Nazareth House HIV clinic, some patients, some Congolese men drink coffee or tea. There was in kitchen some sugar, coffee, tea, some milk for staff, patients, and Congolese men on ART services. They served themselves as if they were part of the staff members; everybody is in good mood inside the kitchen while drinking tea or coffee.

The findings support the argument that UNAIDS states, many patients on antiretroviral therapy services stop taking their pills because they cannot afford food to eat with their medication; some return the pills to the clinic for the reason that they cannot take them without food (UNAIDS, 2010). Also, the findings support the argument that lack of food access affects and creates a persistent shock and stress among many of households' migrants is South Africa (Mpedi. & Smit, 2011). Foods affect negatively patients, Congolese who do not have anything to eat when they are taking their ARVs. The following section presents the comparison between the primary healthcare clinic, the Yeoville clinic and Nazareth House.

## 5.6 THE PRIMARY HEALTHCARE CLINIC, THE YEOVILLE CLINIC COMPARED TO NAZARETH HOUSE HIV CLINIC

Previous sections of this research report show different challenges that Congolese men on ART are going through at the two healthcare facilities, the Yeoville primary healthcare clinic (PHC) that is a government clinic and Nazareth House HIV clinic that is a non-government clinic. This section compares the two clinics and highlights different challenges face by Congolese men on ART services. The previous sections show that the Yeoville primary healthcare clinic plays an important role of men health in accessing antiretroviral therapy services. This makes this clinic a typical primary healthcare clinic on men healthcare services.

Patient men on ART, Congolese men on antiretroviral therapy services at the Yeoville clinic interact with healthcare providers who are men. In this regard patients, Congolese men on ART may feel free to express their concern to their colleague men. However, there are more challenges face by Congolese men on ART at the Yeoville clinic than at Nazareth House on access dimensions and other factors.

Access dimensions include opening and closing hours, documentation, services available and human resources; non-citizen men on ART, Congolese men on ART struggle more to access antiretroviral therapy services at this clinic. They have to come at the clinic earlier by 5:00 am the opening time to join the queues the long the street while the official opening time and closing of the clinic are 8: am and 4:00 pm. At 4:00 pm, many Congolese men on ART services are still at their jobs or business that most them close at the same time 4:00 pm, Congolese men on ART services cannot access antiretroviral therapy services at this clinic. To access antiretroviral therapy services at this clinic, the frontline healthcare providers, constitute barriers to patients on ART services, Congolese men on ART access antiretroviral therapy services as patients on ART have to produce documentation before they access antiretroviral therapy services. The Yeoville primary healthcare clinic has a range of services are immense shortage of healthcare providers that has a negative impact on patients, Congolese men on ART services prefer to access antiretroviral therapy at the Yeoville clinic.

Other factors include support networks, secrecy and stigma; and survivalist livelihoods. At this clinic, these factors affect negatively patients on ART services, Congolese men on ART to access antiretroviral therapy. Support networks include social support networks from family members in Johannesburg, people in Johannesburg, family member's back home and people at the clinics. The Yeoville clinic does not have healthcare providers (Social worker) at the clinic that can support patients on ART services, Congolese men on ART services to maintain the connection with the clinic when they are at their home. There is totally a lack of visits from healthcare providers to their patients, Congolese men on ART services. Survivalist livelihoods include job and income, accommodation and food security, the Yeoville clinic limits its activities in providing antiretroviral therapy services to patients, Congolese men on ART services. These aspects affect negatively patients on ART services, Congolese men on ART services at this clinic compared to Nazareth House HIV clinic.

Comparatively to the Yeoville primary healthcare clinic that previous sections show more challenges face by patients on ART, Congolese men on ART services on ART services and it is a typical primary healthcare clinic for men accessing ART, Nazareth House HIV clinic plays on charitable role to patients on ART support group with small projects, visits to patients at their home and cater some tea or coffee in the morning.

#### **CONCLUSION**

There are some objectives that the research report fixed. Through findings and discussions of the treatment experiences of Congolese men on antiretroviral therapy services at a government clinic, the Yeoville primary healthcare clinic and at a non-government, Nazareth House HIV clinic all objectives are achieved. The primary objective of this research report is to explore the treatment experiences of Congolese men in accessing antiretroviral therapy (ART) services at a government and at non-government clinic in Yeoville, Johannesburg. The literature review reveals that South Africa has one of the highest rates of HIV infection and has the largest public sector antiretroviral programme with the health system enrolling a great number of people living with HIV for antiretroviral therapy (Boulle et al., 2008). There are many challenges in access antiretroviral treatment for non-citizens at the healthcare facilities (McCarthy et al., 2009). Findings from this research report reveal that:

There are different treatment experiences with respect to access - opening and closing hours, documentation, services available; other factors - including support networks, secrecy and stigma; and, survivalist livelihoods that affect access dimensions of Congolese men on ART at the two clinics.

Between the two clinics, Congolese men on ART services have more challenges in accessing antiretroviral therapy services at the government clinic than at the non-government clinic. However, findings reveal that at the government clinic, the Yeoville clinic is a typical primary healthcare clinic for the role of health for men on antiretroviral therapy services. The following section is chapter six that gives conclusion and recommendations of the research report.

#### **Chapter Six: Conclusion and recommendations**

This research report explored the treatment experiences of six Congolese men who are accessing antiretroviral therapy services at services at a government clinic, the Yeoville primary healthcare clinic (PHC) and at a non-government clinic, Nazareth House HIV clinic, in Yeoville, Johannesburg. The treatment experiences of six Congolese men on ART services combined with the treatment experiences of twelve healthcare providers who interact daily with patients, Congolese men on ART services at the two clinics provide the findings of this study. To understand their treatment experiences, access dimensions and other factors on antiretroviral therapy services at the two clinics are two aspects that constitute the healthcare system and allow this study to unpack Congolese men on ART treatment experiences.

Access dimensions to antiretroviral therapy services includes opening and closing hours, documentation, services available and human resources revealed as a challenge and experienced differently by non-citizen patients, Congolese men on ART services at the two clinics. At the Yeoville Primary Healthcare Clinic, Congolese men on ART face more challenges to access healthcare services than Congolese men on ART at the Nazareth House HIV clinic. At the opening and closing time, Congolese men on ART have to come earlier at the clinic by 5:00 am to join long queues that are the long the street before the clinic opens at its official time at 8:00 am. With long queues, Congolese men on ART services who cannot come earlier to join the queue experience difficulties to seek the treatment. At the closing time of the clinic at 4:00 pm, many Congolese men on ART services are still at their work as most companies in South Africa close their business by 4:00 pm; Congolese men on ART cannot access healthcare services at this time.

At Nazareth House HIV clinic the opening time is 8:00 am, time that most Congolese men on ART services come to access antiretroviral therapy services. At this particular time at this clinic, there is not a queue for Congolese men on ART services to access their antiretroviral therapy. At the closing time at 5:00 pm, Congolese men on ART services come from their jobs and they can still find the clinic opens and access their antiretroviral therapy services. Such closing time at Nazareth House HIV clinic is an opportunity for Congolese men on ART services to access healthcare services and plan their day. Documentation as findings revealed is an important aspect in order to access healthcare services at the Yeoville primary healthcare clinic comparatively to Nazareth House HIV clinic. At the Yeoville clinic, Congolese men on ART services require to produce proof of address, cell phone number or referral letter that gives them the rights to access healthcare at the clinic. While documentation should not be required to everyone who needs to access healthcare services, antiretroviral therapy at the clinic in South Africa (NDOH, 2006). Often, this situation is created by frontline healthcare providers who do not follow the legal legislation of the country (Moyo, 2010). At Nazareth House HIV clinic, documentation is not a challenge for Congolese men on ART services. Congolese men on ART services access to healthcare services without producing any documentation. Nazareth House is a non-profit clinic it offers antiretroviral treatment to patients, Congolese men as an act of charity. A service available at the two clinics, the Yeoville Primary Healthcare Clinic has a range of HIV related services including health for men that makes the Yeoville clinic a typical primary healthcare clinic. Though, there is an immense shortage of staff members that is common for many public healthcare services in South Africa (Cullinan, 2006). This situation impacts negatively to patients, Congolese men on ART services. Contrary to Nazareth House HIV clinic that offers few specific HIV services antiretroviral therapy services, HIV counseling and Testing (HCT) and Outreach Programme to HIV patients. The clinic has many staff members who cover all different services of the clinic.

Other factors include support networks, secrecy and stigma; and survivalist livelihoods for Congolese men on ART services at the two clinics. These factors negatively affect Congolese men on ART services to access their antiretroviral therapy services. Support networks include social support networks from family members in Johannesburg, people in Johannesburg, family member's back home and people at the clinics. The findings revealed that the support networks affect Congolese men on ART services and they experience them differently at the two healthcare facilities. At the Yeoville primary healthcare clinic, there is not structural social support networks that connect directly to patients, Congolese men on ART services outside of the clinic. Congolese men on ART services struggle to get the social support networks from the healthcare providers when they leave the clinic as the clinic does not have a follow up to patients, Congolese men on ART services. From the time patients, Congolese men on ART services are at their home they lose the contacts with the clinic they will come again on the day of their appointment unless they fall sick and decide to come at the clinic before the day of their consultation to see the healthcare providers.

Comparatively to Nazareth House HIV clinic, Congolese men on ART services benefit from the social support networks support group and home base team's visits of healthcare providers. Patients, Congolese men on ART services who have 14 days of absence at the clinic they see the visits of healthcare providers or support's group members at their home. Such supports enable patients, Congolese men on ART services to continue to access antiretroviral therapy at the clinic. Secrecy and stigma include ARVs are secret and disclosure: Similarly, at the two healthcare facilities, these factors affect negatively patients, Congolese men on ART services. Most Congolese men on ART services are secretive in accessing their antiretroviral therapy and they do not disclosure their HIV status to their relatives. Some Congolese men who are married disclose to their wives but prevent them not to inform other relatives. This factor affects negatively the way Congolese men access antiretroviral therapy services at the two clinics. Survivalist livelihoods include job and income, accommodation and food security. These factors experienced and affect differently Congolese men on ART services and at the two healthcare facilities. The Yeoville primary healthcare clinic does not provide food to patients, Congolese men on ART services. Patients on ART services come on the day of appointment collect the medication or consult the healthcare providers then go home. Compare to Nazareth House HIV clinic, patients on ART services benefit from food, accommodations and small projects from the support group. Patients, Congolese men on ART services are allowed by the clinic to cater themselves for breakfast in the morning when they want and patients on ART who are very sick cannot work or walk are provided by parcels of food; they can also sleep in the hospice of Nazareth House when their case is serious. There are small projects of the design made by beats that come from the support group that is not under Nazareth HIV clinic's supervision. In the projects, only patients on ART services can work and earn small money monthly. This is a good thing at Nazareth House HIV clinic for patients, Congolese men on ART services that living conditions in South Africa are difficult (Lakika, 2011).

In summary, access dimensions and others allow this research to understand the treatment experiences of Congolese men on ART services at a government clinic and at a nongovernment clinic. Treatment experiences of Congolese men on ART reveal more challenging at a government clinic than at a non-government clinic. However, at a government clinic, the Yeoville clinic is typical primary healthcare clinic for its role of men's health on ART services.

#### **6.1 Recommendations**

The results summarized in the previous section on treatment experiences of Congolese men on antiretroviral therapy services at the two clinics in Yeoville, Johannesburg show the need to this study to make some recommendations. These recommendations may change the different challenges experienced by non-citizen patients, Congolese men on antiretroviral therapy services at the two levels of the healthcare system access dimensions and other factors.

At the level of access dimensions:

- Extended opening and closing hours of the clinics.
- Extended number of staff members at the clinics and promoting sleeping with paying over-time services to healthcare providers on antiretroviral services.
- Training of frontline healthcare providers on the rights of migrants on access to healthcare services including antiretroviral therapy services.

At the level of other factors:

- Providing soup kitchen to patients on antiretroviral therapy services at the clinics
- Providing shelters/or hospice to patients on antiretroviral therapy services.
- Extended campaigns on HIV related services to non-citizen patients on antiretroviral therapy services at the clinic.

#### References

Ahmed, Q. A., Arabi, Y. M., & Memish, Z. A. (2006). Health risks at the Hajj. *The Lancet*, 367(9515), 1008-1015.

Amisi, B., & Ballard, R. (2005). In the absence of citizenship: Congolese refugee struggle and organisation in South Africa. A Case Study for the UKZN Project Entitled: Globalisation, Marginalisation and New Social Movements in Post-Apartheid South Africa, University of Kwazulu-Natal.

- Amisi, B. (2006). An exploration of the livelihood strategies of Congolese refugees. New ssues in refugee research., Working paper number 123
- Anarti, J. (2005). Reversing the spread of HIV/AIDS: What role has migration played? In: UNFPA (ed.) International Migration and the Millennium Development Goals. Selected papers of the UNFPA Expert Group Meeting, Marrakech, Morocco, 11–12 May 2005. New York, UNFPA.
- Banks, I. (2001). No man's land: men, illness, and the NHS. *BMJ: British Medical Journal*, 323(7320), 1058.
- Baumgartner, T., & Clinton, S. (1998). Conducting and Reading Research in Health and Human Performance. Boston: WCB/McGraw-Hill.
- Beall, J., Crankshaw, O., & Parnell, S. (2000). The Causes of Unemployment in Post-apartheid Johannesburg and the Livelihood Strategies of the Poor. *Tijdschrift voor economische en sociale geografie*, 91(4), 379-396.
- Berkman, L., & T., G. (2000). Social Integration, social networks and health. In: Berkman LF, Kawachi I, .
- Bhugra, D., & Becker, M. A. (2005). Migration, cultural bereavement and cultural identity. *World Psychiatry*, 4(1), 18.
- Boulle, A., P., Bock, M., Osler, K., Cohen, L., Channing, K., Hilderbrand, E., et al. (2008). Antiretroviral therapy and early mortality in South Africa and early mortality in South Africa. *Bultin of the World Health Organisation* 86:678-687.
- Carrasco, L. N., Vearey, J., & Drimie, S. (2011). Who cares? HIV-related sickness, urban rural linkages, and the gendered role of care in return migration in South Africa. *Gender & Development*, 19(1), 105-114.
- Cloete, A., Simbayi, L. C., Kalichman, S. C., Strebel, A., & Henda, N. (2008). Stigma and discrimination experiences of HIV-positive men who have sex with men in Cape Town, South Africa. *AIDS Care 20*(9), 1105-1110.
- COJ. (2011:31). Growth and Development Strategy, 2011. Johannesburg, South frica, City of Johannesburg.
- Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & and Mdntyre, D. (2009). The health and health system of South Africa: Historical roots of current public health challenges. *Lancet, 374*, 817-834.
- CoRMSA. (2008). Protecting Refugee, Aslyum seeker and Immigration in South Africa.

- Crush, J., & Tawodzera, G. (Eds.). (2011). *Medical Xenophobia: Zimbabwean Access to Health Services in South Africa*. Cape Town: Idasa, 6 Spin Street, Church Square, Cape Town, 8001, and Southern African Research Centre, Queen's University, Canada.
- Cullinan, K. (2006). Health services in South Africa: A basic introduction. *Health-e News* Service.
- Daftary, A., Padayatchi, N., & Padilla, M. (2007). HIV testing and disclosure: a qualitative analysis of TB patients in South Africa. *AIDS care, 19*(4), 572-577.
- DOH [South Africa]. (2006). Memo: Access to comprehensive HIV and AIDS care, including antiretroviral treatment. Pretoria, South Africa, Department of Health.
- Fabian, J. (2008). *Ethnography as Commentary: Writing from the Virtual Archive.*: Durham, Duke University Press.
- Family Health International, Mack, N., & Woodsong, C. (2005). Qualitative research methods: A data collector's field guide. 6-9.
- Galdas, P. M., Cheater, F., & Marshall, P. (2005). Men and health help-seeking behaviour: literature review. *Journal of advanced nursing*, 49(9), 616-623.
- Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American psychologist*, 40(3), 266.
- Gigliotti, E. (2002). A confirmation of the factor structure of the Norbeck Social Support Questionnaire', *Nursing Research.*, Volume (5): 276-84.
- Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R., et al. (2002). What does access to health care mean? *Journal of health services research & policy*, 7(3), 186-188.
- Hamilton, M., Razzano, L., & Martin, N. (2007). The Relationship between Type and Quality of Social Support and HIV Medication Adherence. *Journal of HIV/AIDS & Social Services: Research, Practice, and Policy. 2007;6(12):* 36-63.

Hammersley, M., & Atkinson, P. (2007). Ethnography: Principles in practice: London, Routledge.

- Harper, I., & Raman, P. (2008). Less than human? Diaspora, disease and the question of citizenship. International Migration. 46(5), 3-26.
- Harris, B., Goudge, J., Ataguba, J. E., McIntyre, D., Nxumalo, N., Jikwana, S., et al. (2011). Inequities in access to health care in South Africa. *Journal of Public Health Policy*, 102-123.
- HRW. (2009). Discrimination, Denial, and Deportation: Human Rights Abuses Affecting Migrants Living with HIV. . New York Human Rights Watch.
- Huff Rouselle, M., & Pickering, H. (2001). Crossing the public-private sector divide withreproductive health in Cambodia: out-patient services in a local NGO and the nattional MCH clinic. The International journal of health planning and management 16(1), 33-46.
- Huff Rousselle, M., & Pickering, H. (2001). Crossing the public-private sector divide with reproductive health in Cambodia: out-patient services in a local NGO and the national MCH clinic. *The International journal of health planning and management*, *16*(1), 33-46.
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community based research: assessing partnership approaches to improve public health. *Annual review of public health*, 19(1), 173-202.
- Johnson, L. F. (2012). Access to antiretroviral treatment in South Africa, 2004-2011. Southern African Journal of HIV Medicine, 13(1).

- Johnston D, Stall R, & K., S. (1995). Reliance by gay and intravenous drug users on friends and family for AIDS-related care. *AIDS Care*, 7, 307.
- Kalichman, S. C., Simbayi, L. C., Cain, D., Cherry, C., Henda, C. N., & Cloete, A. (2007). Sexual assault, sexual risks and gender attitudes in a community sample of South African men. *AIDS care, 19*(11), 20-27.
- Kaplan, R., & Toshima, T. (1990). The functional effects of social relationships on chronic illness and disability

New York: John Wiley;.

- Knowlton, A., Hua W, & C., L. (2005). Social support networks and medical service use among HIV-positive injection drug users. :*Implications to intervention. AIDS Care.*, 17, 497-492.
- Lakika, D. (2011). Understanding Illness and Treatment-seeking behaviour among Congolese Migrants in Johannesburg. *Forced Migration Studies Programme. Johannesburg, University of Witwaterstand.*
- Landau. (2005). ed. Forced migrants in the new Johannesburg: towards a local government response. Johannesburg: Forced Migration Studies Programme, University of the Witwatersrand, 2005.
- Landau, L., & , S. W. K., A. (2009). Human Development Impacts of Migration: South Africa Case Study. Johannesburg, UNDP: Human Development. Reports/Research Paper.
- Landau, L. B., & A. Wa Kabwe-Segatti, K. (2009). Human Development Impacts of migration: South Africa Case Study. *Johannesburg*, *UNDP: Human Development*. . *Reports/Research Paper*.
- Landau, L. B., & Wa Kabwe-Segatti, A. (2009). Human Development Impacts of migration: South Africa Case Study. Johannesburg, UNDP: Human Development. Reports/Research Paper.
- Landau;. (2006). Protection and dignity in Johannesburg: shortcomings of South Africa's urban refugee policy. *Journal of Refugee Studies*, 19(3), 308-327.
- Landau, L. (2007). Discrimination and development? Immigration, urbanisation and sustainable livelihoods in Johannesburg. *Development Southern Africa*, 24(1), 61-76.
- Lurie, M. N., Williams, B. G., Zuma, K., Mkaya-Mwamburi, D., Garnett, G. P., Sturm, A. W., ... , et al. (2003). The impact of migration on HIV-1 transmission in South Africa: a study of migrant and nonmigrant men and their partners. *Sexually transmitted diseases*, *30*(2), 149-156.

Lurie, M. N. (2006). The epidemiology of migration and HIV/AIDS in South Africa. *Journal of Ethnic and Migration Studies*, 32(04), 649-666.

- MacPherson, D. W., & Gushulak, B. D. (2001). Human mobility and population health: new approaches in a globalizing world. *Perspectives in Biology and Medicine* 44(3), pp. 390–401.
- Marinankunda, L., Loos, J., & Alou, T., Assebide (2009). It is better not to know": Perceived barriers to HIV Voluntary Counselling and Testing among Sub-Saharan African migrants in Belgium. *AIDS Education and Prevention*,, 21(6), 582-593.
- Mavhu, W., Dauya, E., Bandason, T., Munyati, S., Cowan, F. M., Hart, G., ... &Chikovore, J. (2010). Chronic cough and its association with TB–HIV co-infection: factors affecting help-seeking behaviour in Harare, Zimbabwe. *Tropical Medicine & International Health*, 15(5), 574-579.
- Mavungu, M. (2007). Social Capital, Economic Performance and Political Engagement: A case study of Congolese immigrants in Central Johannesburg. (*Doctoral dissertation*).

- Mbonu, N. C., Van den Borne, B., & De Vries, N. K. (2009). A model for understanding the relationship between stigma and healthcare-seeking behaviour among people living with HIV/AIDS in sub-Saharan Africa. *African Journal of AIDS Research*, 8(2), 201-212.
- McCarthy, K., M. F. Chersich, J. Vearey, G. Meyer-Rath, A. Jaffer, Simpwalo, S., et al. (2009). Good treatment outcomes among foreigners receiving antiretroviral therapy in Johannesburg, South Africa. *International Journal of STD & AIDS 20*, 858-862.
- McIntyre, D. I., Thiede, M., & Birch, S. (2009). Access as a policy-relevant concept in low-and middle-income countries. *Health Econ Policy Law*, 4(2), 179-193.
- Mekomen, Yared, PLC, M. R., Sanders, Tibebu, & Emmart. (2010). *Equity and Access ART in Ethiopia* Washigton, DC: .
- Mitchell, S. K., Kelly, K.J.M., Potgieter, F. E., & Moon, M. W. (2007). Assessing social preparedness for antiretroviral therapy in a generalised AIDS epidemic: a diffusion of innovation approach. *AIDS Behaviour* 13(1), 76-84.
- Mkant, W. (2005). Use of Health Care Services Among Persons Living with HIV Infection: State of the Science and Future Directions. *AIDS Patient Care STDs*, 19(8), 473-485.
- Moyo, K. (2010). Street level interface: the interaction between health personnel and migrant patients at an inner city public health facility in Johannesburg (Doctoral dissertation).
- Mpedi. L.G., & Smit.N. (2011). Access to Social Services for Non-Citizens and the Portability of Social Benefits within the Southern African Development community. *CICLASS, South Africa*.
- MSF. (2009). No Refuge, Access Denied: Medical and Humanitarian Needs of Zimbabweans in South Africa. Johannesburg, Medecins Sans Frontieres (MSF).
- NDOH. (2006). Memo \_ access to comprehensive HIV and AIDS care including antiretroviral treatment: Pretoria: Department of Health.
- Nuwaha, F. (2006). Determinants of choosing public or private health care among patients with sexually transmitted infections in Uganda. *Sexually transmitted diseases*, 33(7), 422-427.
- Nunez, L., & Wheeler, B. (2012). Chronicles of Death Out of Place: Management of Migrant Death in Johannesburg. *African Studies*, 71(2), 212-233.
- Parker, A., & Tritter, J. (2006). Focus group method and methodology: current practice and recent debate. *International Journal of Research and Method in Education*, 29(1), 23-37.
- Patton, M. Q. (1987). *How to use qualitative methods in evaluation (Vol. 4)*: Sage Publications, Incorporated.

Peberdy, S., & Dinat, N. (2011). *Migration and Domestic Work in South Africa: Worlds of Work, Health and Mobility in Johannesburg*. Southern African Migration Programme (SAMP))

- Penchansky, R., & Thomas, W. (1981). "The Concept of Access: Definition and Relationship to Consumer Satisfaction "Medical Care 19(2): 127-140.
- Penrod, J., Preston, D. B., Cain, R. E., & Starks, M. T. (2003). A discussion of chain referral as a method of sampling hard-to-reach populations. *Journal of Transcultural Nursing*, 14(2), 100-107.
- Roura, Maria, Busza, J., Wringe, A., Mbata, D., Urassa, M., et al. (2009). Barriers to Sustaining Antiretroviral Treatment in Kisesa, Tanzania: Follow up Study to Understand Attrition from Antiretroviral Program *AIDS Patient Care and STDs*, 23(3), 1-8.
- RSA. (1996: 27(3)). Republic of South African Constitution.

SACBC (2012). SABS report, Dec 2012 from http://aidsoffice.sacbc.org.za/category/aids office-reports ( Accessed on 15/07/2013).

- Schneider, H., McIntyre, D., & et al. (2006). Researching Equity in Access to Health Care (REACH). Proposal for IDRC Research Grant. Johannesburg, University of the Witwatersrand.
- Shisana, O., Rehle, T., Parker, W., Zuma, K., Bhana, A., Connolly, C., et al. (2005). South African National HIV Prevalence, HIV Incidence, Behaviour and Communication. Survey , 2005. Cape Town, South Africa: HSRC Press.
- Steinberg, J. (2005). A Mixed Reception: Mozambican and Congolese Refugees in South Africa.: Institute for Security Studies.
- Skinner, D., & Mfecane, S. (2005). Stigma, discrimination and its implications for people living with HIV/AIDS in South Africa. SAHARA J (Journal of Social Aspects of HIV/AIDS Research Alliance), 1(3), 157-164.
- UNAIDS. (2010). Report on the Global AIDS epidemic.
- UNAIDS. (2012). UNAIDS, Report on the Global AIDS Epidemic,2012. Retrieved 23/12/2012, 2012, from

<http://www.unaids.org/en/resources/campaigns/20121120\_globalreport2012/globalrep ort/>

- Unge, C., Johannson, A., Zachariah, R., Some, D., Van Engelgem, I., & Ekstrom, A. M. (2008). Reasons for unsatisfactory acceptance of antiretroviral treatment in the urban Kibera slum, Kenya. *AIDS Care 20*(2), 146-114.
- UNHCR. (2012). UNHCR Global Appeal 2013 update. Retrieved 16/01/, 2013, from <a href="http://www.unhcr.org/pages/49e485aa6.html"></a>
- Vass, J. (2003). The relationship between labour market dynamics and HIV/AIDS prevalence: a literature review. Paper presented at the conference The Challenge of Growth and Poverty: The South African Economy Since Democracy, Annual TIPS/DPRU Forum, Indaba Hotel, Johannesburg, South Africa, 8–10 September 2003.
- Vearey, J. (2008). Migration, access to ART, survivalist livelihood strategies in Johannesburg. African Journal of AIDS Research 7 (3) 361-374
- Vearey, J. (2011). Learning from HIV: Exploring migration and health in South Africa. *Global Public Health*(1), 1-13.
- Vicsek, L. (2007). A Scheme for Analyzing the Results of Focus Groups. *International Journal Qualitative Methods*, 6 (4) 20-34.
- Vigneswaran, D. (2007). 'Lost in space': Residential sampling and Johannesburg's forced migrants. Migration Methods and Field Notes No. 4. Johannesburg, South Africa, University of the Witwatersrand, Forced Migration Studies Programme.
- Waddell, E. N., & Messeri, P. (2006). Informal social support for HIV medical care. *Journal of HIV/AIDS & Social Services*, 5(3-4), 121-139.
- Wood, K. (2004). The Moral Economy of AIDS in South Africa. Nattrass N. Cambridge: Cambridge University Press, 2003, pp. 224,£ 19.95 (PB). ISBN: 0521548640. International Journal of Epidemiology, 33(6), 1416-1417.
- Zuckerman, J. N., Rombo, L., & Fisch, A. (2007). The true burden and risk of cholera: implications for prevention and control. *The Lancet infectious diseases*, 7(8), 521-530.

### **Appendices**

#### Appendix 1: Healthcare providers' interview guide

#### **INTERVIEW SCHEDULE FOR HEALTH PROVIDERS**

## TOWARDS UNDERSTANDING EXPERIENCES OF ACCESSING ANTIRETROVIRAL TREATMENT SERVICES AMONG CONGOLESE MEN AT CLINICS IN YEOVILLE, J OHANNESBURG

#### Demographic information of health provider

-How long have you been working in this healthcare facility?

-How old are you?

-What is your position (function) in this healthcare facility?

-What is the reason for you to come to work in Johannesburg?

-What is your nationality?

.....

# 1. What do Congolese men experience in governmental and non-governmental clinics with regards to access to ART at clinics in Yeoville?

-When do you open and close this clinic?

-What is the scale or number of non-citizens/cross-border women and men seeking medical treatment at this healthcare facility on a daily basis?- Of these, what proportion are men?

-Of these proportion of men, approximately how many Congolese? Have you ever been given any training or information on migrant rights to health generally?

-Have you ever been given any training on migrant rights to ART specifically?

-Can you tell me, to the best of your knowledge, what rights migrants have to access ART?

-In your opinion what rights should migrants have to access ART?

-How many non-citizens would you say you assist each week at this site?

- Which countries do the non-citizens/cross-borders frequenting this facility come from? Of these countries, how do you provide drugs/medication to non-citizen/cross-border men who do not speak English and any of South African language?

- What are the most difficult parts about providing antiretroviral services to men?

- What are the most difficult parts about providing antiretroviral services to women and men?

-To the best of your knowledge; what rights do non-citizens/cross-borders have to access healthcare services in this healthcare facility?

- Which health services in particular are they entitled to?

-There have been reports in the media and research reports that cross border migrants are sometimes denied primary health care services. Does this happen here in this clinic?

- If it happens; what is normally the reason for this?

- Have you ever been in a position where you had to deny treatment to a patient because they did not have identity documents?

- How often do you find yourself in this position?

- Does this also happen with undocumented South Africans?

- What do you do in the case of South African nationals; do you give them treatment or not?

- How do you differentiate between nationals and non nationals if they both do not have papers?

-What do the following documents mean to you?

- Do you refer to any of them in the decisions you make regarding the provision of healthcare to undocumented migrants

-The national department of health directives of 2006 and 2007

- The Gauteng department of health directive of 2008

- The constitution of South Africa.

# We are finished with the interview, is there anything you would like to ask or add?

Thank you

#### Appendix 2: Congolese men on ART interview guide

#### INTERVIEW SCHEDULE FOR CONGOLESE MEN ON ART

## TOWARDS UNDERSTANDING EXPERIENCES OF ACCESSING ANTIRETROVIRAL TREATMENT SERVICES AMONG CONGOLESE MEN AT CLINICS IN YEOVILLE, JOHANNESBURG

#### **Demographic information of respondent:**

-How long have you been in Johannesburg?

-Where do you live here in Johannesburg?

-How old are you?

-What country are you from (home country)

-Where were you born?

-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)?

-What is your health status?

-How long have you been taking your medication/drugs (ARVs)?

\_\_\_\_\_

-What is the name of this clinic?

When does it open and close?

-When did you test for HIV and why did you test?

-When did you start your ART?

-Did you test before you come to South Africa?

-What were the reasons that made you come to this clinic?

-How many public and private clinics are there in your area?

-Have you ever been denied any health services in one of these clinics?

- If yes, what was the problem?

-What is the name of that clinic?

-Where is your nearest primary healthcare clinic?

-What is its name?

-Compare this clinic (Nazareth House/Yeovillel) to other healthcare clinics, what was the reason for you to come in this clinic?

What the mode of transport to you use to come in this clinic?

2. What is the acceptability, affordability and availability dimensions of access ART experienced among Congolese men in governmental and non-governmental clinics in Yeoville?

- What is that you have to possess with you before you access to the treatment in this clinic?

-What happens if you do not have it?

- In the last three months, were there times when you were waiting for long time to collect your medications/drugs (ARVs) in this clinic?

-If yes, what was the problem?

-In the last three months, have you ever been a victim of assault because of your nationality in this clinic?

-If yes, what happened?

-Who did it to you?

- What is your experience in this clinic, do they treat you with respect when you need your medications/drugs (ARVs)?

-How long does it take to walk to the nearest clinic?

-Are there any transport challenges to get to come here in this clinic?

-If yes, what are these challenges?

- What is the means of transport do you use to get in this clinic?

- In the last three months, how much did you pay for you transport to come here in this clinic?

-Do you feel safe to collect your medications/drugs (ARVs) in this clinic?

- If no, what is the problem?

-Have you ever been denied access to the public/private health services?

-What were the reasons?

-Do you this you would be denied services if you were to visit public/private health services?

-If yes, why?

- At what time do you take your medications/drugs (ARVs)?

- Who chose this time for you?

-If so, why?

- What was the reason for you to test for HIV in Johannesburg?

-How much time have you tested since you are in Johannesburg?

- Why?

-Did you test where you come from?

-Why?

# 3. How do the social networks, livelihoods, income, housing and food security situations contribute to the experiences of access to ART in the lives of the Congolese men at Yeoville clinics?

-In the last three months, has anyone in your household supported you?

-What is the relationship with you and the person who supported you?

-What kind of support was it?

-Do healthcare providers in this clinic support you?

-Who (doctor, nurse, counsellor) supported?

-What was his/her support to you?

-How often is that support to you?

- Who looks after you when you feel sick?

-How would they look after you?

-Have you disclosed your HIV status to anyone?

-If so, who and why this person/these people?

-Does anyone know you are on ART?

-If yes, who and why did you tell this person/these people?

-In last three months, what have you been eating?

-Can you tell me what you have eaten and drank in the last 24 hours?

-Do you think your access to food has changed since you are in ART?

-What has changed?

-In last three months, when food security was poor?

-What do you do when you do not have enough food in your household?

-Does anyone in household help you with food?

-In the last three months, were there times you take medications/drugs without food?

- In the last three months, were there times went out hungry?

-How many times do you eat day?

-How many times a day do you sleep?

-What do you do to maintain your health good?

-Can you describe the place you are staying?

-Is it a flat or room?

-How many people are you staying within your sleeping room?

-How many people sleep with you on the bed?

-How many are you in your flat or room?

-Do you take your drugs when you are at home/outside?

-If so, Why?

-What do you do in order to survive?

-How many hours a day do you work?

-What kind of work do you do?

-Are you self employed?

-How would you describe your job?

-Last week, how many hours did you work?

-Are you working according to your training or profession?

- Why not?

2. How is the antiretroviral therapy provided to Congolese men in nongovernmental clinic shed light on the results of a previous research that found that non-citizens have better antiretroviral treatment outcomes than South African citizens (McCarthy et al, 2009)?

- In the last three months, have you ever missed to collect your medications/drugs (ARVs)?

-If yes, what were the reasons?

-If no, what do you do to plan your appointment?

-In the last three months, have you had complain about your health?

-If no, what can be the reasons?

-If yes, what did you do to solve the problem?

We are finished with the interview, is there anything you would like to ask or add?

#### Thank you

#### **Appendix 3: Health Department letter of confirmation for the Yeoville clinic (Region F)**



Sity of Johannesping Heal 5 Department

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PO BA Braam Sourt-Sourt21044 (et 12.49113-407-75.3 2107 - av (2.400-11-308-466 2013

17 July 2012

#### TO WHOM IT MAY CONCERN

This is to confirm that the City of Johannesburg: Health Department agrees in principle in allowing Mr. Adrien Bazolakio Swambo, from the University of the Witswatersrand, to conduct a research study in Region F.

Final approval by the Executive Director: Health is subject to the receipt of the ethics approval to be awarded by the University and the final protocol of the CoJ Research Committee.

17/07/2012 DR. BASKI DESAL

DIRECTOR: PUBLIC HEALTH 011 407 6607 082 464 9551

cc: Executive Director, Dr. R. Bismilla

#### **Appendix 4: Ethics Clearance Certificate**

\_\_\_\_ UNIVERSITY OF THE WITWATERSBAND, KOUANNESBURG Division of the Depoils Registrat (Reason of the HEMAN RESUARCH RITHICS & OMMITTER (MEDICAL) R14:49 Mr Adrien Bazolakia M120849 CLEARANCE CERTIFICATE Towards Understanding Experiences of Accessing to Amiretroviral Treatment Services among Congolese Men in Ycoville Clinics VROJECT. in Johanneaburg (ravised title) Mr Adrien Bazolakio. African Centre for Migration & Society (ACMS) <u>INVESTIGATORS</u> DEPARIMENT 31/08/2012 <u>DATE CONSIDERED</u> Approved inaconditionally DECISION OF THE COMMUTTEE Unless otherwise specified this ethical cleargage is valid for 5 years and may be renewed apon llista application. aw. (Protessor PL Cleaton-Jones) CHAIRPERSON ..... 2)/11/2012 <u> 11 A TE</u> \*Quidelines for written 'informed consent' attached where applicable ce: Superviser : Or to Vesrey ..... \*\*\*\*\*\* DUCLARATION OF INVESTIGATOR(S) To be completed in haplicate and ONE OUPY returned to the Secretary at Rocan 10004, 10th Fluor, sense rouse, ourversey. 1/We fully understand the conditions under which I and/we are antiorized to carry out the abuvementioned there name an event and the constraints once, which is one we are anothered to dary out the approximation of the protocol of the compliance with these conditions. Should any departure to be research and twie generance to ensure compliance who these connitions. Should any acparitie to en-contemplated from the research procedure as approved lowe undertake to resubinit the postocol to the Committee. Lagree this completion of a year's progress report. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES... t

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#### Appendix 4: Nazareth House HIV Clinic letter of Confirmation

Ŀ Nazareth House Johannesburg Clinic of Hope and Love . Date: 18 October 2012 Adrien Bazolakio Wits African Centre for Migration & Sociely 0727405349 ÷ Re: <u>Confirmation for approval of a study comparing the experiences of Congolese and</u> <u>SA males living with IIIV/Aidsta Yeoville Community</u> ī ţ ı. This letter serve to authorize the request by Andrien Bazolakio to conduct her research project with Clinic of Hope situated in Nazareth House Johannesburg. The research is expected to start in October 2012 and depending on the availability of information it should finish by the end on the year. i Thank you for your time and we are looking forward to interacting with you. And we would like to wish you luck with your research. I I Sincerely, ł Bempulato ART Clinic Head. Sr Sylvia ı. : . ł ..\_\_) ŧ į · \_---

#### Appendix5: Audio-taping Logged Consent form

#### Audio-Taping: Logged Consent Form

I give my consent to be autio 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: "Exploring experiences of antiretroviral therapy services among Congolese men in Yeoville clinics. Johannesburg". I understand that after the tapes will be kept for 2 years after publication, or for 6 years if no publication results. I also understand that I am free to withdraw this consent at any line.

#### PARTICIPANT:

I agree to participate in this research project I do not agree to participate in this research

Witness Two:.....Signature:

#### **Appendix 6: Audio-Tapping written Consent Form**

#### Audio-Taping: Written 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: "Towards understanding experiences of accessing to antiretroviral therapy services among Congolese men in Yeoville ellnics, Juhannesburg". Understand that after the tapes will be kept for 2 years after publication, or for 6 years if no publication results. I also understand that Lain free to withdraw this consent at any time.

#### FOR WRITTEN CONSENT ONLY - PARTICIPANT:

| I ugree to participate in this research project | I do not agree to participate in this research |
|---|--|
|   |  |