Socio-demographic factors affecting adherence to antiretroviral therapy in a wellness centre in South Africa

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DECLARATION

I, Portia Thandazile Simelane**,** declare that this thesis: “Socio-Demographic Factors Affecting Adherence to Antiretroviral Therapy in a Wellness Centre in South Africa” is submitted for the degree of Doctor of Philosophy in Population Studies of the North-West University. The thesis has not been submitted before, in part or in full, for any degree or examination at this or any other institution. All materials used from other sources have been duly acknowledged and referenced in the thesis.

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APPROVAL

This is to certify that the thesis has been submitted as a fulfilment of requirements of the award of the degree of Doctor of Philosophy in Population studies of North-West University Mafikeng Campus with my approval.

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DEDICATION

To Jehova Bal-Perazim, The Master of Breakthroughs!!! Glory, Honour, Majesty and Adoration Belongs to Him Forever and Ever. I will forever be grateful to God for granting me the strength, determination and patience to successfully finish this Phd.

To my late Mom for the great work that she did in empowering me with the greatest weapon of all: Education. This dissertation is dedicated to her memory.

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ABSTRACT

Patients' non-adherence to antiretroviral treatment remains a public health challenge in most developing countries, including South Africa. Although the Government avails all efforts to ensure ART availability in hospitals around the country, non-adherence to ART is still a major concern. Accordingly, quantitative and qualitative data were collected from patients enrolled into treatment between 2010 and 2014. These mixed methods were applied at a wellness centre in the Mpumalanga province of South Africa to examine the effect of selected social and demographic factors on patients' antiretroviral therapy treatment. The sample size of the quantitative approach was 777 patients enrolled on ART, of which 486 patients made up the group of patients who have not defaulted, while 291 patients made up the group of defaulting patients. On the other hand, the qualitative survey covered 20 patients, including 10 defaulters and 10 non-defaulters, to ascertain the psychosocial factors influencing ART uptake at the Piet Retief Wellness Centre.

The quantitative approach, therefore, indicated that the patients started defaulting from the first month of initiating treatment and all patients ended defaulting by the 55 months. In terms of the socio-demographic predictors, while there was no statistically significant association between gender and marital status on the one hand and treatment default on the other, age was significantly and positively associated with treatment default. Also, educated patients were less likely to default on treatment compared to their less educated counterparts. Similarly, employed patients and patients who resided in urban areas were more likely to default on treatment. Subsequently, the findings from the qualitative analysis revealed that poor service quality negatively influence ART uptake, adverse effects from ART negatively affect ART uptake and barriers / challenges to ART uptake as faced by patients, such as financial, psychological and physical barriers negatively affect the uptake of ART. Interventions aiming at dealing with these issues as identified and discussed in the study have to be developed and put in place to ensure success in the administration of ART in Mpumalanga province of South Africa.

In conclusion, interventions that will support people on ART in wellness centres around the country should be developed and strengthened. Accordingly, all organizations should develop an HIV and AIDS workplace policy, that the Government of South Africa through the National Department of Health monitor and emphasize the importance of ensuring ART quality services in all HIV clinics around the country and finally interventions in terms of finances to meet the escalating food and transport demand for people on ART should be put in place to ensure that adherence is for a lifetime. There is also a need to undertake further research on socio-demographic and psychosocial factors affecting patients' adherence to ART utilizing the survival analysis, focusing on all wellness centres in South Africa.

Key Words: *Piet Retief, HIV and AIDS, Antiretroviral treatment, Patients, Defaulters, Non-defaulters, Wellness Centre, Survival Analysis, Health Belief Model, South Africa.*

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AIDS : Acquired Immunodeficiency Syndrome

ART : Antiretroviral Therapy

HBM : Health Belief Model

HIV : Human Immunodeficiency Virus

IDI : In-depth interview

NDH : National Department of Health

REACH : Reach on Access to Care in the Homeless

STATS SA : Statistics South Africa

NSP : National Strategic Plan

UN : United Nations

UNAIDS : Joint United Nations Programme on HIV/AIDS

USA : United States of America

USAID : United States Agency for International Development

WHO : World Health Organization

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND OF THE STUDY

It has been more than 30 years since the first case of HIV was reported around the world and the AIDS epidemic grew from less than 10 million being infected worldwide in 1990 to 36.9 million people being infected in 2017 (UNAIDS, 2018). With regard to HIV and AIDS mortality, it has been reported that 940 000 people have died of HIV and AIDS-related illnesses as at the end of 2017 (UNAIDS, 2018). Variations in terms of HIV prevalence rates, which is the total number of people living with HIV and AIDS within a country, have been witnessed between developed and developing countries. For example, while Asia and Pacific regions constituted a total of 5.2 million people living with HIV and AIDS in 2017, there were 19.6 million people infected with HIV in sub-Saharan countries in the same year (UNAIDS, 2018).

In fact, Africa is the worst affected region in terms of the HIV prevalence. While sub-Saharan Africa constitute only a third of the global population, more than 25 per cent of all HIV infections are found in the region with a total of 19.6 million people who are HIV positive (UNAIDS, 2018). In support of this, the United Nations Programme on HIV/AIDS (UNAIDS,2017) states that sub-Saharan Africa remains the most heavily affected region in the world, accounting for 43% of all new infections in 2016. On the other hand, the Eastern Europe and Central Asia regions are the least affected as there were only 321 800 people living with HIV and AIDS in 2015 (UNAIDS, 2016). Sub-Saharan Africa has indeed suffered a double blow from the HIV pandemic as this region is also dealing with issues related to poverty, a shortage of skilled labour, very weak economies and collapsing health care systems within these countries.

The epidemic in sub-Saharan Africa continues to affect individuals, families, households, communities and businesses negatively. The disease has had a major impact on the economies of African countries and has delayed the development of many countries around the world, particularly sub-Saharan African countries (UNAIDS, 2016). Countries in sub-Saharan Africa spend US$30 per year on treatment costs for HIV for every infected person, while the total health spending is below US$10 per year in most countries in Africa (UNAIDS, 2016). Moreover, it has been shown that patients who are HIV positive spend up to four times longer in hospitals compared to non-HIV patients and in the majority of countries in sub-Saharan Africa, for example South Africa, 60 to 70 per cent of hospital expenditure will be due to HIV and AIDS in few years to come (UNAIDS, 2016). Other studies have found that the effect of HIV and AIDS on national economies include high death rates, decreased life expectancy and a huge burden on the health systems of these countries (David & Li, 2008).

Southern Africa remains the area most severely hit by the HIV and AIDS epidemic and it is a host to the nine countries with the highest HIV prevalence in the world (Van Dyk, 2013). These countries are Swaziland with 25.9% prevalence rate, followed by Botswana and Lesotho with 25% and 23.4% prevalence rates respectively. Zimbabwe has a prevalence rate of 18.1%, while South Africa, Zambia and Malawi has a prevalence rate of 16.9%, 14.3% and 12.7 % respectively (Van Dyke, 2013). Malawi remains the least affected country among the nine.

South Africa is among the countries that are most affected by the HIV and AIDS epidemic with a total of 7.52 million people living with HIV and AIDS in South Africa (UNAIDS, 2018). AIDS is still reported to be the leading cause of death among adults in South Africa. In 2015, a total number of 162 445 people died in South Africa from HIV-related illnesses, which was 30.5% of all deaths (UNAIDS, 2016). In addition to this, deaths from HIV and AIDS in 2011 numbered 270 000 (Statistics South Africa, 2015). HIV prevalence in the total population is 10.2 per cent and HIV incidence in the 15–49 age group is 11.1 per cent. About 60 to 80 per cent of the people infected with HIV are also infected with opportunistic infections such as tuberculosis (Statistics South Africa, 2015). HIV and AIDS have negatively affected the economy of South Africa. In fact, the disease has hugely reversed the great strides the country has made in the domain of socio-economic development.

Globally, there has been great achievement in reversing the spread of the disease through various efforts. This has been witnessed through the reduction in HIV and AIDS prevalence from 24.7 million people in 2006 to 22.2 million in 2010 (UNAIDS,2016). In addition to this, there has been a reduction in new HIV infections from 1.9 million people in 2007 to 1.8 million people in 2010 (UNAIDS,2016). Finally, there has been a decline in mortality rates, a decrease in the number of new infected people and a reduction in AIDS mortality from more than 2 million in 2005 to 1.4 million in 2010 (Nachega et al., 2016). Furthermore, annual AIDS-related deaths have decreased by 43% since the first 2003 UN target for decreasing AIDS mortality rates (UNAIDS, 2016). Also, there has been a reduction in AIDS-related mortality in some of the worst affected regions of the world such as Eastern and Southern Africa where AIDS-related mortality has declined by 36% since 2010 (UNAIDS, 2016).

However, in spite of the decline in mortality rates, countries around the world are still facing serious challenges resulting from new HIV infections. For example, in 2015 there were 2.1 million new HIV infections worldwide, adding up to a total of 36.7 million people living with HIV (UNAIDS, 2016).The challenge of new infections without a doubt negates the gains countries have made globally in the fight against HIV and AIDS. This portrays the impression that there are still people around the world who practise risky sexual behaviours, which include not adhering to ART and then engaging in unprotected sex, resulting in new infections and re-infections of the HIV-positive patient (UNAIDS, 2016). The persistently increasing number of new HIV infections resulting from non-adherence to ART and unprotected sex resulting to HIV re-infections calls for urgent interventions to be taken by all countries globally in ensuring equitable access to ART. There is therefore an urgent need to ensure that there is adequate availability of ART globally as a strategy to ensure that people adhere to treatment as per the specification of hospital staff where they have been initiated into ART.

1.1.1 Global ART Coverage

Worldwide, the first ART drug (zidovine) was approved for use in 1987 and its primary purpose was to prevent mother to child transmission of HIV. However, South Africa only made this drug available after 2002 (Van Dyke, 2013). The late introduction of ART in South Africa resulted in the deaths of more than 300 000 people as they could not access treatment at a time when they needed it the most (Van Dyk, 2013). The primary goals of antiretroviral therapy is to improve the quality of life, to reduce HIV-related morbidity and mortality and to provide maximal and durable suppression (UNAIDS, 2014). Accessing antiretroviral treatment (ART) on time is very crucial to the health of HIV-positive people, and in reducing the transmission of HIV (Kim et al., 2017). In 2015, the World Health Organization (WHO, 2016) released revised global guidelines for HIV treatment and care, with the recommendation that every person who tests positive for HIV should be recommended for ART regardless of the CD-4 count, a policy referred to as “test-and-treat” policy that commissions all countries around the world to ensure that all patients who test positive for HIV are introduced into treatment.

The success of the “test-and-treat” policy was evidenced by the fact that in 2015 there was a total of 17 million people on ART globally (UNAIDS, 2016), a tremendous improvement from the total number 15 million people on ART in 2010. This constituted a global coverage of 46% of the total number of people who should be provided with ART. The global increase in the number of people accessing treatment has also hugely contributed to the decline in AIDS-related mortality rates. While in Latin America and the Caribbean, treatment coverage reached 55% between 2010 and 2015, treatment coverage for the Asian and Pacific region doubled from 19% to 41 % (UNAIDS, 2016). Eastern Europe and Central Asia still face challenges in terms of ART accessibility as the treatment coverage in 2015 was 21%, which was a marginal increase from 2010, that means about one in five people has access to treatment (UNAIDS, 2016).

On the other hand, in sub-Saharan Africa, ART coverage increased from 24% in 2010 to 55% in 2015, which resulted in a regional total of 10.3 million people on treatment (UNAIDS, 2016). For example, countries in which treatment coverage was increased by more than 25 and above percentage points between 2010 and 2015 include Botswana, Zambia, Zimbabwe, Mozambique, Swaziland and Uganda, among many others (UNAIDS, 2016). All these countries constitute the Southern African countries.

1.1.2 South Africa's Response to HIV and AIDS

South Africa has one of the largest HIV epidemics globally and of the estimated 36.9 million people living with HIV and AIDS in the world, 7.52 million people are in South Africa (UNAIDS, 2018). According to Statistics South Africa (2015), the HIV prevalence in the total population is 12.7%. Following a recommendation that was made by UNAIDS (2014) that all countries must scale up ART to ensure that people living with HIV have access to treatment, the administration of ART was scaled up in local clinics in several sub-Saharan African countries. This has resulted in clinics having tremendous increase in the number of patients on ART, from an estimate of almost 100 000 people in 2003 to 3.9 million in 2009 (Ayalu & Sibhatu, 2011). In South Africa, the number of people living with HIV and AIDS is about 7.52 million, reaching the 90-90-90 target (StatsSA, 2018). The 90-90-90 target is a recommendation by UNAIDS (2014), which requires countries to scale up HIV testing so that 90 per cent of the people living with HIV are aware of their status, 90 per cent of the people diagnosed with HIV are linked to antiretroviral treatment (ART) and 90 per cent of those on ART adhere to treatment and have undetectable levels of HIV in their blood (UNAIDS, 2014).

In terms of ART availability, South Africa, has the largest ART programme worldwide with a total of 4.3 million people on treatment (UNAIDS, 2018). This shows that the country has invested a lot of money and other resources into AIDS treatment. In support of this, the National Strategic Plan for HIV, TB and STIs 2017-2022 (NSP, 2016) states that the South African government pays for 80 per cent of the total R23 billion currently used towards HIV and TB services. Despite these advantages, ART uptake and adherence remain suboptimal in South Africa. Studies on patients ART default conducted around the different Provinces in South Africa revealed that the issue of ART defaulting is a major challenge. For examples, Rosen et al. (2007) conducted 32 studies on ART non-adherence and discovered that at two years of treatment, 38% of patients had defaulted from treatment. Further, Fox and Rosen (2010) made an analysis of 33 studies which also revealed an overall non-adherence rate of 28%. This means that only 72% of patients faithfully adhered to ART. In addition to this, a systematic review of South African ART cohorts published between 2008 and 2013 found that approximately only two-thirds of patients who initiated ART remained in care four years later (Erasmus *et a*l., 2014). Thus, even though ART has been available in public health centres in South Africa since 2003, adherence to treatment still remains a challenge. ART is a lifelong treatment and requires patients to adhere diligently to medication on a daily basis. Several scholars have observed that getting patients to adhere diligently to treatment every day for their lifetime is one of the greatest challenges that need serious attention (Talam et al., 2008).Within this context, the South African AIDS Council (2011) has recommended that any barriers preventing patients from accessing ART-related services such as testing, treatment and care needs to be removed by the government through the Department of Health to ensure that patients benefit from this life saving treatment.

1.1.3 Adherence to ART

Adherence to ART is one of the most important predictors of treatment efficacy. Adherence is defined as taking medications or interventions correctly according to prescription **(**Van Dyk, 2013). In support of this, Sharma et al., (2013) defines adherence as the extent to which the patient continues an agreed-upon mode of treatment. ART medication adherence results in improving the survival rates of patients and it helps in preventing drug resistance (UNAIDS, 2014). For HIV positive patients to benefit from ART fully, strict adherence to treatment instructions is critical. There are different methods for assessing adherence, and the level of adherence is specific, not only to places and patient groups but also to the method of adherence measurement used. They include direct methods such as biologic markers and body fluid assays, or indirect methods such as self-report, interview, pill counts, missing ART refill appointments, pharmacy records, computerized medication caps, and viral load monitoring (Osterburg & Blaschke, 2005). While a combination of these methods may be employed in South Africa generally, the methods used for non-adherence is missing ART refill appointment and patient self-report given its ease of implementation and use of already existing resources (Osterburg & Blaschke, 2005).The current study utilized the same method.

Globally long-term patient retention on ART is now being considered one of the major challenges facing public sector ART programmes (Sasaki et al.,2012) . According to Kim et al. (2014), non-adherence is the most important factor known to be associated with treatment failure for HIV patients in both developed and developing countries. Studies conducted around the world show that there is a relationship between socio-demographic factors and non-adherence to medication. For example, a study conducted by Inui, Yourtee and Williamson (1976) on adherence to anti-hypertensive regimens with the aim to emphasize strategies for increasing regimen adherence, revealed that educating patients about the importance of adhering to medication resulted in patients being more knowledgeable about hypertension, the dangers of hypertension and the benefits of adhering to medication. Therefore, educating patients on the medication, side effects and the dangers on being non-adherent to the medication is a very important consideration on the part of both the service providers and the country as a whole.

Regarding non-adherence to ART globally, studies conducted in different parts of the world stress the increasing challenges of non-adherence to ART by patients. For example, in North America, a pooled analysis of adherence studies found that 45% of patients on ART were not adherent to ART (Nachega et al., 2006). Further, studies conducted in Brazil on ART non-adherence revealed that 34% of patients were not adhering to their medication (Bonolo et al., 2005). In Spain, researchers discovered that 43% of patients on ART were not adhering to ART (Gordillo et al., 1999).

With regard to sub-Saharan Africa, this region has the highest number of people living with HIV and AIDS compared to the rest of the world. Out of the estimated 34 million people infected with the virus in the year 2010, 68% resides in sub-Saharan Africa (UNAIDS, 2011). The sub-Saharan Africa region is also hit hard by the challenge of non-adherence to ART medication. Studies conducted in sub-Saharan Africa attest to this challenge of ART non-adherence among patients. For example, a study that was conducted by Rosen et al. (2007) observed that ART programmes in Africa have only managed to retain approximately 60% of patients on therapy at two years after initiation of therapy. Another study that was conducted by Nachega et al. (2006) on ART adherence estimated that the rate of adherence in sub-Saharan Africa is 77 per cent, and the non-adherence rate in the adult population was estimated between 33 and 88 per cent depending on the measure of adherence used. It ranges from patient reports to patient file reviews for missed ART appointments. Further to this, a systematic review of data from ART programmes in sub-Saharan Africa (SSA) reported ART default rates of 23% at 12 months, 25% at 24 months to 30% at 36 months, with most ART defaulting occurring within the first year after ART initiation (Fox and Rosen, 2010). In sub-Saharan countries, varying high levels of non-adherence at country levels have been witnessed. For example, a study that was conducted by Elul et al. (2013) found that 23% of ART patients were non-adherent based on a 30-day recall. In rural Zambia, a study that was conducted by Sasaki et al. (2012) revealed that 40% of the patients who were on ART were not adherent.

In the Southern African region, pooled analysis of African adherence studies have reported non-adherence to ART to be 23% and above (Mills et al., 2006). In South Africa, research indicates that adult retention in ART is deteriorating over time, with patients who started ART more recently being more likely to default compared to those who initiated ART in earlier years (National Department of Health, 2015). Other studies conducted in South Africa have also revealed that the issue of retention is a major challenge. For example, in 32 studies reviewed by Rosen et al. (2007), the retention rate at two years of treatment was at 62%. Moreover, in an analysis of 33 studies, they found a retention rate of 72% at 3 years of treatment.

A study conducted by Cornell (2010) in Khayelitsha, South Africa, among 3 595 adults enrolled in HAART over 5 years showed that the cumulative proportion of patients remaining in care at 54 months after initiation on treatment was 78%. This shows that generally patients on ART in South Africa default on treatment. Another study that was conducted in the Western Cape province of South Africa conducted by Boulle et al. (2008**)** found that 14.7% of the patients defaulted treatment. Furthermore, a study that was conducted in the Gauteng, Eastern Cape and Mpumalanga provinces of South Africa showed an ART default rate of 28%. In KwaZulu-Natal Province, Vella et al. (2010) found that ART default rate was 19%. In addition to this, a study that was conducted in the Eastern Cape by Ford, Reuter, Bedelu, Schneider and Reuter (2006) showed that the ART default rate was 24.9%. In her research on ART adherence following the national antiretroviral rollout in South Africa, Van Dyk (2011) discovered that only 40.1% of the patients could reach optimum adherence levels of 90% and above, while 49% reached adherence levels between 70% and 80 per cent (Van Dyk, 2011). In addition to this, a further 10.9% could not even reach adherence levels of 70 % (Van Dyk, 2011).

ART is a complex treatment that requires not only availability of the clinical sites, but serious monitoring to ensure that patients carefully adhere to the treatment regimens to prevent drug resistance and improve on the survival rate of patients.

1.2 Statement of the Problem

As the above review of studies on the prevalence of HIV and AIDS and non-adherence on antiretroviral treatment clearly shows, not much has been done on the subject of the socio-demographic factors that affect HIV patients' adherence to ART, especially in the South African context, Mpumalanga province. This gap in the existing body of knowledge is lamentable, especially given the concern in recent years about the rate of re-infection in the country (information presented at a recent HIV and AIDS conference held in Durban in 2016 highlighted the problem of re-infection). According to the HIV and AIDS Global Report by UNAIDS (2010), there were about 1.2 million people in South Africa who received ART treatment in the year 2009, while the WHO (2013) estimates that South Africa has the largest antiretroviral treatment (ART) programme in the world, with more 2.2 million people on HIV treatment in 2012.

Thus, even though ART has been available in public health centres in South Africa since 2003, adherence to treatment still remains a challenge. ART is a lifelong treatment and therefore requires patients to adhere diligently to medication on a daily basis. Several scholars have observed that getting patients to adhere diligently to treatment every day for their lifetime is one of the greatest challenges and it needs serious attention (Talam et al., 2008). Within this context, the South African AIDS Council (2011) has recommended that any barriers preventing patients from accessing ART-related services, such as testing, treatment and care, should be removed by the government through the Department of Health to ensure that patients benefit from this life-saving treatment.

Despite the above-mentioned challenges in regard to patients' adherence to HIV and AIDS treatment, there is a paucity of studies on the issue of ART non-adherence in South Africa as a whole, and in particular adherence at the Piet Retief Wellness Centre, which is one of the major clinics in the country providing HIV and AIDS treatment. Out of the total of 12 381 patients who had been initiated into treatment between 2005 and 2014, a total of 3 560 patients had defaulted treatment at Piet Retief Wellness Centre.

The aim of the present study is to contribute to the existing literature by examining the socio-demographic factors affecting patients' adherence to ART. In addition to the socio-demographic factors, studies conducted in different parts of the world have shown that psychosocial factors also affect adherence to ART (e.g. Goudge & Ngoma, 2011; Lakey & Drew, 1997; Dlomo, 2010; Yoder, Mkize, & Mzimande, 2009). This study was conducted at the Piet Retief Wellness Centre in the Mpumalanga province of South Africa. This centre is an antiretroviral treatment facility (where people are introduced into ART and are monitored for a lifetime), which is a section of the Piet Retief Hospital in the Mpumalanga Province of South Africa. In South Africa, it is a fundamental requirement by the National Department of Health (NDH) for any ARV treatment facility to be accredited before providing ART to patients. Piet Retief Wellness Centre was accredited in 2005 and since then has been providing a comprehensive package of HIV and AIDS services to patients. The Centre is an out-patient facility and to date, a total of 12 381 patients have been initiated into ART. As mentioned above 3 560 of these patients have defaulted from ART.

At the Piet Retief Wellness Centre, prior to a patient being initiated on ART, a readiness assessment is carried out as a basis to support the patient with adherence to the treatment. To this effect, an adherence checklist is used to guide the counsellors on the topics that should be emphasized during the ART readiness assessment. Patients are taught about the treatment regimens, side effects and the importance of adherence to ART. In spite of all the efforts made by the Wellness Centre to educate patients on the importance of adhering to ART, there is still a high number of patients who default from ART.

1.3 Justification of the Study

Previous studies conducted on the socio-demographic factors affecting patients' adherence to ART in South Africa and in other places around the world have hugely relied on patients' self-reports as one of the methods for measuring ART adherence. The main limitation of self-reports by patients is the problem of social desirability where the patient is tempted to give answers that they perceive to be desirable. This results in data that are not reliable. The present study seeks to make a contribution to knowledge by making use of clinical files of the subjects (both defaulters and non-defaulters) to collect the data for the study. This approach brings about the benefits of reliability as the information that will be utilized is recorded on the patients' files and it is reliable compared with the controversial approach of self-reports, which comes with issues such as social desirability.

Furthermore, while previous studies conducted on these issues have focused only on those patients who have defaulted from treatment, the current study adds value to literature whereby patients who have defaulted by the time of the survey and those who have not are compared. The importance of such knowledge for policy makers and clinic staff cannot be overemphasized in that an understanding of the socio-demographic factors affecting adherence to ART will positively contribute to efforts to ensure that interventions are put in place to support patients to adhere to ART. The Cox regression (survival analysis) was utilized in this study for multivariate analysis as survival analysis examines and models the time it takes for an event to occur. The Cox proportional hazard model was used to examine the effect of multiple factors. The benefits of using the Cox regression proportional hazard model for this particular study is that while the conventional regression method normally used by many studies conducted on the socio-demographic factors and adherence treats patients that have not defaulted at the time of the survey as missing cases, survival analysis treats such cases as censored. Even though patients who would have not defaulted at the time of the survey would default at some point in time, survival analysis is able to consider the experiences of such patients based on the experiences of all patients on ART. This therefore would provide us with information about the totality of the default experience of patients, which the conventional regression technique is unable to provide.

1.4 Objectives

1.4.1 General Objective Study

The general objective of the study is to examine the socio-demographic factors that affect patients' adherence to ART at the Piet Retief Wellness Centre in the Gert Sibande District of Mpumalanga province in South Africa.

1.4.2 Specific Objectives

The specific objectives of the study were:

- to examine the socio-demographic risk factors associated with antiretroviral therapy (ART) non-adherence at Piet Retief Wellness Clinic.
- to examine the perspectives of patients on the quality of service delivery influencing the uptake of ART in Piet Retief Wellness Centre.
- to examine the perspectives of patients on the adverse effect of ART on the individual.
- to examine the challenges/ barriers to ART adherence in Piet Retief Wellness Centre.

1.5 Hypothesis

H_0 (Null-Hypothesis): there is no difference in the association between gender, age, marital status, place of residence, educational status, employment status) and ART default.

H_1 (Alternative Hypothesis): there is a difference in the association between gender, age, marital status, place of residence, educational status, employment status and ART default.

1.6 Definition of Terms

1.6.1 A Wellness Centre: In this particular study, a Wellness Centre refers to a clinic, a sub-section of a regional hospital which serves patients with HIV. Generally this Wellness Centre is responsible for the management of HIV/AIDS in terms of treatment and care.

1.6.2 Defaulters: Defaulters are those Patients on ART who have missed their monthly ART refill.

1.6.3 Triangulation: The use of the quantitative and qualitative methodology in the same study.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The literature review in this chapter discusses the health belief model and the various components of the model as they relate to the current study and the assumptions of the model. Secondly, the chapter draws knowledge from other studies conducted on the socio-demographic risk factors associated with ART non-adherence, particularly in South Africa. Thirdly, the chapter presents a review of studies on the perspectives of patients on how the quality of service influences the uptake of ART. Fourthly, the chapter reviews the literature on the perspectives of patients with regard to ART effects on the body of the patient. Finally, the chapter discusses patients' perspectives on the barriers and challenges to treatment adherence.

2.1.1 Theoretical Framework: The Health Belief Model

The health belief model (HBM) emerged from the research of several social psychologists in the 1950s who sought to explain why some individuals declined participation in preventive health care programmes such as immunization and tuberculosis screening that could aid with early diagnosis and prevention of the disease (Janz & Becker, 1984). The major components of the HBM are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy and cues to action (Hayden, 2009; Stanhope & Lancaster, 2000).

The HBM helps to explain the association between health beliefs and the performance of preventive health behaviours. According to Champion, Menon & Skinner (2002), the HBM has been used extensively in the study of health screening behaviours ranging from influenza inoculations, seatbelt use, nutrition, chronic illness, smoking, breast cancer screening, both self-examination and mammography, health beliefs and AIDS-related health behaviours.

The HBM includes a belief component, an attitude component and a behaviour component. The belief component pertains to what the individual assesses as the true situation, while the attitude component pertains to how the individual feels about the situation. Together, these two components work as the driver for the individual to behave in a specific manner (Shillitoe & Christie, 1989). However, the HBM has been revised and expanded over the years to include a self-efficacy component and a cue to action or stimulus component based on the research of Albert Bandura. It has been extensively used by social science researchers to explain and predict health-related behaviours (Shillitoe & Christie, 1989).

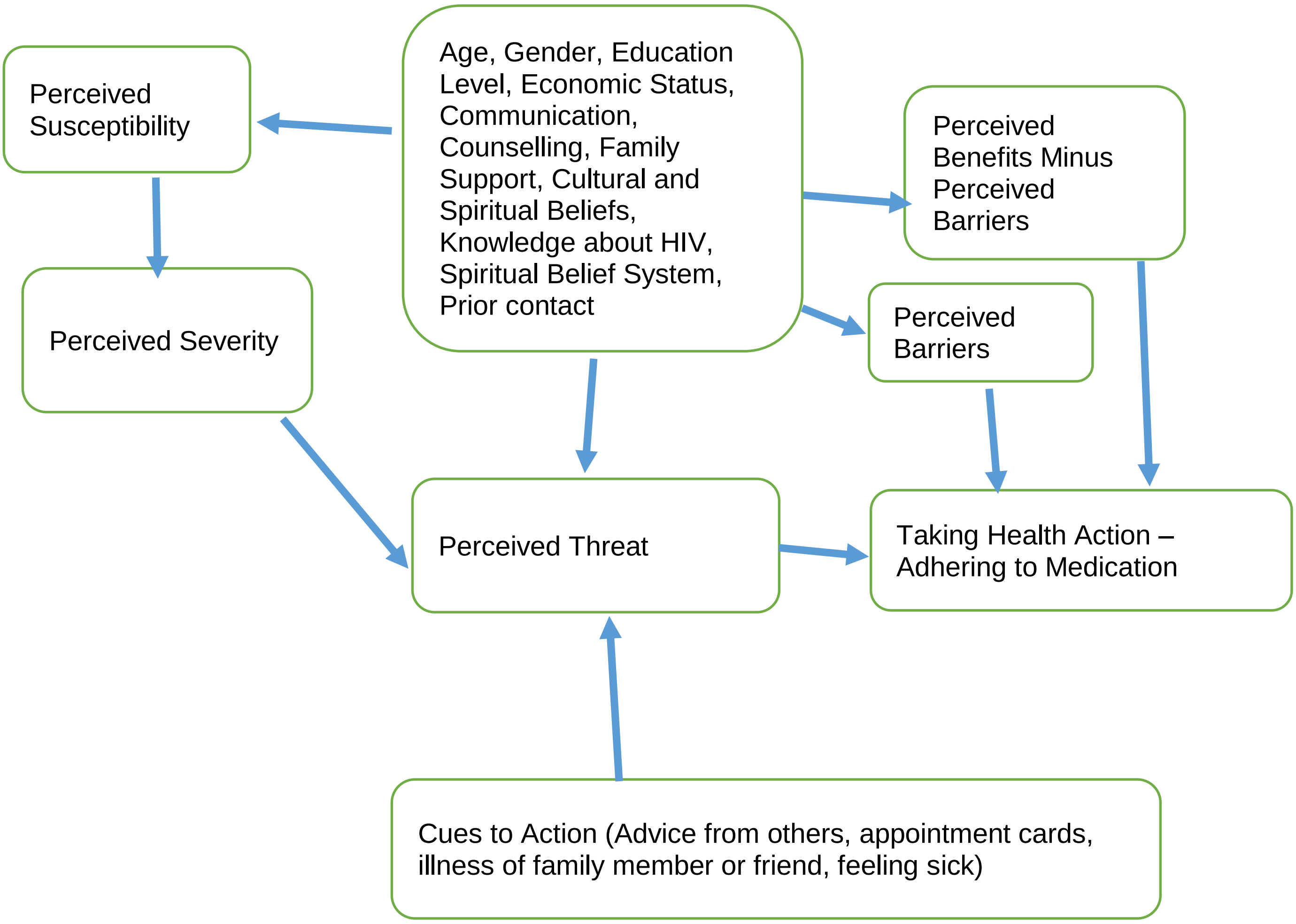

Figure 2-1: Theoretical framework: The Health Belief Model

Source: Janz & Becker (1984)

2.2 Assumptions of the Health Belief Model

According to Janz and Becker (1984), the HBM is based on three assumptions. Firstly, it assumes that a person will take a health-related action if that person feels that a negative health condition can be avoided. Secondly, the HBM also assumes that a person will take action if that person has a positive expectation that by taking a recommended action, they will avoid a negative health condition. Finally, the HBM assumes that a person takes a health-related action if the person believes that she/he can successfully take the recommended action.

The present study is guided by the assumptions of the HBM as it pertains to patients' adherence to ART after he/she has been introduced to ART. It is assumed that those who adhere to ART: (i) feel that falling sick and dying because of HIV and AIDS infection can be avoided; (ii) believe that adhering to ART will be effective in preventing them from falling sick and finally dying from HIV. The HBM is made up of six key components, which are cognitive-based stipulating specific factors that a person who believes himself/herself to be healthy must consider when deciding whether or not to adopt a recommended health behaviour. These six components of the health belief are operationalized in the present study, namely perceived susceptibility, perceived severity, perceived threat, perceived benefits, perceived barriers, cues to action and self-efficacy.

Perceived Susceptibility: This refers to one's own opinion of how serious a condition is and what its consequences are. When one recognizes that they are susceptible to getting a certain problem or condition, it does not really motivate them to take the necessary action until they appreciate that getting the condition would have serious physical, psychological and social implications (Hayden, 2009). It is when one realizes the magnitude of the negative consequences of a condition that they would take the necessary action to avoid it. For the current study, perceived susceptibility is achieved when HIV positive patients believe that they are less susceptible to AIDS when they take their ARVs. As a result, their adherence to their medication will be enhanced. If they do not feel susceptible, adherence will be low (Hayden, 2009). This perception is influenced by various factors as indicated in Figure 2.2, such as gender or cultural beliefs. When patients do not have decision-making powers or authority when it comes to sex, they may feel helpless and susceptible.

Perceived severity is the perception of the seriousness associated with contracting a specific illness or of leaving it untreated (medical, clinical and possible social consequences). This indicates an individual's belief about the seriousness or severity of the disease. This may also come from the beliefs a person has about the difficulties a disease would create or the effects it would have on his or her life in general (Hayden, 2009). This perception is likely to influence an individual to take a health action of adherence due to the experience of contact with the disease, which leads to a perceived threat of deterioration or even death. For the current study, the knowledge and beliefs of the consequences of having HIV/AIDS that were investigated included wasting (losing weight), skin rashes (black spots), hospitalization, loss of job due to absenteeism and early death.

Perceived threat is the combination of perceived susceptibility and the perceived severity of a health condition, resulting in perceived threat. If the perception of the threat of a disease such as HIV and AIDS for which there is a real risk is serious, behaviour often changes (Hayden, 2009). However, the increased perception of threat does not always lead to a desired health behaviour change. Perception of threat to disease is also influenced by the modifying factors and cues to action (Hayden, 2009; Stanhope & Lancaster, 2000). The current study is amenable to the use of the HBM model in that if an HIV-infected patient or a patient suffering from AIDS believes that adherence to ART will lead to a healthy life that is free from sickness and a long life (as opposed to dying early), they are likely to facilitate the development of strategies that clearly present the desired action, which is adhering to ART.

Perceived Benefits: This refers to the belief in the effectiveness of adopting specific strategies designed to reduce the risk of the severity, morbidity or mortality as a result of being infected with HIV and AIDS. In this case, adhering to ART therapy will reduce the risk of morbidity and mortality for the HIV and AIDS infected patients.

Perceived Barriers: The potential negative consequences that may result from taking particular health actions. These factors include financial, physical and psychological costs; the inability to access resources to take specific actions, or the belief that the threat does not exist for a particular individual, group or region for specific reasons. Strategies to reduce these barriers will be explored and such barriers can be situational, individual, infrastructural or environmental. In this study, barriers that affect the timely utilization of ART, therefore resulting to HIV and AIDS infected patients defaulting from ART will be identified.

Cues to Action: These are strategies to activate readiness, and these occur when an individual feels the desire to take the necessary action after believing that he/she has the capacity to do so. Also, when he/she believes that the required action will benefit him/her and knowing how to deal with the expected barriers. Firstly, this requires motivation on the part of the person to have the desire to comply with a prescribed action or treatment. Secondly, the individual should have the concern about the health matters and lastly, the individual has to be willing to seek and accept health care and engage in positive health activities. Private or public events such as physical signs of a health condition, a friend or acquaintance that has contracted the condition or publicity, media attention that motivates people to take action.

For this particular study, cues to action would involve broadcasting of programmes educating the Nation on HIV and AIDS, both on TV and Radio stations; hosting talk-shows in schools and community centres to motivate those who have already embarked on treatment to adhere to medications, those who have defaulted to get hospital assistance to get re-initiated into treatment etc.

Self-efficacy: This refers to the strength of an individual’s belief in his own ability to respond to novel or difficult situations and to deal with any associated obstacles or setbacks (Peltzer, 2000). This is confidence in one’s ability to take action. The individual should feel that they are capable of taking the necessary action correctly because it is that confidence that would motivate them to take the action.

In terms of the current study, self-efficacy will be assessed by the adherence to ART of the HIV and AIDS infected patients without the help of others. Some of the factors that could build their confidence would be having adequate knowledge and skills on ART adherence; being actively involved in HIV prevention and treatment activities and having knowledge of the availability of support for adherence and treatment.

Further the HBM model has a component on socio-demographic characteristics such as gender, Age, Marital Status, Education level, HIV Knowledge, Cultural belief, Spiritual Belief, Racial Group and Home language. This component of the model will be used to assess the influence of the patients’ socio-demographic factors being gender, age, marital status, education level, HIV knowledge, cultural belief, spiritual belief and home language and default to ART.

Based on the HBM discussed above, the study will adopt the following conceptual framework to show how the distilled factors affect the proximate factors which in turn affect Patients’ non-adherence to ART. The distilled factors as shown on the conceptual framework help to explain the variations in the proximate factors, which therefore explain variations in Patients non-adherence to ART. As described in Janz and Becker (1984) model, the distilled factors comprise individual factors including socio-demographic factors. On the other hand, the proximate factors comprise of the psychosocial factors of the HBM including perceived susceptibility, perceived severity, perceived benefits and perceived barriers.

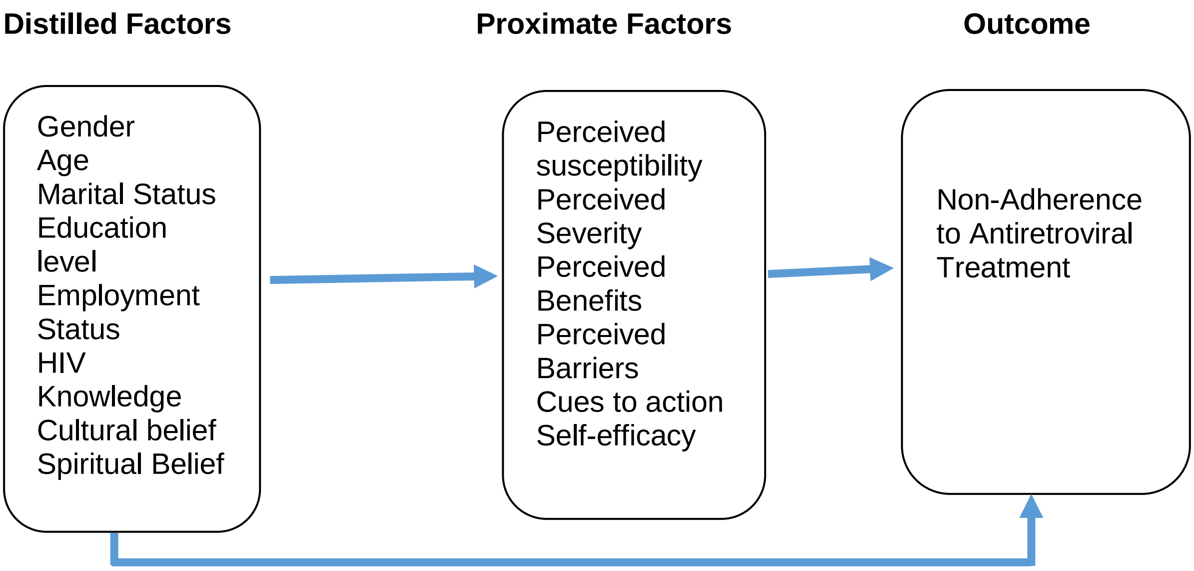

Figure 2-2: Conceptual framework

2.3 Non-Adherence to Medication in Developing Countries and South Africa

Non-adherence to medication is perceived as a potential threat to the long-term success of HIV treatment. According to Nam et al. (2008) non-adherence is the most important factor known to be associated with treatment failure for HIV patients in both developed and developing countries. For instance, studies conducted in different parts of the developed world have revealed that achieving optimal levels of treatment adherence is challenging in even resource rich settings. For example, Machtinger and Bangsberg's (2006) study of adherence to ART in developed countries revealed that adherence in HIV infected patients is estimated to be closer to 70%, regardless of the variation of the assessment methods used and the group of people studied.

Developing countries are the worse hit by the challenge of non-adherence to ART due to the limited resources in their country. With regard to sub-Saharan Africa, this region has the highest number of people living with HIV and AIDS compared to the rest of the world. Out of the estimated 34 million people infected with the virus in the year 2010, 68% resides in sub-Saharan Africa (UNAIDS, 2011). The sub-Saharan Africa region is also hit hard by the challenge of non-adherence to ART medication. Studies conducted in sub-Saharan Africa attest to this challenge of ART non-adherence among patients. For example, a study that was conducted by Rosen et al. (2007) observed that ART programmes in Africa have only managed to retain approximately 60% of patients on therapy at two years after initiation of therapy.

Another study that was conducted by Nachega et al. (2016) on ART adherence estimated that the rate of adherence in sub-Saharan Africa is 77 per cent, and the non-adherence rate in the adult population was estimated between 33 and 88 per cent depending on the measure of adherence used. It ranges from patient reports to patient file reviews for missed ART appointments. Further to this, a systematic review of data from ART programmes in sub-Saharan Africa (SSA) reported ART default rates of 23% at 12 months, 25% at 24 months to 30% at 36 months, with most ART defaulting occurring within the first year after ART initiation (Fox and Rosen, 2010). In sub-Saharan countries, varying high levels of non-adherence at country levels have been witnessed. For example, a study that was conducted by Elul et al. (2013) found that 23% of ART patients were non-adherent based on a 30-day recall. In rural Zambia, a study that was conducted by Sasaki et al. (2012) revealed that 40% of the patients who were on ART were not adherent. In the Southern African region, pooled analysis of African adherence studies have reported non-adherence to ART to be 23% and above (Mills et al., 2006).

Further, a study that was conducted in Uganda among 234 patients found that the level of adherence was ranging between 82-95 per cent (Balikuddembe et al., 2012). Similarly, a study that was conducted in Tanzania among 340 participants revealed that only 94% of the patients were adherent to 95% of their prescribed medication (Watt et al., 2010). In Botswana, a study that was conducted by Vriesendorp et al. (2007) revealed a mean adherence level of between 85% and 98% using medicine monitoring and self-report. Further, in Cameroon, a prospective study that was conducted among HIV positive patients found that only 78 of patients adhered to their medication six months after starting treatment (Rougemont et al., 2009). In addition to that, a study that was conducted in Rwanda by Jean-Baptiste (2008) among HIV positive patients who were on ART reported an overall adherence rate of 73 per cent. This shows that interventions should be put in place to deal with the problem of ART nonadherence.

A study that was also conducted in rural Zambia also assessed the rate of adherence using self-report among 518 study participants. The study found that only 88% of the study participants had not missed their ARV's in the past four days. Among HIV positive pregnant women, a cross-national study that was conducted in Nigeria revealed an adherence rate of 80.6% among HIV positive pregnant women (Ekama et al., 2012).In some parts of the developing world, there are even lower levels of adherence to ART in comparison to some other countries. For instance, a study that was conducted in Benin among 125 HIV infected outpatients demonstrated an adherence rate of 58.1% which was significantly lower than those reported in many other sub-Saharan African countries (Erah & Arute, 2008).

In other resource-limited settings of the developing world other than sub-Saharan Africa, comparable rates of low ART adherence has been observed. For example, a longitudinal study that was conducted in China reported declining rates of ART adherence over time. Between the baseline period, 3 months and 6 months respectively, the average adherence rates declined from 91%, to 88% (Wang et al., 2009). In Brazil, a study on adherence among 412 participants in Brazil showed an adherence rate of 74% on the prescribed medication over a five days period (Silva et al., 2009). Similarly, in Cuba a study that was conducted among HIV positive patients indicated an adherence rate of 70% (Aragones et al., 2011). In fact, worse case adherence scenarios have been documented in studies conducted in various parts of the developing world. For example, a study that was conducted in India by Cauldbeck et al. (2009) found out that the overall adherence was 60.6% among HIV infected adults. This therefore means a total of 39.4% of HIV positive patients were not adherent of ART.

ART non-adherence in South Africa

Antiretroviral non-adherence has been recognized as a major problem for patients receiving treatment for HIV and AIDS (UNAIDS, 2015). Adherence can be defined as the extent to which the behaviour of an individual changes with the given rules from the health provider (Sabate, 2003). In order for HIV positive patients to fully benefit from ART, medication adherence level of at least 95% and above is required (WHO, 2016). The benefits of adhering to ART is that it suppresses the viral load, increases the CD4 cells count and minimizes resistance to the drugs which results in improved quality of life of an infected person (WHO, 2016).

In fact, Clotet et al. (2008) concluded that adherence to ART is a good predictor of clinical outcome among patients on ART. On the other hand, non-adherence to ART can be defined as the failure to take medicine timely, wrong dosage or premature termination of medication (UNAIDS, 2016). Medication adherence is the backbone of treatment success for any ailment. The availability of ART in South African public and private health institutions has improved accessibility to treatment. Following UNAIDS (2014) recommendation requiring the administration of ART to be scaled up in local clinics in Sub-Saharan African countries. A tremendous increase in the number of patients on ART, from an estimate of almost 100 000 people in 2003 to 3.9 million in 2009 was attained (Ayalu et al., 2011). As far as South Africa is concerned, the number of people on treatment in South Africa is about 4.3 million, resulting into the largest treatment programme in the whole world (UNAIDS,2018).

In South Africa, research indicates that adult retention in ART is deteriorating over time, with patients who started ART more recently being more likely to default compared to those who initiated ART in earlier years (National Department of Health, 2015). Other studies conducted in South Africa have also revealed that the issue of retention is a major challenge. For example, in 32 studies reviewed by Rosen et al. (2007), the retention rate at two years of treatment was at 62%. Moreover, in an analysis of 33 studies, they found a retention rate of 72% at 3 years of treatment.

A study conducted by Cornell (2010) in Khayelitsha, South Africa, among 3 595 adults enrolled in HAART over 5 years showed that the cumulative proportion of patients remaining in care at 54 months after initiation on treatment was 78%. This shows that generally patients on ART in South Africa default on treatment. Another study that was conducted in the Western Cape province of South Africa conducted by Boulle et al. (2008) found that 14.7% of the patients defaulted treatment. Furthermore, a study that was conducted in the Gauteng, Eastern Cape and Mpumalanga provinces of South Africa showed an ART default rate of 28%. In KwaZulu-Natal Province, Vella et al. (2010) found that ART default rate was 19%. In addition to this, a study that was conducted in the Eastern Cape by Ford, Reuter, Bedelu, Schneider and Reuter (2006) showed that the ART default rate was 24.9%. In her research on ART adherence following the national antiretroviral rollout in South Africa, Van Dyk (2011) discovered that only 40.1% of the patients could reach optimum adherence levels of 90% and above, while 49% reached adherence levels between 70% and 80 per cent (Van Dyk, 2011). In addition to this, a further 10.9% could not even reach adherence levels of 70 % (Van Dyk, 2011). ART is a complex treatment that requires not only availability of the clinical sites, but serious monitoring to ensure that patients carefully adhere to the treatment regimens to prevent drug resistance and improve on the survival rate of patients.

Van Dyke (2013) states that for ART to be effective, at least an adherence rate of 90% and above is needed to suppress the virus sufficiently, to avoid the risk of mutation and to prevent the development of drug resistant strains and drug failure. South Africa, just like other countries in the developed and developing regions, is faced with the challenge of patience non-adherence on ART. For instance, a study that was conducted by Van Dyke (2011) found that only 40.1% of the patients on ARVs could reach optimum adherence levels of 90% or above.

In South Africa, research indicates that adult retention in ART is deteriorating over calendar time, with patients who started ART more recently being more likely to default than those who initiated ART in earlier years (National Department of Health, 2015). Other studies conducted in South Africa have also revealed that the issue of retention is a major challenge. For example, in 32 studies reviewed by Rosen et al. (2007) the retention rate at two years of treatment was at 62%. Moreover, in an analysis of 33 studies, they found a retention rate of 72% at 3 years of treatment.

2.3 Socio-Demographic Risk Factors Associated with ART Non-Adherence

Studies conducted around the world show that there is a relationship between socio-demographic factors and non-adherence to ART. The following socio-demographic risk factors which form part of the theoretical framework will be discussed in details and these are; gender, age of the patient, level of education, marital status, employment status, place of residence, culture and patient knowledge about HIV and AIDS.

2.3.1 Age of the patient and ART non-adherence

Studies conducted from different parts of the world indicate that the age of a patient is one of the determining risk factors for ART non-adherence. These studies have documented a statistically significant association between age and adherence, with better adherence observed among patients of the age group 35 years and above (Beer et al., 2012; Fumaz et al., 2008; Nozaki et al., 2011; Ortego et al., 2011; Sullivan et al., 2007; Tapp et al., 2011; Wasti et al., 2012).

In Tanzania, a study that was conducted by Watt et al. (2010) demonstrated that non-adherence is associated with patients between the age groups 29 years and below years and those who are above the age of 50 years. In support of this, Wenger et al., *(*1999) found that adherence to ART increases with age whereby patients above 30 years were found to be more adherent than those below that age group. Also, a study that was conducted by Shigdel et al. (2014) found that after 50 years of age, ART adherence decreased significantly with increasing age. A study that was conducted by Okoronkwo et al. (2013) revealed that in terms of patients' age and non-adherence to ART, patients who were 40-49 years old were the mostly non-adherent compared to patients below that age group. Such observations call for interventions in terms of policy with regard to ART adherence and patient age.

Barclay et al. (2007) conducted a study in Los Angeles (United State of America) whereby they compared the adherent rates between young and old participants. The results of the study showed that there was a statistically significant difference in the rate of adherence between the two age groups whereby poor adherence was twice as high for younger participants (68%) compared to older participants.

In contrast, other studies found that there was no statistically significant association found between the age of the respondents and their adherence to antiretroviral therapy (Aragones et al., 2011; Birbeck et al., 2009; Serna et al., 2008; Sharma et al., 2013; Venkatesh et al., 2010).

2.3.2 Gender of patients and ART non-adherence

Research conducted in different parts of the world indicate that the gender of a patient influences ART uptake that women are more likely to adhere to ART compared to men (Kekwaletswe & Morojele 2014; Marcellin et al., 2008; Nguyen et al., 2013; Unge, et al., 2010). A more in-depth analysis of the association between gender and ART adherence was done in Botswana by Weiser et al. (2003). They investigated the barriers to ART adherence for HIV patients. The study revealed that females were more likely to adhere to ART than males, as females are more likely to seek healthcare services than men. Further, this study concluded that the reasons why females are more likely to adhere to ART than males is due to the fact that females are more likely to attend voluntary counselling and testing (VCT) services, (Weiser et al., 2003).

In South Africa, a study that was conducted by Abah et al. (2015) on the factors affecting ART adherence revealed that women were more likely to adhere to ART compared to males. Further, a study that was conducted in South Africa by Ngarina et al. (2013) discovered that when employed, women are more likely to adhere to ART compared to males.

However, other studies concluded that men are more adherent to ART compared to females (Beer et al., 2012; Fumaz et al., 2008; Ortego et al., 2008; Sullivan et al., 2007; Tapp et al., 2011; Wasti et al., 2012). On the other hand, other studies reported a lack of association between gender and adherence (Aragones et al., 2011; Sarna et al., 2008; Sharma et al., 2013; Venkatesh et al., 2010). Other studies reported better adherence for men than for women (Alakija et al., 2010; Elul et al., 2013; Graham, et al**.,** 2013; Marcellin et al., 2008; Wakibi et al., 2011). However, lower adherence is observed for men who have sex with men (Munene & Ekman 2015). On a different note, research conducted in other parts of the world showed no association between gender and ART adherence, (Nyambura et al., 2012; Weiser et al., 2010).

2.3.3 Marital status and ART adherence

The marital status of the patients has been identified as one of the socio-demographic risk factors to ART non-adherence. This is shown by research conducted in different parts of the world which has shown that married people are more likely to adhere to ART compared to unmarried people (Aspeling & Van Wyk., 2008; Boyer et al., 2011; Graham et al., 2013; Jaquet et al., 2010; Kisenyi et al., 2013; Mahlangu 2008; Martin et al., 2013; Medley, 2014; Ngarina, 2013; Sanjobo, 2008; Uzochukwu et al., 2009; Van Dyke, 2008; Weiser et al., 2010). Further, a study that was conducted by Bello (2011) revealed that married patients are more adherent compared to those who are not married. The study revealed that where spouses of married patients were aware that they were on ART, such patients were more adherent compared to those where the spouse was not aware that the patient was on ART. The author argued that this was due to the fact that when one’s spouse was aware that they are on treatment, support was provided to the person who was on ART which encouraged consistency in taking ART medication.

On the other hand, different studies conducted by various scholars concluded that respondents who were single were more likely to default from ART compared to those who were married, (e.g Afolabi et al., 2009; Alakija, et al., 2010; Boyer et al., 2011; Idindili et al., 2012; Marcellin et al., 2008; Mbonye et al., 2013; Ngarina, et al., 2013; Okoronkwo et al*.,* 2013).

However, other studies revealed that there was no statistically significant association between marital status and adherence (Birbeck et al., 2009; De & Dalui, 2012).

2.3.4 Culture and ART non-adherence

People live in a community and they have to abide by their local cultural and religious rituals which can influence adherence to ART. Religion for this particular study is used as a proxy for culture. As part of their religious belief, many people use herbal medicine with the hope to treat HIV. For instance, in a study that was conducted by Peltzer et al. *(*2010) on ART adherence among HIV patients in KwaZulu-Natal, the findings from this study showed that the use of herbal medication for HIV was associated with lower adherence. This therefore means that where patients have a strong belief for their religion above conventional medical approaches in the treatment of HIV, this will then result in increased non-adherence to ART (Groh et al., 2011; Penn et al., 2011; Musumari et al*.,* 2014).

Various studies have reported that religion is both a barrier and a promoter of ART adherence (e.g. Jaquet et al., 2010; Lyimo et al., 2014; Morojele et al., 2014; Musumari, 2014; Nachega et al., 2006; Penn et al., 2011; Roux & Kouanfack, 2011). Studies conducted by different scholars reported that some patients who are on ART believe that God provided knowledge to health experts to make ART work and this promotes adherence (E.g. Groh et al., 2011; Musumari et al., 2014; Penn et al., 2011; Watt et al., 2008).

Wasti et al. (2012) conducted a study in Nepal that revealed that religious ceremonies such as Ramadan have resulted in people of the religious group to stop ART due to fasting. In this study, a Muslim reported that he stopped his morning dose of ART because of Ramadan. This study revealed that religious practices contribute to patient’s non-adherence to ART. In this particular study, patients defaulted ART because their religion required them to fast from sunrise to sunset and therefore they ended up not taking their ART (Wasti et al.,2012).

2.3.5 Level of education and ART non-adherence

The level of education has been identified as one of the risk factors for ART non-adherence. Specifically, it has been found that lower levels of education are associated with non-adherence (e.g. Alakija et al., 2010; Birbeck et al., 2011; Erah & Arute, 2008; Kekwaletswe & Morojele, 2014; Meleku, 2015; Moralez, 1999; Negash & Ehlers, 2013; Peltzer et al., 2010; Sipter et al., 1999). A detailed analysis of the relationship between education levels and ART non-adherence was conducted in Botswana by Weiser et al. (2003). The findings from this study revealed that as education level increased, adherence to ART increased too. The results of this study showed that for those who were at tertiary institutions, non-adherence to ART was lower compared to those with no formal schooling.

Patients with no formal education are more likely to default treatment compared to those with formal education (e.g. Afolabi et al., 2009; Bello et al., 2011; Bhat et al., 2009; Hegazi et al., 2010). Similarly, Mckinney et al. (2014) conducted a study in Malawi on the determinants of antiretroviral therapy adherence among women. The aim of the study was to investigate the perspectives of healthcare providers with regard to the challenges of non-adherence on ART. Patients who had defaulted on ART were interviewed for this particular study. The study concluded that a patient's education level facilitated their adherence to ART.

A study by El-Khatib et al. (2010) in South Africa revealed that people with less than 11 years of schooling had higher levels of non-adherence compared to people with more than 11 years of schooling. Also, in Tanzania, Watte et al. (2010) reported that patients with low levels of education tended to have poor ART adherence levels. On the contrary, a study conducted by Birbeck et al. (2009) showed no association between the literacy status of participants and their level of adherence, in fact, this study reported that the literacy status of HIV infected patients was not statistically associated with their adherence to medication.

2.3.6 Employment status and ART non-adherence

Employment status is one of the socio-demographic factors for which conflicting findings have been observed regarding ART non-adherence. Some studies show that people who are employed are more likely to adhere to ART medication than those who are unemployed (e.g. Boyer et al., 2011; Goudge & Ngoma, 2011; Hegazi et al., 2010; Maqutu et al., 2010; Okoronkwo et al., 2013; Peltzer et al., 2011; Weiser et al., 2003). A more thorough analysis of the relationship between employment status and ART non-adherence was conducted by Pratt et al. (1998) and Martinez et al. (1998). The results from these studies revealed that people who were in high-income employment had no difficulty in adhering to ART compared to patients who were unemployed.

In a study that was conducted by Grierson et al. (2000), unemployment was mentioned as one of the reasons for high non-adherence to ART. According to these researchers, poverty increased the levels of non-adherence to patients on ART. In addition to this, a survey of 924 Australian HIV positive people revealed that lack of employment negatively affected ART-adherence as patients could not afford the money for clinic visits for medication refill (Katabira, 2002).

In other studies conducted around the world, financial challenges such as transport costs, health facility costs and financial insecurity, arising from unemployment, were associated with non-adherence (e.g. Bezabhe et al., 2014; Nyanzi-Wakholi, et al., 2009; Penn et al., 2011; Rasmussen et al., 2013; Skovdal et al., 2011; Talam et al., 2008).

2.3.7 Place of residence and ART non-adherence

The place of residence, either rural or urban has been identified as a risk factor for ART adherence by various studies. A study that was conducted by Maquthu et al. (2010) on the impact of the place of residence revealed that as residential status changed from rural to urban, adherence to ART improved as well.

Further, a study that was conducted by Peltzer et al. (2010) in KwaZulu-Natal, South Africa with the aim of assessing factors including information, motivation and behavioural skills model (MBD) contributing to antiretroviral (ART) adherence six months after commencing ARVs at three public hospital in KwaZulu-Natal South Africa. ART adherence for urban residents was found to be 3 times greater than that of rural residents.

In India, long travel time to ART centres has been identified as one of the major causes of ART non-adherence (e.g. Cauldbeck et al., 2009; Sarna et al., 2008). This is despite efforts by India’s Ministry of Health of ensuring that ART centres are closer to villages, people still prefer travelling long distances to access ART in pursuit of avoiding being stigmatized in their local communities (Wakibi et al., 2011).

2.3.8 Health literacy (Knowledge about HIV)

Generally, knowledge about the disease that a person has helps enhance cooperation from the side of the patient in terms of the treatment of that particular disease. This includes information on what the disease is, how the disease is transmitted, ways of treating the disease (in case it is treatable) and ways of managing the disease (where it is incurable).

In many developing countries, health literacy is linked to education level and as such, research conducted in South Africa by Kalichman and Simbayi (2004) concluded that health literacy positively affected adherence to ART medication. In other words, the more informed the patients are in particular to the importance of faithfully taking their medication and the dangers of defaulting treatment, patients are less likely to default from treatment. This research also observed that in the majority of resource-constrained countries, there are low levels of HIV and AIDS knowledge. In these countries many patients consider medication only as a tertiary measure following the onset of symptoms rather than as a prophylactic intervention (Kalichman & Simbayi, 2004)

2.3.9 Treatment side effects (ARVs) and ART non-adherence

The management of side effects as a result of ART is key in the success of treatment as this impact on the quality of life for those living with HIV and AIDS. Van Dyke (2015) argues that among the most important factors in the success of treatment is how well a patient tolerates the ARVs drugs. Treatment adherence is sustaining the continuity in taking the treatment to avoid defaulting. Side effects such as diarrhoea, rash, headaches and body shaping effects is associated with ART non-adherence (e.g. Afolabi, et al., 2009; Elul et al., 2013; Groh et al., 2011; Kip et al., 2009; Mahlangu, 2008; Penn et al., 2011; Sanjobo et al., 2008; Skodval et al., 2011).

In addition to that, a study that was conducted by Ayalu et al. (2011) in Africa with the aim of identifying the medication side effects associated with ART revealed that ART side effects act as a barrier to ART adherence. Symptoms such as skin rash, vomiting and dizziness were identified to be barriers to ART adherence. Further, Bhengu et al. (2008) conducted a study on the side effects experienced by HIV infected individuals who were on ART therapy in KwaZulu-Natal Province, South Africa. The study found that from the all patients that were interviewed, they had experienced one or more of the following medication side effects, fatigue and tiredness, rashes, headaches and insomnia. Other side effects reported included sadness, disturbing dreams, numbness and pain. This study concluded that side effects are associated with ART non-adherence.

In addition to socio-demographic factors, studies conducted by different scholars indicate that psychosocial factors also act as a barrier to ART adherence. For example, Okoronkwo et al. (2011) conducted a study on non-adherence factors in relation to their socio-demographic characteristics in Nigeria. This study constituted of 221 participants and a validated structured questionnaire was used to collect data from the study participants. The results of this study revealed a high non-adherence rate of 85% to ART as a result of personal factors. The most common personal factors to non-adherence were forgetfulness, a busy schedule, side effects and drugs.

Further, other factors, particularly psychosocial factors such as a supportive family structure and disclosure of ones HIV status positively improved ART adherence. With regard to a supportive family structure and its impact on ART adherence, Zuurmond (2008) found that a strong supportive family and support group meetings for people living with HIV and AIDS are some of the factors that can influence adherence to ART. In addition to this, the study revealed that factors that have resulted in people not adhering to ART include stigmatization and discrimination in relation to HIV/AIDS status, drugs, inaccessibility of ART clinics and poor quality of ART service delivery (Zuurmond, 2008). Moreover, Bearman & La Greca (2002) found that emotional support from friends, family and community was a strong predictor of adherence. With regard to treatment supporters and its impact to ART adherence, many studies have found that treatment supporters for patients could improve ART adherence (e.g. Goudge & Ngoma, 2011; LaKey et al., 1997; Dlomo, 2010; Yoder et al., 2009). In support of this, a study that was conducted by William (2008) found that support groups, food schemes and disability grants are ways of improving ART adherence in communities.

With regard to disclosure of one's HIV status, different studies have reported that when people living with HIV and AIDS were hiding and skipping their medicine to avoid disclosure, non-adherence was observed (e.g. Alemu et al., 2011; Bajunirwe et al., 2009; Chi et al., 2009; Muya et al., 2015; Olowookere et al., 2008; Phiri et al., 2010; Roux et al., 2011). Where an HIV positive person has disclosed their status to their spouses, children and other family members, that was seen as a predictor of receiving support and observed to be associated with adherence (Goudge et al., 2011; Lyimo et al., 2012; Nachega et al., 2006; Penn et al., 2011; Ramadhani et al., 2007; Ross et al., 2011; Skovdal et al., 2011; Van Oosterhout et al., 2005; Weiser et al., 2003). The importance of disclosure for one's HIV and AIDS status was also raised in the International HIV and AIDS Conference which was held in 2015 in Durban, South Africa. Reports presented in the conference revealed that women in particular have been hiding their ARV's for fear of losing their spouses and resulted in defaulting medication.

2.3.10 Perspectives of patients on the quality of service influencing ART non-adherence

Service quality plays a vital role in ensuring patients adherence to ART. According to the World Health Organization (WHO, 2016), the low levels of HIV treatment adherence around the world is very worrying. Factors related to the health facility such as long waiting times, limited clinic hours, crowded clinics and lack of privacy in the consultation room have been reported to be a barrier to ART adherence, especially for working people who need time off work to collect medication (e.g. Audu et al., 2014; Bezabhe et al., 2014; Hardon et al., 2007; Jaquet et al., 2010; Penn et al., 2011; Rasmussen et al., 2013; Sanjobo et al., 2008; Skovdal et al., 2011).

In a worldwide survey of 59 ART around the world, WHO (2016) discovered that poor service quality was a cause for patients' non-adherence to ART. The findings from this evaluation showed that in most ART clinics patient records were missing and interruptions ART supply due to drug stock-out. Further, with regard to quality of ART services, a study that was conducted by Maquthu et al. (2010) revealed that long waiting times at the clinics, lack of support from staff, low staff to patient ratio and unavailability of medication resulted in ART non-adherence. This therefore shows that there is still a lot of work that has to be done not only in South Africa but also in other countries around the world to support patients on ART to adhere to the medication.

2.4 Conclusion

In conclusion therefore, socio-demographic risk factors as well as psychosocial factors associated with ART non-adherence have been discussed with reference to the Health Belief Model. Various studies have shown that the age of a patient, gender, education level, and employment status contribute to ART non-adherence. Further, perspectives of patients on the quality of service influences the uptake of ART was discussed. Finally, perspectives of patients with regard service quality as well as barriers to ART adherence have been explored.

CHAPTER 3: QUANTITATIVE AND QUALITATIVE ANALYTICAL TECHNIQUES AND OUTCOMES

3.1 Introduction

This chapter details the methodology that was adopted for this study to answer the research questions. The chapter provides detailed information on the study setting, sources of data, study design, analytical procedures comprising methods and techniques used to analyse data, variables adopted in the study, summary of analytical plan and ethical consideration.

3.2 Geographic Setting: Piet Retief Wellness Centre, Mpumalanga province, South Africa

Piet Retief Wellness Centre is situated in the Mpumalanga Province of South Africa, under the Gert Sibande District, Mkhondo Municipality. The Gert Sibande District is one of the three district municipalities in Mpumalanga province and is situated in the eastern boundary of Mpumalanga province. It is boarded by Swaziland in the East, KwaZulu-Natal in the South, Free State in the West and Gauteng in the North (StatsSA, 2016). The district comprises of an area of approximately 31 842km². The area is 61% rural and 39% urban. The total population in Gert Sibande is 943,137 people (StatsSA, 2016).

Approximately eighty six per cent (86%) of the population does not have medical insurance and therefore depend on the Department of Health for healthcare service delivery. HIV prevalence rate is 40.5 %, which is the highest prevalence rate among all the districts in Mpumalanga province and is more than double of the country's HIV prevalence rate which is currently estimated at 12.6% for the year 2017 (StatsSA, 2017). It is estimated that at least 33% of the inhabitants of Gert Sibande are not employed (Gert Sibanda Health District Report, 2013).

In terms of economic activities, the Gert Sibande District Municipality is characterized by vast farming areas with mining, forestry and agriculture being the main economic activity. This area has the highest population in the district and draws a lot of migrant labour from other provinces and neighbouring cities. According to StatsSA (2015), about 17.9% Mpumalanga residents were born in Gauteng, 16.4% were born in Limpopo while 12.3% were born outside South Africa**.** As such, in terms of ethnicity, the District is made of the following ethnic groups Zulu, 82.8%; Afrikaans-speaking, 7.8%; English-speaking, 5.0%; others, 4.4%. This provides a cultural diversity in the area as a whole as multiple languages are used for communication purposes (Statistics South Africa, 2015**).** Figure 3-1 shows a map of Gert Sibande district, Mkhondo Municipality in the Mpumalanga province where the quantitative and the qualitative data were collected.

Figure 3-1: The map of Gert Sibande District, Mkhondo Municipality in Piet Retief*, Mpumalanga province providing details of the selected municipality from which quantitative and qualitative data were collected.*
Source: http://www.mkhondo.gov.za/index.php/tourism/maps/district-map

3.3 Research Approach

This study utilized a mixed method research approach (both qualitative and quantitative approach) to achieve its objectives. The quantitative approach was used to examine the effect of Socio-demographic factors on patients' adherence to ART treatment at the Piet Retief Wellness Centre. On the other hand, the qualitative approach was used to understand the reasons why HIV and AIDS infected patients default from ART and their experiences regarding the service quality at Piet Retief Wellness Centre. Creswell (2009) points out that the mixed research approach involves collecting and analysing data to characterize a group, concept or phenomenon. It uses both quantitative and qualitative methodologies. Quantitative methodologies include surveys, measurement tools, charts and record reviews, (Creswell, 2009). For this study, charts and record reviews were used to collect data from patients' files. On the other hand, qualitative methodologies include a range of designs such as interviews, direct observation, and analysis of texts/documents or of audio/video-recorded speech or behaviour (Creswell, 2009). For this particular study, in-depth interviews were used.

3.4 The Study's Population

According to McMillan & Schumacher (2006, p. 169), "A population is a group of elements or cases that conform to specific criteria and to which the researcher intend to generalize the results of the research." For the current study, the population/universe was all HIV and AIDS infected patients receiving treatment at Piet Retief Hospital Wellness Centre. Since its inception in 2005, the Wellness Centre has enrolled a total of 12 381 HIV and AIDS patients. The Wellness Centre has records of all the patients who are enrolled into treatment, including patients who have defaulted and those who have not defaulted. All the patients at the Centre live in the Piet Retief area and the Wellness Centre has their addresses and contact details. This study was limited to only patients who had received ART from the Wellness Centre between the period 2010 and 2014. The study employed primary and secondary data to answer the research questions. The primary data were collected through face-to-face interviews with the study respondents. The respondents are both men and women aged 15-49 years who are associated with antiretroviral uptake in Piet Retief Wellness Centre from the year 2010 to 2014. They comprise both defaulters and non-defaulters with regard to ART. There were 20 patients who were interviewed altogether, 10 defaulted and 10 non-defaulted patients for the primary data. The secondary data came from information from the patients' clinical files available at the Piet Retief Wellness Centre. This set of data came from a sample of patients who were enrolled into ART between 2010 and 2014.

3.5 Analytical Techniques

3.5.1 The Sampling Design

The present study used both probability and non-probability sampling designs to select its participants at the Wellness Centre at Piet Retief. Specifically, the study used stratified random sampling (probability sampling design) to select the participants for the quantitative component of the study. Black (2004) has noted that stratified random sampling is used when the researcher wants to highlight a specific subgroup within the population. Further, this sampling method ensures that a representative sample is drawn from the population (Black, 2004). The total number of patients initiated into ARV treatment at the Wellness Centre between the years 2010 and 2014 was 7773 patients. For the purposes of the current study, the sampling was limited to the population of recently initiated patients, for example, between 2010 and 2014. The clinic keeps two lists of patients, namely, patients who have defaulted from ART (n=2911) and those patients that have not defaulted from ART (n=4862). It is significant to note that the existence of the lists of defaulters and non-defaulters naturally divides the universe into two strata.

On the other hand, a non-probability sampling technique, the purposive sampling technique, was used to collect qualitative data from the patients. Consistent with this technique, participants were contacted for the individual in-depth interviews. The qualitative interviews were conducted with patients regardless of their default status.

3.5.2 Sample Size and the sampling process for quantitative data

According to McMillan and Schumaster (2010), a sample size should comprise of at least 10 per cent of the study population. Therefore, the sample fraction for the present study is 10 per cent of the total study population from each stratum (4862*0.10=486 for non-defaulters) and (2911*0.10= 291 for defaulters). Thus, a total number of 486 patients from the non-defaulted group, and a total number of 291 patients from the defaulted group were drawn for the collection of quantitative data. However, for the collection of qualitative data, the sample size for interviews was 10 patients from each stratum, which is the minimum amount of sample that can be drawn for in-depth interviews to reach saturation point (Guest et al., 2006).

The sampling process for quantitative data

The first step in the sampling process involved organizing the patients' files according to the two "natural" strata, namely, defaulted and non-defaulted patients. The second step in the sampling process was to use simple random sampling technique to select a total of 291 patients from the defaulted strata, and to select a total of 486 patients from the non-defaulted strata. This yielded a total sample size of 777 patients (291+486 =777). The following process was followed in selecting the 291 files from the list of defaulted patients' files defaulted patients. Firstly, the files were arranged according to the years in which patients were enrolled in ART. For example, all patients who were enrolled into treatment in the year 2010 and defaulted were all grouped together from January to December. Thus, the files were grouped according to the year 2010,2011,2012,2013 and 2014 for both patients who defaulted from patients and those who have not defaulted from patient. After that, the files were randomly selected from each year between 2010 till 2014 and a total of 291 defaulted patients were selected. Arranging the files according to the year of enrolment into treatment was to ensure that the sampled patients are representative of the study population which is all patients who were enrolled into treatment at Piet Retief Wellness Centre between 2010 and 2014.

This same process was repeated for those patients who had not defaulted from treatment. Patients' files were also arranged according to the years, 2010, 2011, 2012, 2013 and 2014. Files were randomly selected across the years from one to 486. This process also ensured that the files were representative of the population enrolled into ART between 2010 and 2014 for those patients who had not defaulted treatment.

3.5.3 Qualitative Aspect of Analysis

The sampling process for qualitative data

Patients' files from the list of defaulted patients (291) and those patients who had not defaulted treatment (486) were selected purposively to collect qualitative data. This process involved reviewing each file to ensure that all the patients contact details were available on the files. A total number of 10 files from those patients who had defaulted from treatment and 10 who had not defaulted from treatment were drawn. Phone calls were made to those patients whose files had adequate contact details to invite them to participate in the study. Those patients who agreed to be part of the study were then considered a part of the study sample. All 10 patients in each stratum agreed to be part of the study. As such, the response rate was 100 per cent.

3.5.3 Research Instrument

Data collection

The study used two data collection instruments to collect data from the patients who had been selected for the study as follows:

For the quantitative data, the socio-demographic data were collected from the patients' files using a data collection template developed by the researcher. The data collection template was used to collect the following information from the patients' files; Clinical Information (Date of starting treatment, date of initial default) (if the patient had defaulted), date last seen in the clinic and date of death (if patient had died). This information would yield an outcome with the following measurable dimensions: Time to default; Time in the system without defaulting; and Status defined as still living; Lost to follow-up; Died (HIV-related); or Died (other causes).

For the qualitative data, interviewers were trained to conduct face-to-face interviews with the selected patients to collect these data. A total of 20 patients were interviewed. Of these patients, 10 had defaulted ART while the other 10 had not defaulted ART. The interview was 20 minutes on average. Of these patients, 12 patients were females while 8 patients were males. An interview guide was used to collect the data in a face-to-face format. The questions asked aimed to elicit answers pertaining to patients' perceptions of the factors which cause HIV and AIDS patients to default from ART, patients HIV and AIDS knowledge (perceived susceptibility), perceptions of the patients on the seriousness of HIV and AIDS (perceived severity), barriers to ART adherence (perceived barriers), benefits of adhering to ART (perceived benefits), physiological body changes on the patients resulting from ART uptake and service quality at Piet Retief Wellness Centre. These questions were also seeking to collect data that would enable us to understand the reasons why HIV and AIDS infected Patients default from antiretroviral treatment.

3.5.4 Analytical procedures for both Quantitative and Qualitative Analysis

There were two broad analysis with regards to the data analysis. The quantitative data were analysed with the use of Survival (The Cox proportional hazard model) while the qualitative analysis was analysed using NVIVO software.

3.5.4.1 Quantitative procedures

The study utilized univariate, bivariate and multivariate (survival analysis) approaches to identify the socio-demographic factors affecting patients' adherence to ART by HIV patients who are both defaulters and non-defaulters. The following sections provide more information on the analytical process used by the study. SPSS version 25.0 was used for the analysis.

3.5.4.2 Univariate approach

A univariate statistical approach is used to provide background characteristics of the respondents associated with non-adherence to ART. Univariate Analysis was used whereby descriptive statistics such as percentages, means and medians was used to determine the distribution of individual factors in the study's model.

3.5.4.3 Bivariate approach

A bivariate approach explained the relationship among the categorical variables of the main variable. The bivariate analysis was used to look for associations among the categorical variables, for example in ART defaults. This entailed the relationship between the sets of socio-demographic factors on one hand, and the relationship between these factors and the outcome variables. The bivariate analysis also involved examining the relationship between the background characteristics and the other components of the HBM. The Pearson's chi-square statistics (X^2) are applied to assess the association between ART default against the selected categorical variables, such as gender, age, marital status, place of residence and level of education and other

HBM proxies. The chi-square test is carried out to examine the association of the proportional distribution of the categorical independent variables against the dependent variables. The level of significance of associations is established at 95% and the level of significance of the association is defined to be 5 % or 0.05.

Accordingly, the formula of the Pearson's Chi-squares test of association is defined as follows:
$X^2=\sum(Oi- Ei)/ Ei$

where; X^2 = computed Chi-squares;
$\sum$ = sigma notation/ summation sign;
Oi = observed frequencies where i=1,2, 3, etc
Ei = expected frequencies where i= 1,2,3,etc

The decision criteria is based on the stated Null-Hypothesis. Normally, the H_0 (Null-Hypothesis) is stated as: "there is no difference in the association between selected categorical variables of each main independent variable against any categorical variables of a dependent variable". The decision criterion is that if the computed X^2 is higher than the one picked from the standard, under a given degree of freedom (df) , then the Ho is rejected, implying that there are differences among the given categorical variables in the distribution of the target.

3.5.4.4 Multivariate analysis:

Survival Analysis and Cox regression analysis was used to assess the effects of socio-demographic factors on the timing of default. Since the central research question the current study involved the collection of data on the history of events such as the dates of enrolment on ART treatment, of first and subsequent defaults, and of birth, the study utilized Event History Analysis broadly in its effort to answer the research questions. Specifically, the study used Cox regression (Survival analysis) for the multivariate analyses as Survival analysis examines and models the time it takes for an event to occur (Fox & Weisberg, 2011). The Cox proportional hazard regression model was used to assess the effects of socio-demographic factors on the timing of default in the taking of antiretroviral treatment (ARV's) in a multiple regression framework (Fox & Weisberg, 2011). The Cox model is written;

$$h(t)=h_0(t)\times\exp\{b_1x_1+b_2x_2+...+b_px_p\}$$

Where the hazard function $h(t)$ is the dependent variable, which is dependent on a set of p covariates $(x_1, x_2, ..., x_p)$ whose impact is measured by the size of the respective coefficients $(b_1, b_2, ..., b_p)$.The term h_0 is the baseline hazard, which gives the value of the hazard if all the x_i are equal to zero. Empirically, estimating Cox regression involves the status, time and covariate variables. The status variable is the dependent variable, h (t) in the regression which is expected to be a binary response, that is, the ART treatment experience of a patient. The dependent variable is therefore whether or not a patient has ever defaulted. The goal of survival analysis is not only to examine the effects on the time until an event occurs, but also to assess the relationship of survival time to explanatory variables. Explanatory variables (covariates or independent variables) assess the impact of certain characteristics such as level of education, receiving treatment, age etc. The responses were coded 0 for those patients who indicated that they had never defaulted, while those that indicated that they had ever defaulted are coded 1.

For the purposes of the present study, the Life Table method was used to examine the relationship between selected individual socio-demographic factors and the timing of default by patients. The Cox proportional hazard model was used to examine the effect of multiple factors on adherence to ART. The benefits of using the Cox Regression Proportional Hazard model for this particular study is that while the conventional multiple regression method as normally used by many studies treat patients that have not defaulted at the time of the survey as missing cases, Survival analysis treat such cases as censored. This means that even though some patients would have not defaulted at the time of the survey, some will default over time. Survival analysis is able to consider the experiences of such patients by calculating cumulative proportions of all patients who would eventually default. Thus, survival analysis therefore is able to provide us with information about the totality of the default experience of patients.

Qualitative data analysis

The study used qualitative data to complement the secondary data. In-depth one on one interviews were conducted with both patients who had defaulted and those who had not defaulted treatment. The qualitative data were analysed using NVIVO software. Since the central objective of the present study was to examine the socio-demographic factors affecting patients' adherence to ART, the qualitative data served to provide more information on why patients default on ART. Interviews were audio-recorded, transcribed and analysed using thematic analysis and NVIVO 8 software. To analyse the transcribed and translated interviews, the following process was followed; interviews were read several times to identify major themes and ideas. A detailed list of categories was created to reflect the major themes which emerged from the interviews. From there, the categories were examined to note any similarities and differences within each category so that the frequency with which a category occurs could be quantified. Typical quotes from patients would be presented to illustrate the different reasons resulting to default in antiretroviral treatment. Among the themes that were discussed in the qualitative data is the socio-demographic factors affecting patients adherence to ART, the perspectives of patients on the quality of service delivery influencing the uptake of ART at Piet Retief Wellness Centre and the perspectives of Patients on the physiological bodily changes as a result of ART on the individual. The final theme that was covered is on the challenges/ barriers to ART adherence. These themes covered in the qualitative analysis are in line with the quantitative data themes in terms of providing more information on why the patients default on treatments.

3.5.5 Measurement of Study's Variables

Table 3-1 below shows the independent and dependent variables for this study, their definition and how they will be measured.

Table 3-1: Measurement of study's variables

Variable	Definition	Measurement
Dependent Variables		
ART Default (time to default)	Patient status whether they have defaulted from ART or not	*Status variable: 0=Never defaulted ART 1= Have defaulted ART *Time variable: 0 to 60 months Days and months will be used to measure the dependent variable.
Independent Variables		
Gender	Sex of the respondent either male or female.	1= Male 2=Female
Age	The age of the respondents in years.	1=16-19 2=20-34 3=35 and above
Education	Level of education of the respondent.	0=No education 1=Primary 2=Secondary 3=Post-secondary (college/university/ TVET colleges etc)
Marital Status	Living arrangement of the respondents in terms of marriage	1=Married 2=Never married 3=Cohabitating 4=Divorced 5=Widowed
Employment Status	How the respondent gets income	1=Not employed 2=Still studying (student) 3=Employed with a salary 4= Self employed
Area of Residence	The area where the respondent usually resides.	1=Rural 2=Urban

3.5.6 Piloting of the Questionnaire for the Study

A pilot study was conducted with two patients at the clinic who were not part of the study to test the questionnaire (interview guide) for further adjustment. In other words, piloting the questionnaire helped to modify the questionnaire in terms of issues such as the wording of items and the order in which they appeared in the questionnaire. Thus this process of piloting aimed to enhance with validity (face validity and content validity) and reliability of the research instrument. According to De Vos et al. (2005), face validity is the appearance of the questionnaire, while content validity refers to the extent to which the items on the questionnaire assess the content or how well the content material was sampled.

Moreover, Flores and Antonsen (2013) state that content validity is based on the extent to which a measurement reflects the specific intended domain of the content. This approach presumes that a good, detailed description of the content domain must be in place. Validity was ascertained by having the questionnaire reviewed by a colleague and a medical officer who is a specialist in the field of HIV treatment and care to confirm the relevancy of the questionnaire for this particular study. On the other hand, reliability was enhanced by ensuring that questions were asked according to the set order on the questionnaire. Similarly, during data collection (fieldwork), the researcher avoided expanding and probing more than anticipated according to the questionnaire.

3.5.7 Ethical Considerations

The following process was followed to obtain ethical approval before conducting the study:

- We obtained approval from Piet Retief Wellness Centre to access the records of HIV patients who have been initiated into ART between the period 2010 and 2014.

- We submitted the research protocol to the National Health Research database and obtained the provincial approval from the Mpumalanga Provincial government approval to conduct research at Piet Retief Hospital Wellness Centre.

- We submitted the research protocol and obtained approval from the Research Ethics Committee of the North-West University.

- At the interview phase of the study, the interviewers were asked to explain the aims and objectives of the research to the study participants to obtain informed consent. In addition to that, they explained to the study participants that being part of the study was voluntary and they were allowed to withdraw from the study anytime during the interview.

- Study participants were assured of confidentiality with regard to their responses. Every intending participant who was willing to be part of the study signed the informed consent form.

- Finally, the study ensured confidentiality and privacy of patients and records accessed during the study. The researcher and an assistant were the only people who were allowed to access the patients’ records and as well interview the patients who will participate in this study. Patients will be identified by numerical codes, not their real names. The data captured for the study will be accessible to the researcher only and will be used for the purpose of the study only. The findings will be shared in prepared PowerPoint slides with the hospital, the participants and the province.

CHAPTER 4: DETERMINANTS OF ART ADHERENCES AND DEFAULTS

4.1 Introduction

This chapter presents analysis of the socio-demographic factors influencing the uptake of antiretroviral treatment (ART) at Piet Retief Wellness Centre. The information on the socio-demographic characteristics of the respondents was extracted from the patients' clinical files. This section of the analysis deals with the distribution of these socio-demographic characteristics of the respondents, while subsequent sections deal with the bivariate and multivariate results of the analysis.

4.2 Univariate Analysis

For the distribution of the individual background factors that affect adherence to ART or univariate analysis, we used descriptive statistics such as simple proportions or percentages, means and medians.

4.2.1 ART default

Long-term patients' retention to ART is now being considered as one of the major challenges facing public sector ART programmes globally (WHO, 2013). According to Nam et al. (2008) non-adherence is the most important factor known to be associated with treatment failure for HIV patients in both developed and developing countries. Studies conducted in different parts of the world stress the increasing challenges of non-adherence to ART by patience. For example, in North America, a pooled analysis of adherence studies found that 45% of patients on ART were not adhering to ART (Mills et al., 2006). Further, studies conducted in Brazil on ART non-adherence revealed that 34% of patients were not adhering to their medication (Bonololo et al., 2013). In Spain, researchers discovered that 43% of patients on ART were not adhering to ART (Gordillo et al., 1999).

With regard to SSA, this region has the highest number of people living with HIV and AIDS compared to the rest of the world. Out of the estimated 34 million people infected with the virus in the year 2010, 68% resides in sub-Saharan Africa (UNAIDS, 2011). The sub-Saharan Africa region is also hit hard by the challenge of non-adherence to ART medication. Studies conducted in sub-Saharan Africa attest to this challenge of ART non-adherence among patients. For example, a study that was conducted by Rosen et al. (2007) observed that ART programmes in Africa have only managed to retain approximately 60% of patients on therapy at two years after initiation on therapy. Another study that was conducted by Mills et al. (2006) on ART adherence estimated that the rate of adherence in sub-Saharan Africa is 77 per cent, and non-adherence rate in the adult population was estimated between 33 and 88 per cent depending on the measure of adherence used which ranges from patients' reports to patients file reviews for missed ART appointments.

Further to this, a systematic review of data from ART programmes in SSA reported ART default rates of 23% at 12 months, 25% at 24 months to 30% at 36 months with most ART defaulting occurring within the first year after ART initiation (Fox & Rosen, 2010). In sub-Saharan countries, varying rates of non-adherence at country levels have been witnessed. For example, a study that was conducted by Elul et al. (2013) found that 23% of ART patients were non-adherent based on a 30-day recall. In rural Zambia, a study that was conducted by Sasaki et al. (2012) reveal that 40% of the patients who had been on ART were not adherent.

In the Southern African region, pooled analysis of African adherence studies has reported non-adherence to ART to be 23% and above Mills et al. (2006). On the other hand, in South Africa, research indicates that adult retention in ART is deteriorating over time, with patients who started ART more recently being more likely to default compared to those who initiated ART in earlier years (NDH, 2013). Other studies conducted in South Africa have also revealed that the issue of retention is a major challenge. For example, in 32 studies reviewed by Rosen et al. (2007) the retention rate at two years of treatment was at 62%. Moreover, in an analysis of 33 studies, they found a retention rate of 72% at 3 years of treatment.

A study conducted by Cornell (2010) in Khayelitsha, South Africa, among 3,595 adults enrolled in HAART over 5 years showed that the cumulative proportion of patients remaining in care at 54 months after initiation on treatment was 78%. This shows that generally patients on ART in South Africa default on treatment. ART is a complex treatment which requires not only availability of the clinical sites, but serious monitoring to ensure that patients carefully adhere to the treatment regimens so as to prevent drug resistance and improve on the survival rate of patients.

Figure 4-1 shows the percentage distribution of patients enrolled at Piet Retief Wellness Centre between 2010 and 2014.

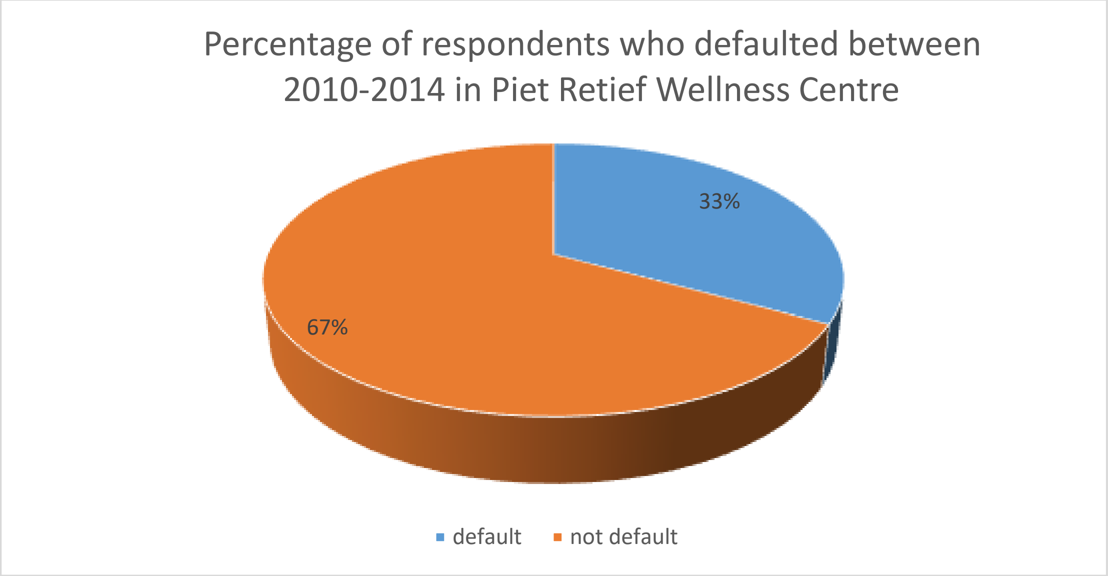

Figure 4-1: Percentage distribution of ART defaulters at Piet Retief Wellness Centre in South Africa between 2010 and 2014.

As observed in Figure 4-1 of the 777 patients who were enrolled in ART at Piet Retief Wellness Centre between 2010 and 2014, 33% defaulted while 67% took their medication without fail. This finding corroborates other studies conducted in South Africa that have also revealed that the issue of retention to ART is a major challenge. For example, in 32 studies reviewed by Rosen et al. (2007) in South Africa the retention rate at two years of treatment was at 62%.

Another study that was conducted in the Western Cape Province of South Africa by Boulle et al. (2008) found that 14.7% of the patients defaulted. Further, a study that was conducted in the Gauteng, Eastern Cape and Mpumalanga Provinces of South Africa showed an ART default rate of 28%. On the other hand, in KwaZulu-Natal Province, Vella et al. (2010) found that ART default rate was 19%. In addition to this, a study that was conducted in the Eastern Cape by Ford et al. (2006) observed that the ART default rate was 24.9%. In her research on ART adherence following the national antiretroviral rollout in South Africa, Van Dyk (2011) discovered that only 40.1% of the patients could reach optimum adherence levels of 90% and above while 49% reached adherence levels between 70% and 80 per cent (Van Dyk, 2013). In addition to this, a further 10.9% could not even reach adherence levels of 70 % (Van Dyke, 2011).

4.2.2 Gender

Gender is a socio-demographic factor and research conducted in different parts of the world has shown that the gender of a patient influences ART uptake. This observation is based on the premise that women are more likely to seek clinical interventions compared to males (Weiser et al., 2003). Specifically, studies have shown that women are more likely to adhere to ART compared to men (Kekwaletswe & Morojele 2014; Marcellin et al., 2008; Nguyen et al., 2013; Unge et al., 2010). Research conducted in different parts of the world has shown that the gender of a patient influences ART uptake, although the findings are not definitive. Some studies have revealed that women are more likely to adhere to ART compared to men (e.g Abah et al., 2011; Kekwaletswe & Morojele, 2014; Marcellin et al., 2008; Ngarina et al., 2013; Nguyen et al., 2013; Unge et al., 2010; Weiser et al., 2003). These studies conclude that the reasons why females are more likely to adhere to ART than males is due to the fact that females are more likely to attend VCT services compared to men.

However, other studies have found that men are more adherent to ART compared to females (e.g. Alakija et al., 2010; Beer et al., 2012; Elul et al., 2013; Fumaz et al., 2008; Graham et al**.,** 2013; Marcellin et al., 2008; Ortego et al., 2008; Sullivan et al., 2007; Tapp et al., 2011; Wakibi et al., 2011; Wasti et al., 2012). But, still research conducted in other parts of the world has shown no association between gender and ART adherence (Aragones et al., 2011; Nyambura,et al., 2012; Sarna et al., 2008; Sharma et al., 2013; Venkatesh et al., 2010; Weiser et al., 2012).

Table 4-1: Frequency and percentage distribution of characteristics of respondents enrolled at Piet Retief Wellness Centre between 2010 and 2014.

Variables	Frequency (N)	Percentage (%)
Gender		
Female	435	66.0
Male	342	44.0
Total	777	100
Age		
15-24	62	8.0
25-34	274	35.2
35-44	267	34.4
45-74	174	22.4
Total	777	100
Marital Status		
Ever married	487	62.7
Never married	290	37.3
Total	777	100
Education		
No education	178	22.9
Primary	342	44.0
Sec and higher	257	33.1
Total	777	100
Employment Status		
Employed	256	33.0
Not employed	521	67.0
Total	777	100
Place of residence		
Rural	338	43.5
Urban	439	56.5
Total	777	100

Table 4-1 shows that the majority of the respondents are female (66%) while males comprised of 44%. The results show that there are more females on ARVs compared to males.

This study was interested in investigating the influence of socio-demographic factors on ART non-adherence. The age of a patient has been identified as one of the risk factors for ART non-adherence. Findings from various studies have shown that the age of an individual has a significant influence on ART non-adherence (Beer et al., 2012; Fimaz et al., 2008; Nozaki et al., 2011; Ortego et al., 2011; Sullivan et al., 2007; Tapp et al., 2011; Wasti et al., 2012). These studies have documented a statistically significant association between age and adherence, with better adherence having been observed among older patients above the age group 31 years and older, while non-adherence have been observed from patients below age 30 years and those above 50 years. For this study, age was divided into five categories: 15-24 (8.0%); 25-34 (35.2%); 35-44 (34.4%); and 45-74 (22.4%).

Looking at the age groups for this study, the modal age group of patients is the 25-34 (35.2%), followed by the 35-44 (34.4%). The age group 45-74 has the third highest percentage of patients enrolled into ART while the group with the least percentage (8.0%) of patients enrolled into ART is the 15-24. The age distribution of this study is consistent with the general trends in HIV and AIDS rates where the most affected population comprises of young adults within the age groups 18 to 40 years (StatsSA, 2016).

4.2.3 Marital status

Marital status has been identified as one of the socio-demographic risk factors to ART non-adherence (Mahlangu, 2008). In fact, many studies conducted around the world have concluded that married people are more likely to adhere to ART compared to unmarried people (Aspeling et al., 2008; Boyer et al., 2011; Graham et al., 2013; Jaquet et al., 2010; Kisenyi et al., 2013; Martin., et al., 2013; Medley, 2014; Ngarina 2013; Sanjobo, 2008; Uzochukwu et al., 2009; Van Wyk, 2008; Weiser et al., 2010).

The above studies concluded married people are more likely to adhere to ART because of the support that they receive from their spouses. These authors conclude that this is due to the fact that when one’s spouse is aware that they are on treatment, support is provided to the person who is on ART which encouraged consistency in taking ART medication. However, other studies found no association between marital status and ART adherence (e.g Birbeck et al., 2009; De & Dalul, 2012; Mitiku et al., 2013; Fogarty et al., 2002; Melaku et al., 2016).

In the present study, Table 4-1 shows that the majority of the respondents (62.7%) are currently married while the never married account for 37.3 per cent.

4.2.4 Education

Education has been identified as one the risk factors for ART non-adherence (Weiser *et* al., 2003). Specifically, it has been found that lower levels of education are associated with non-adherence (e.g. Alakija et al., 2010; Birbeck et al., 2011; Erah & Arute, 2008; Kekwaletswe & Morojele, 2014; Meleku, 2015; Moralez, 1999; Negash, 2013; Peltzer et al., 2010; Sipter et al., 1999). In the present study, education was grouped into three main categories: No education (22.9); Primary education (44.0); and Secondary and higher education (33.1). The modal educational attainment was primary education which constituted 44 per cent of the sample, while those with no education constituted 22.9% of the sample.

4.2.5 Employment status

As a socio-demographic factor, employment status was included based on the premise that many studies have concluded that financial challenges such as transport costs, health facility costs and financial insecurity, arising from unemployment, were associated with non-adherence (e.g. Bezabhe et al., 2014; Nyanzi-Wakholi, et al., 2009; Penn et al., 2011; Rasmussen et al., 2013; Skovdal et al., 2011; Talam et al., 2008). Another study that was conducted by Gierson et al. (2000) revealed that unemployment was one of the major reasons for high non-adherence to ART.

According to these researchers, poverty increased the levels of non-adherence to patients on ART. A survey of 924 Australian HIV positive people revealed that lack of employment negatively affected ART-adherence, as patients could not afford the money for clinic visits for medication refill (Katabira et al., 2002). At Piet Retief Wellness Centre, while only 33.0 per cent of the patients are employed, a total of 67.0 per cent of the patients are unemployed.

4.2.6 Place of residence

The nature of the place where a person resides has been identified as a risk factor for ART adherence by various studies (e.g. Cauldbeck et al., 2009; Maquthu et al., 2010; Pelzer et al., 2010; Sarna et al., 2008). The results of these studies reveal that people residing in rural areas are more likely to default on ART compared to people residing in urban areas. In addition, these studies showed that adherence also improved as patients changed areas of residents from rural to urban areas. For this study, while 43.5 per cent of the patients reside in rural areas, 56.5 per cent of the patients reside in urban areas.

4.3 The Bivariate Analysis of the Categorical Variables of the Main Variables

This section presents the results of the bivariate analysis. The aim of this component of the analysis is to examine the relationship between the dependent variable on one hand, and each of the set of categorical independent variables, on the other hand. Specifically, in this section of the chapter, we employ both cross tabulation and the Kaplan-Meier survival analysis to examine the associations between the dependent variable (ART default) and the independent variables (socio-demographic factors). The Pearson Chi-square is used to test the association among the categorical variables of each main variable with a critical value of $p<0.1$ as the criterion.

Table 4-2: The relationship between socio-demographic characteristics and ART default status

Variables	Treatment default (%)	Degree of freedom	Pearson X^2	p-value
Gender		1	1.2807	0.258
Female	36.1			
Male	40.1			
Age		3	19.6964	0.000
15-24	62.9			
25-34	37.6			
35-44	36.3			
45-74	31.6			
Marital Status		1	2.0101	0.156
Ever married	35.9			
Never married	41.0			
Education		2	82.8959	0.000
No education	66.8			
Primary	28.4			
Sec and higher	30.3			
Employment Status		1	43.4101	0.000
Employed	21.5			
Not employed	45.9			
Place of residence		1	193.0023	0.000
Rural	65.4			
Urban	16.6			

Gender and treatment default

Table 4-2 shows the results for the present study. As the table shows, there is no relationship between a patient’s gender and their treatment default status. Even though males have a general tendency to treatment default than females, the relationship is statistically insignificant. This relationship is further illuminated by the results of the Kaplan-Meier survival analysis as illustrated in Figure 4-2.

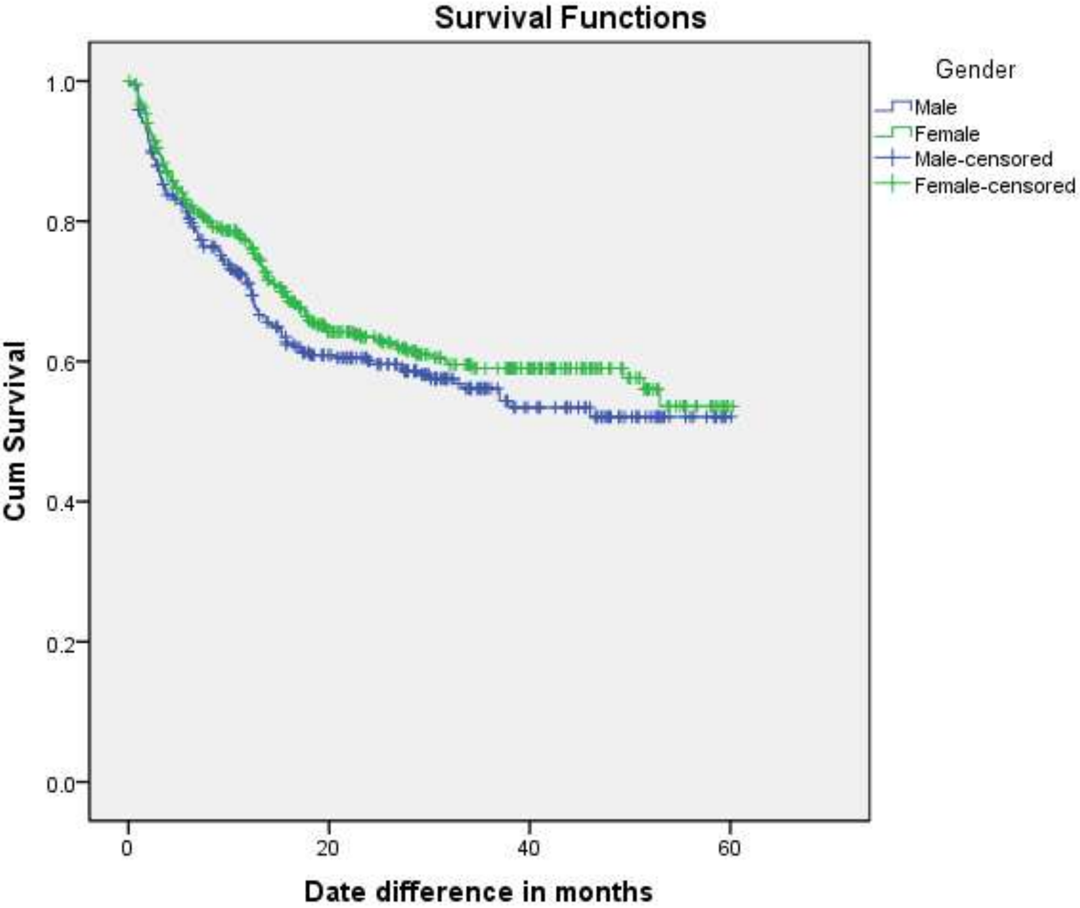

Figure 4 - 2: Kaplan-Meier survival analysis of the relationship between gender and treatment default by patients

In terms of the age of patients, Table 4-2 shows clearly that there is a statistically significant relationship between age and treatment default status of a patient. Specifically, the table shows that there is an inverse relationship between age and treatment default status in that as a patient gets older, the chances of default decline and vice versa. In other words, young patients are much more likely than their older counterparts are to default from ART treatment (62.9% vs. 31.6%). This finding is further shown by the results of the Kaplan-Meier survival analysis shown in Figure 4-2 which shows that respondents between the ages of 15-24 have the highest hazard risk of treatment default.

For example, the figure shows that about 80% of respondents between the ages of 15-24 years had defaulted by 60 months of treatment. The graph shows that the hazard risk line of respondents between the ages of 15-24 years dropped faster than all other ages.

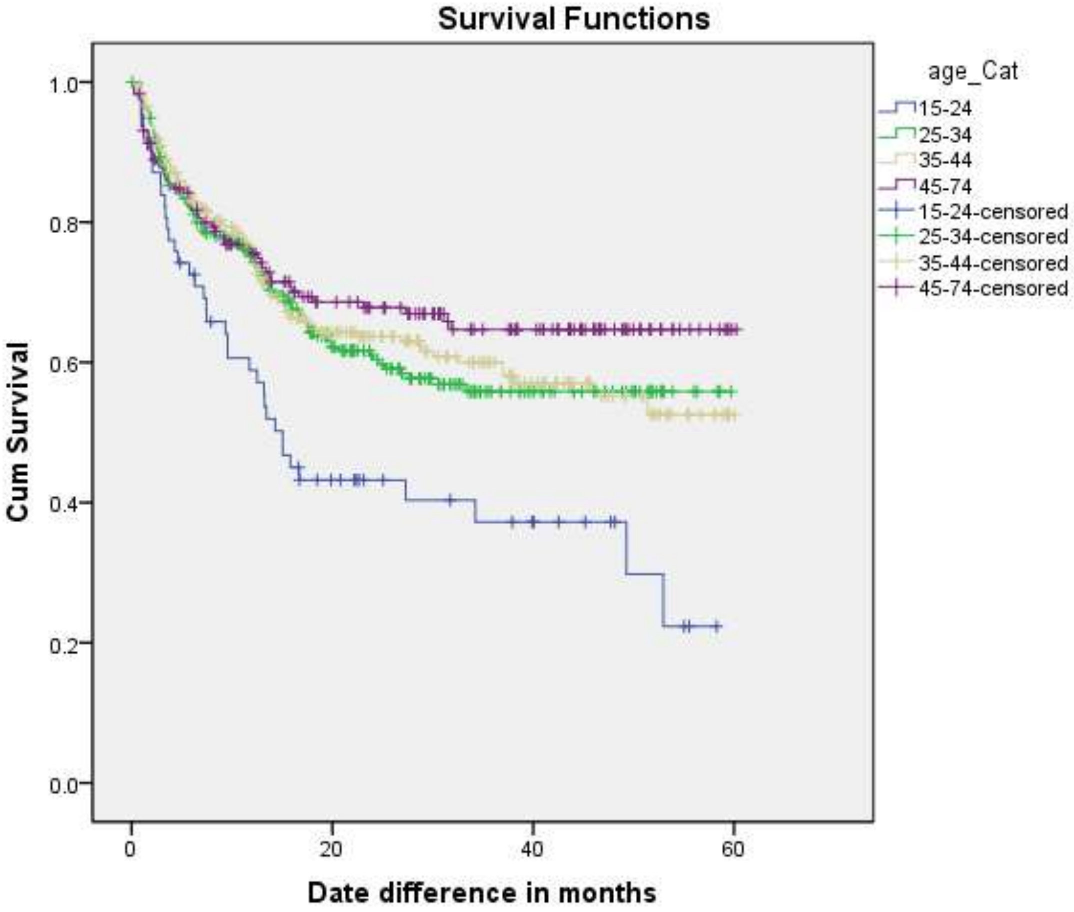

Figure 4-3: Kaplan-Meier survival analysis of the relationship between age and treatment default

As far as marital status is concerned, Table 4-2 and Figure 4-4 show that the relationship between marital status and treatment is statistically insignificant.

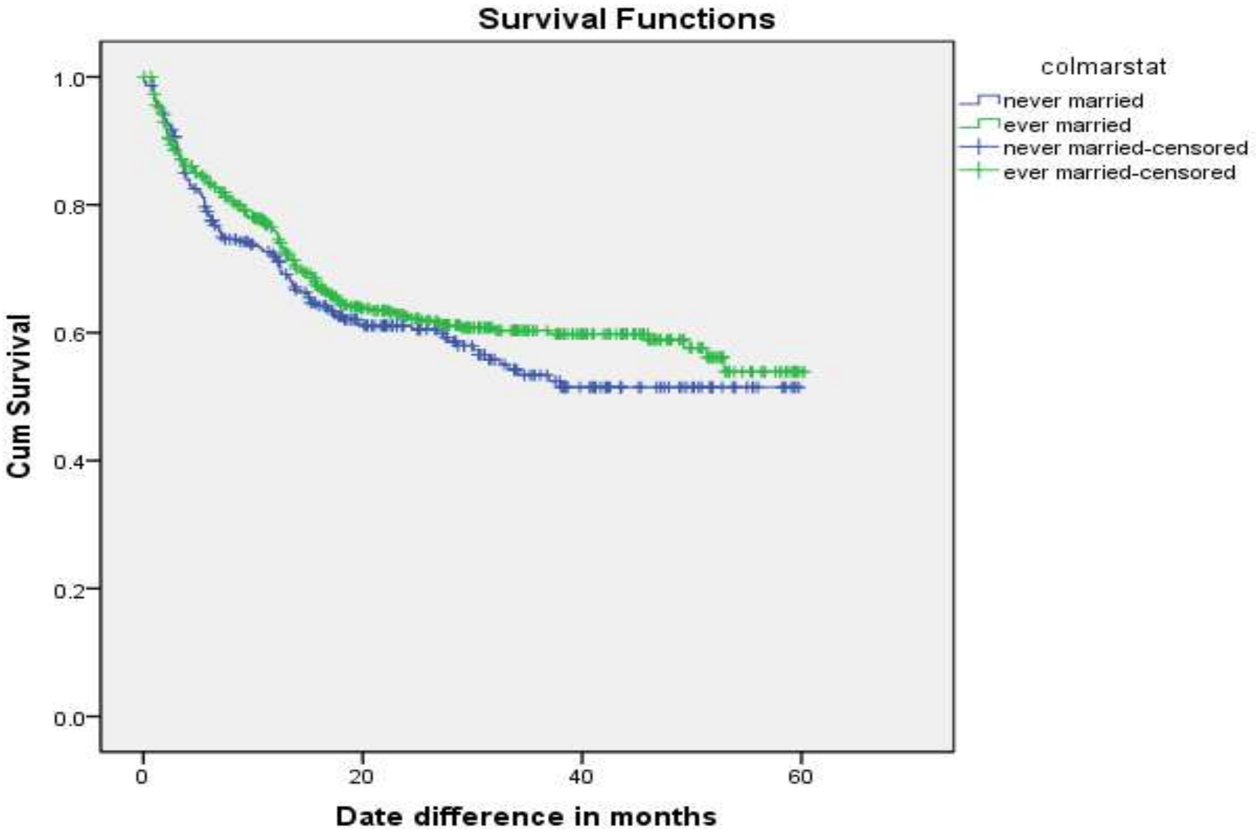

Figure 4-4: Kaplan-Meier survival analysis of the relationship between marital status of respondents and treatment default

Education affects treatment default of ARV. Table 4-2 shows that the prevalence of treatment default was highest (66.8%) among respondents who have no education. Primary education had treatment default of (28.4%) while secondary and higher education had a treatment default of 30.3%. The corresponding results of the Kaplan-Meier analysis are shown in Figure 4-5 which shows that compared to respondents that have primary, secondary and tertiary education, the graph shows that respondents without any formal education have the highest hazard risk of treatment default. For example, the graph showed that about 20% of respondents that had no education remained on treatment at 60 months. The graph shows that the hazard risk line of respondents without any formal education dropped faster than all other categories of education.

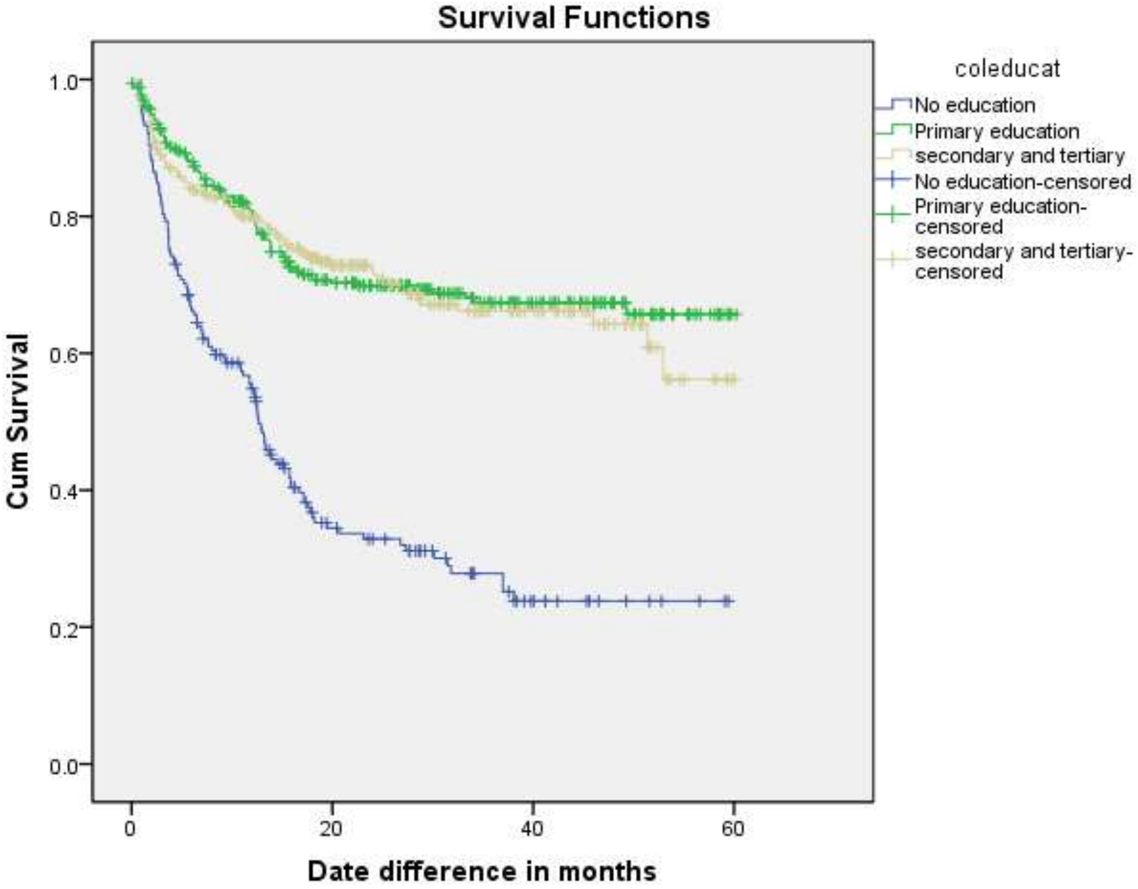

Figure 4-5: Kaplan-Meier survival analysis of the relationship between educational level of respondents and treatment default

Table 4-2 and Figure 4-6 show that there is a significant relationship between employment status and ART non-adherence whereby employed people are more likely to adhere to ART compared to the unemployed. As Table 4-2 shows, there is a statistically significant relationship between employment status and treatment default by patients. For example, the table shows that treatment default is higher (45.9%) among unemployed respondents compared to those that were employed, while it is lower among patients who are employed (21.5%). Figure 4-6 compared to respondents that are employed and unemployed, respondents that are unemployed have the highest hazard risk of treatment default. For example, at 40 months, about 40% of unemployed respondents remained on treatment compared to about 70% of employed respondents.

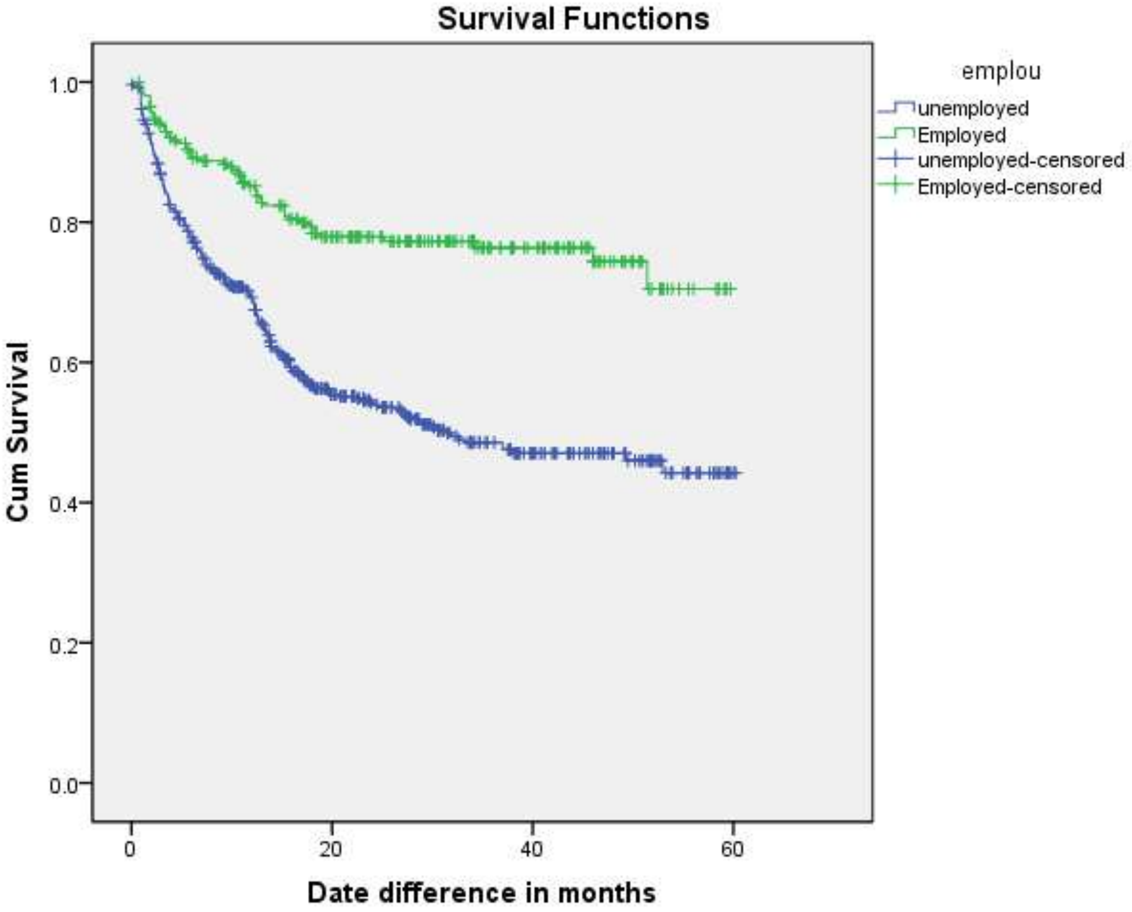

Figure 4-6: Kaplan-Meier survival analysis of the relationship between employment status of respondents and treatment default

Table 4-2 shows that there is a significant relationship between the place of residence and ART default whereby people residing in rural areas are more likely to default compared to those residing in urban areas. At Piet Retief Wellness Centre, treatment default is more (65.4%) prevalent among respondents residing in rural areas compared to 16.6% of those residing in urban areas. The findings in Table 4-2 about the relationship between place of residence and treatment default by patients is further supported by the results of the Kaplan-Meier survival analysis as shown in Figure 4-6. Specifically, compared to respondents residing in urban areas, the graph shows that respondents residing in rural areas have higher hazard risk of treatment default. The survival functions showed that at 60 months, only about 20% of respondents living in rural areas remained on treatment compared to about 80% of respondents living in urban areas.

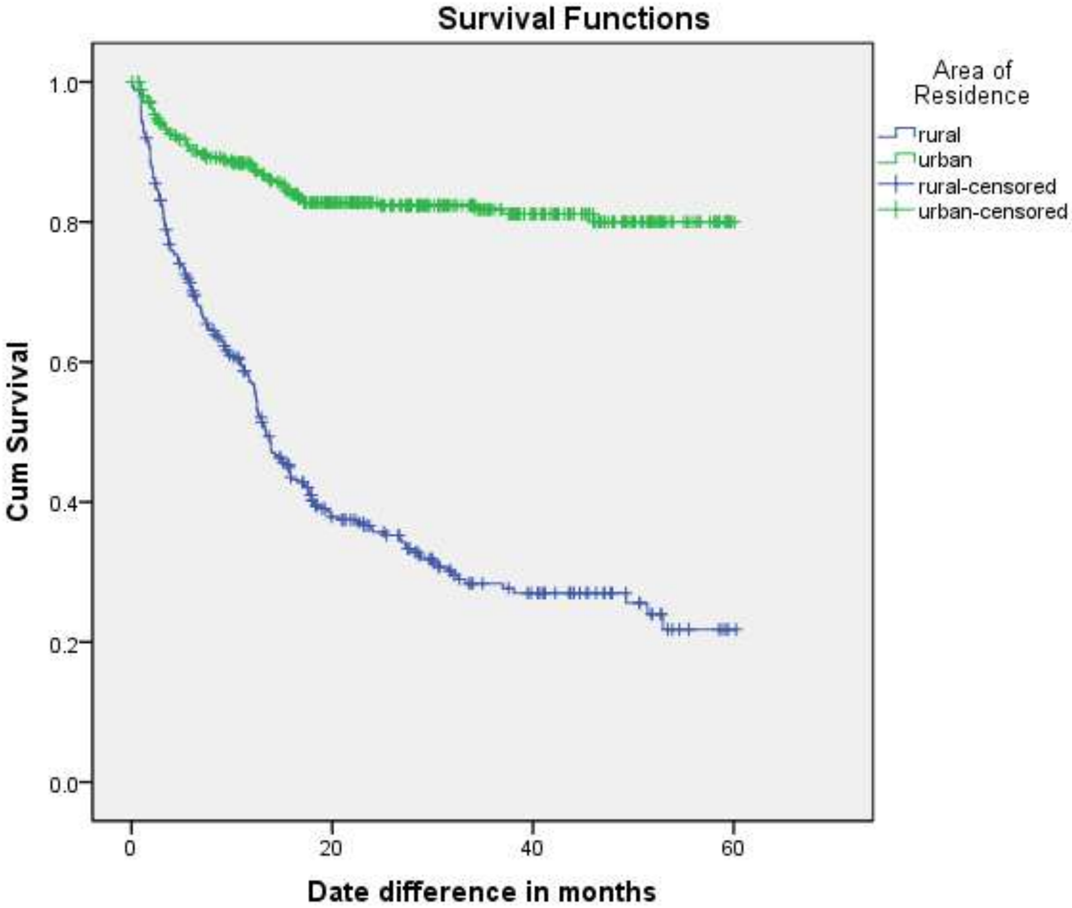

Figure 4-7: Kaplan-Meier Survival Analysis of the Relationship between Place of Residence and Treatment Default

4.4 Multivariate Analysis

While in the preceding sections of the chapter the predictor socio-demographic factors have been examined individually, in this section the Cox regression analysis is used to examine the effects of socio-demographic factors on the timing of default at the same time. In other words, in this section, we examine the effects of individual effects of the factors after adjusting for the effects of the other factors in the model.

Due to the dynamic nature of the study’s central research question, event history analysis is used broadly in its effort to test the study’s hypotheses. Specifically, the Cox proportional hazard regression model is used to assess the effects of socio-demographic factors on the timing of default in the taking of antiretroviral treatment (ARVs) in a multiple regression framework (Fox & Weisberg, 2011). The Cox model is written:

$$h(t) = h_0(t) \times \exp\{b_1x_1 + b_2x_2 + ... + b_px_p\}$$

Where the hazard function $h(t)$ is the dependent variable, which is dependent on a set of p covariates $(x_1, x_2, ..., x_p)$ whose impact is measured by the size of the respective coefficients $(b_1, b_2, ..., b_p)$.The term h_0 is the baseline hazard, which gives the value of the hazard if all the x_i are equal to zero. Empirically, estimating Cox regression involves the status, time and covariate variables. The status variable is the dependent variable, h (t) in the regression which is the time it takes for an event to occur.

Figure 4-8 shows the overall time to treatment default. The graph shows that patients started defaulting from the first month of initiating treatment. At the end of 55 months of treatment, all patients who defaulted have exited.

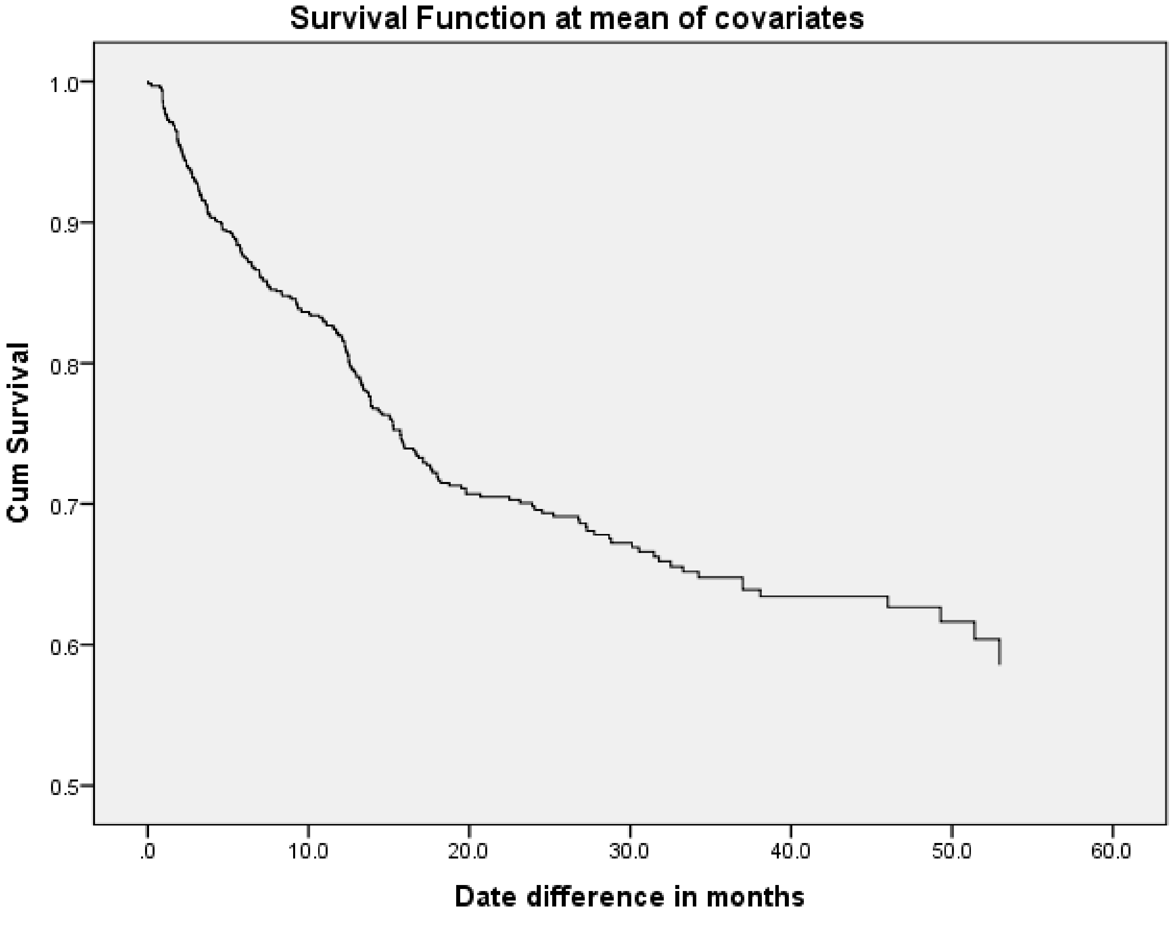

Figure 4-8: Survival Curve for ART Treatment Default

Table 4-3 shows the results of the Cox regression model which shows the hazard risk of treatment default according to socio-demographic characteristics of respondents. As far as gender is concerned, even though in the bivariate analysis males appeared to be more likely than females to default, after adjusting for the effects of all the factors in the model, the hazard of treatment default is 1.2 times higher among female respondents compared to male respondents, even though as the table shows, the relationship between gender and treatment default is statistically insignificant.

In terms of age, while the bivariate analysis revealed that younger patients aged 15-24 are more likely to default, as they appeared to have higher default rates, after adjusting for all the other factors in the model (multivariate) the hazard of treatment default was 2.2 times higher among respondents age 25-34 years compared to respondents between the ages of 15-24. Similarly, the hazard of treatment default was 1.5 times higher among respondents between the ages of 35-44 compared to those between the ages of 15-24 years. In addition, the hazard of treatment default is 1.5 times higher among respondents between the ages of 45-74 years compared to those between the ages of 15-24 years.

In terms of marital status, the bivariate finding was confirmed by the Cox regression analysis results because after controlling for all the factors in the model, the hazard of treatment default shows that there’s no difference in treatment default in terms of marital status. Consistent with the HBM, we expected single people to default more compared to married people due to lack of the support a spouse provide by reminding a patient to take their medication on time or even assist with finances when one person has been enrolled on treatment.

As far as education goes, we found that there is an inverse relationship between educational attainment and ART treatment default. The default rate was 2.0 times higher among respondents who had primary education compared to respondents who had no education. As shown in Table 4-2, the employment status of a patient affects ART treatment default status. Specifically, the table shows that the hazard of treatment default is 2.0 times higher among employed respondents compared to unemployed respondents.

Finally, with regard to area of residence, Table 4-2 shows that contrary to the bivariate analysis in which rural residents appeared to have higher treatment default rates than their urban counterparts, the hazard risk of treatment default is 4.5 times higher among respondents living in urban areas compared to respondents living in rural areas.

Table 4-3: Cox regression analysis of the relationship between socio-demographic factors and hazard risk of ART default

Variables in the Equation	B	SE	Wald	df	Sig.	Exp(B)	95.0% C.I. for Exp(B)	
							Lower	Upper
GENDER								
Male (RC)								
Female	.168	.119	1.982	1	.159	1.183	.936	1.493
AREA OF RESIDENCE								
Rural (RC)								
urban	1.516	.139	119.242	1	.000	4.554	3.469	5.978
AGE GROUP								
15-24 (RC)								
25-34	.792	.218	13.161	1	.000	2.209	1.439	3.388
35-44	.401	.172	5.469	1	.019	1.494	1.067	2.090
45-74	.421	.171	6.037	1	.014	1.524	1.089	2.133
MARITAL STATUS								
Never married (RC)								
Ever married	-.009	.121	.006	1	.939	.991	.781	1.257
EDUCATION								
No education			41.635	2	.000			
Primary	.713	.158	20.272	1	.000	2.040	1.495	2.781
Secondary and higher	-.152	.158	.925	1	.336	.859	.631	1.170
EMPLOYMENT STATUS								
Unemployed (RC)								
Employed	.682	.157	18.750	1	.000	1.978	1.452	2.693

4.5 Main Findings and Discussion

This chapter was limited to the analysis of the quantitative component of the data and examined the socio-demographic risk factors affecting adherence to antiretroviral treatment (ART) among HIV positive patients at the Piet Retief Wellness Centre in the Mpumalanga province of South Africa between 2010 and 2014. The quantitative component of the data were analysed at three levels, namely, univariate, bivariate and multivariate. Among the socio-demographic factors examined were gender, age, education, marital status, employment status, and place of residence. As far as gender is concerned, while in the bivariate analysis males appeared to be more likely than females to default, after adjusting for the effects of all the factors in the model, the relationship between gender and ART default was found to be statistically insignificant. This finding corroborates the results of other studies that show that there is no relationship between gender and treatment default (e.g. Aragones et al., 2011; Nyambura, 2012; Sarna et al., 2008; Sharma et al., 2013; Venkatesh et al., 2010; Weiser et al., 2012). This relationship is statistically insignificant in the present study. This therefore means that gender is not a predictor of ART non-adherence.

As far as age goes, we found that there is a positive association between age and ART default. This finding is corroborated by Okoronkwo et al. study (2013) which showed that in terms of patients' age and non-adherence to ART, patients who were 45-74 years old were 1.5 more likely to default compared to patients below 40 years. Moreover, Shigdel et al. (2014) found that ART non-adherence increased significantly with increasing age particularly after the age of 50 years. This therefore means that age is a predictor of ART non-adherence.

In terms of marital status, the hazard of treatment default shows that there's no difference in treatment default in terms of marital status, a finding which is similar to that of other studies that revealed that there was no statistically significant association between marital status and adherence (Birbeck et al., 2009; De & Dalul, 2012; Fogarty et al., 2002; Melaku et al., 2016; Mitiku et al., 2013). This finding means that marital status is not a predictor of ART non-adherence.

As far as education is concerned, the present study found that there is an inverse relationship between educational attainment and ART treatment default. The default rate was 2.0 more likely to be among respondents who had primary education compared to respondents who had no education. This finding is similar to the findings of other studies that revealed that lower levels of education are associated with non-adherence (e.g. Alakija et al., 2010; Birbeck et al.,2011; Erah & Arute, 2008; Kekwaletswe and Morojele, 2014; Meleku, 2015; Moralez, 1999; Negash,2013; Peltzer et al.,2010). In addition, in a detailed analysis of the relationship between education level and ART non-adherence in Botswana, Weiser et al. (2003) found that as education level increased, adherence to ART increased too. Specifically, the study found that for those who were at tertiary institutions, non-adherence to ART was lower compared to those with no formal schooling. Also, the study revealed that the lack of treatment default is 0.9 more likely to be for those who were in secondary and tertiary institutions compared to those with no education. This therefore means that education level is a predictor of ART non-adherence.

In terms of employment status, the finding that the hazard of treatment default is higher among employed respondents compared to unemployed respondent is contrary to the findings of some studies that concluded that people who were employed were less likely to default from ART medication compared to those who were unemployed (e.g. Boyer et al., 2011; Goudge & Ngoma, 2011; Hegazi et al., 2010; Maqutu et al., 2010; Okoronkwo et al., 2013; Peltzer et al*.,* 2011; Weise et al., 2003). Also, some studies found that people who were in high income employment had no difficulty in adhering to ART compared to patients who were unemployed (Pratt et al., 1998; Martinez et al., 1998). This therefore means that employment status is a predictor of ART non-adherence whereby employed people are more likely to default compared to unemployed people.

The present study did not control for occupation so was in no position to support or contradict this particular finding. In terms of area of residence, the hazard of treatment default is 4.5 more likely to be among respondents residing in urban areas compared to respondents residing in rural areas. Our finding however is contrary to the findings of other studies on the relationship between area of residence and ART default. For example, in India, long travel time by village people to ART centres has been identified as one of the major causes of ART non-adherence (e.g. Cauldbeck et al., 2009; Sarna et al., 2008). This is despite efforts by the country's Ministry of Health of ensuring that ART centres are closer to villages, people still prefer travelling long distances to access ART in pursuit of avoiding being stigmatized in their local communities (Wakibi et al., 2011).

4.6 Conclusion

It can be observed from Table 4.3 above that the area of residence, age group, educational attainment and employment status are predictors of ART non-adherence. On the other hand, this study found that gender and marital status were found to be non-predictors of ART non-adherence. In conclusion therefore, the findings of the present study have provided empirical evidence to support not only the usefulness of the HBM as a framework for understanding of individuals' health-related decision-making, but more importantly the role of the individuals' access to the social and demographic resources in the society.

CHAPTER 5: THE PERSPECTIVES OF PATIENTS ON THE QUALITY OF SERVICE DELIVERY: THE EFFECT ON THE UPTAKE OF ART IN PIET RETIEF WELLNESS CENTRE.

5.1 Introduction

While Chapter 4 focused on the analysis of the quantitative data, chapter five presents the first part of the analysis of the qualitative data and looks at the perspectives of patients on the quality of service delivery as a possible influence on the uptake of antiretroviral treatment (ART). Specifically, Chapter 5 focuses on patients' experiences with regard to the quality of service at Piet Retief Wellness Centre. The information on the perspectives of patients concerning the quality of service was obtained through in-depth interviews (individual) with patients who have defaulted treatment and those who have not defaulted treatment.

These questions asked aimed at assessing the following components of the HBM; perceived susceptibility, perceived severity, perceived barriers and perceived benefits. The aim of these questions was to collect data that will enable us to understand the reasons why HIV and AIDS infected Patients default from antiretroviral treatment and establish the contribution made by the HBM in explaining why patients choose not to engage in health seeking behaviours which in this case is the uptake of ART.

The questions that were asked sought to ascertain issues pertaining patients' perceptions of the service quality influencing the uptake of ART at the Centre. These questions among others were: patients' observation of the waiting time for medication refill, staffing of medical personnel, attitudes of healthcare workers towards patients and availability of drugs (ART). Further, patients' perceptions of service quality at Piet Retief Wellness Centre was assessed by asking questions on the knowledge of patients and service providers about ART and how open service providers are to discuss HIV and AIDS and ART (perceived susceptibility).

The questions seek to provide more information if patients were provided with counselling (HIV and AIDS and ART education) before getting initiated into ART, ascertaining the HIV knowledge of the patient, ascertaining patients knowledge about the benefits of adhering to ART (perceived benefits) and the dangers of not adhering to ART (perceived threat), ascertain if patients were given clear instructions on how to take their medication by themselves (self-efficacy), ascertain if health providers informed them of the treatment side effects (perceived threat), investigate the attitudes of the health providers on patients' present state (HIV positive status) and investigate if patients' rights at the facility are respected.

5.1.1 Perspectives of Patients on the Quality of Service Influencing ART Non-Adherence

Service quality plays a vital role in ensuring patients' adherence to ART. In a worldwide survey of 59 ART clinics around the world, World Health Organization (WHO, 2016) discovered that poor service quality was a cause for patients' non-adherence to ART. The findings from this evaluation showed that in most ART clinics, patients' records were missing and there were interruptions to ART supply due to drug stock-outs. Among existing gaps in the quality of ART services around the world which resulted in patients non-adherence on ART were; loss to follow-up patients whereby on average 20% of patients were missing on patients records within a year since ART initialization, 73% of patients were not retained on treatment and ART drug stock out whereby about 36% of surveyed clinics experienced interruptions in the supply of ARV drugs. As a recommendation, WHO (2016) has suggested that countries have to ensure that ART services are of good quality to achieve long-term impact on patient's retention on treatment.

Maquthu et al. (2010) study also highlighted the contribution to non-adherence made by poor service quality in countries around the world. The study revealed that long waiting times at the clinics, lack of support from staff, low staff to patient ratio and unavailability of medication resulted in ART non-adherence. Research conducted around the world on the factors affecting service quality of ART include among others; long waiting times, limited clinic hours, crowded clinics and lack of privacy in the consultation room have been reported to be a barrier to ART adherence, especially for working people who need time off work to collect medication (see e.g. Audu et al., 2014; Bezabhe et al., 2014; Hardon et al., 2007; Jaquet et al., 2010; Penn et al., 2011; Rasmussen et al., 2013; Sanjobo et al., 2008; Skovdal et al., 2011).

5.1.2 Themes from In-Depth Interviews on Quality of Service Delivery at Piet Retief Wellness Centre

The following themes and sub-themes presented in Table 5-1 are drawn from the narratives obtained from the respondents who defaulted treatment and those who have not defaulted treatment at Piet Retief Wellness Centre. The implicit hypothesis is that perception of poor service quality by patients would be a strong motivation to default.

Table 5-1: Themes and sub-themes from the in-depth interviews on the quality of service delivery at Piet Retief Wellness Centre

Theme	Sub-theme
ART service quality at the wellness centre	Waiting time for medication refill Staffing of medical refill Attitude of health care providers Availability of drugs (ART)
ART knowledge by service providers and patients	Counselling provided before ART initiation HIV knowledge of the patient Benefits of adhering to ART Dangers of not adhering to ART Clear instructions on how to take medication given Treatment side effects explained by service providers Perspective of throughput services at the facility Patients' rights respected at the facility

5.2 Results

Based on the qualitative analysis, five themes emerged: (i) perspectives on service provider staffing and waiting time at the clinic, (ii) perspectives on the attitude of service providers, (iii) perspectives on clear instructions for taking medication, (iv) perspectives on the benefits of adhering to ART and (v) perspectives on the dangers on not adhering to ART.

5.2.1 Perspectives on the staffing of service providers and waiting time at Piet Retief Wellness Centre

The respondents had a similar concern with regard to the staffing of service providers at the Piet Retief Wellness Centre. In general, the respondents complained that in terms of staffing, there is a need for more doctors and nurses to be added to the current staff. Currently, there is only one doctor who is expected to attend to more than 150 patients per day. In terms of the nursing staff, the respondents reported that normally there is between three to four nurses per day. According to the respondents, this number of nurses is a bit low. This is what most of the respondents said in expressing the need for more health workers at the Wellness Centre:

> *My sister, we need more nurses and doctors in this wellness centre. The government should add more health workers as currently we have only one doctor and at most four nurses a day. This then make us to wait many hours before we get attended to. Imagine one doctor having to attend more than 150*

> *patients a day! If one arrives in the morning, the waiting time is much shorter and bearable, but if you arrive after 1:00pm, since there would be more people including those who would have started at work in the morning like myself before coming to the hospital to collect their ARV's, the waiting time then becomes very long. Given the fact that I stay in the farms and transport from there to the hospital is very scarce, I always arrive in the hospital after lunch. Due to the long ques, one end finishing after 5pm. This becomes a challenge as some of us are coming very far, so we end up even missing our transport back home. (Interview 9: Defaulter, Female, 29 Years old, Employed, Rural).*

The above quotation from defaulter patient 9 shows that employed rural residents are facing a serious challenge with regard to transportation to the clinic. For instance, they have to travel long distances on unreliable public transport from the farms to the wellness centre. Further, upon arrival at the Wellness Centre, they still have to wait for hours being unattended to due to staff shortages ultimately suffer a double challenge. The HBM component, perceived barrier is evident in the report provided by this patient. While unreliable transport acts as a barrier to travel to the wellness centre to collect ARVs, staff shortages also act as a barrier to patients adhering to ART. The quote from defaulter patient 9 shows since she stays in the farms which is far from the wellness centre, she will end up arriving at the wellness centre after lunch, during which many patients would be there as well including those who have to start at work resulting in very long queues. This report support findings from Chapter 4 (quantitative analysis) that revealed that employed patients are more likely to default ART compared to their unemployed counterpart. This finding is similar to other studies which revealed that inadequate staffing promotes ART non-adherence (See E.g. Audu et al., 2014; Bezabhe et al., 2014; Hardon et al., 2007; Jaquet et al., 2010; Penn et al., 2011; Rasmussen et al., 2013; Sanjobo et al., 2008; Skovdal et al., 2011). Similarly, reports on the staffing issue from patients residing in urban areas revealed that during morning hours, waiting time was shorter compared to after lunch:

> *I personally have no problems with the staffing of the health workers especially because I always collect my medication early in the morning. But I once waited for my friend who arrived after lunch to collect her medication, although she stays in the urban area but she had to start at work before she could collect her ARVs. I should say that I did see the great need that day to have more health workers added to assist here at the wellness centre. My friend even confided to me that the reason why she once defaulted was because of the long waiting times when she had to come and collect her medication at the clinic. After lunch (13:00), the service is poor. However, given the fact that most days we will have 3 or 4 nurses and only one doctor per day, these people (nurses and doctor) start work from very early in the morning. By the time it is lunch, they are very tired and hungry. They then go for lunch and leave us unattended. Since we*

> *also ate when we left home, they also have a right to go and eat because they would be very tired and very hungry. So, there is a need to have more health workers in this wellness centre because the job that these people are doing is also very tiresome both psychologically and physically. These are also human beings, we should think for them. The premise lies with the hospital manager to ensure that more health workers are employed to work in this department. (Interview 1: Non-defaulter, Male, 41 Years, Unemployed, Urban).*

The quotation from this patient shows that there is an urgent need to add more doctors and nurses at the Wellness Centre. Long waiting times demotivates patients from attending their appointment at the wellness centre for medication refill. Non-defaulter 1 has reported that in the morning hours, waiting time generally is short and due to the fact that he always collect his ARVs in the morning since he stays closer (urban areas), he has not defaulted so far. Further, given the fact that the majority of employed patients would have to start at work first before they could come to the Wellness Centre to collect their ARVs, it goes without doubt that in the afternoon there would be more patients queuing to collect their ARVs since they cannot afford to lose a whole day's pay. As such, it would make more sense to have even more staff members in the afternoon to accommodate the employed who would have been given only some few hours by their employers to come and collect their ARVs. Due to staff shortages at the wellness centre, patients who would otherwise not default will end up defaulting due to fear of missing their transport back home.

In terms of HBM, inadequate staff shortages act as a barrier to ART adherence. As such, this finding supports the perceived barrier component of the HBM. The findings of the study corroborate other studies whereby factors related to the health facility such as insufficient staffing of health workers, long waiting times and limited clinic hours have been reported to affect the quality of ART service delivery, particularly for working people who need time off work to collect medication (E.g. Audu et al., 2014; Bezabhe et al., 2014; Hardon et al., 2007; Jaquet et al., 2010; Penn et al., 2011; Rasmussen et al., 2013; Sanjobo et al., 2008; Skovdal et al., 2011).

There is a need for more nurses and doctors to be employed at Piet Retief Wellness Centre as patients are made to wait long hours before they receive attention. This in turn negatively affects service quality. A situation like this whereby patients find themselves waiting long hours to receive the ART services could be a reason why employed patients default more compared to unemployed patients at this Wellness Centre. The following are narratives received from employed patients who have defaulted ART at Piet Retief Wellness Centre support this statement:

> *I am not happy with the current staffing at the wellness centre. Since I have to start at work before coming to the wellness centre to collect my ARV's, I always arrive here around 1:00pm. On arrival, the health workers would have gone from*

> *lunch and we would patiently wait to be attended tp. The health care providers are very limited in numbers with only one doctor and around 4 or 5 nurses at most for more than 150 patients daily. This negatively affect us because then one would wait many hours before getting attended to. You know what that means my sister? My employer will not pay me for that day that I spent at the hospital and do nothing in terms of my duties that I was employed for. Do you think I will be in position to lose a whole day's pay from my salary because I have to come and wait here the whole day? Never! There is a serious need to have more health workers added to the wellness centre as it currently service a larger population. Some of us have to beg our employers to give us some few hours to come and collect our medication. But when you arrive here, you find yourself sitting here for the whole day before you are attended to yet you still have to go back to work and our employers say no-work, no-pay. This will then cause some of us to default from treatment because we have to spend the whole day here waiting to get medication. If I was not working, I would be a bit patient with this shortage of staff until the hospital management address it. For those who arrive after lunch, this situation becomes worse I as the health workers break for lunch and we have to wait for a whole hour to get attended to. (Interview 7: Defaulter, Male, 28 years, Employed, Urban).*

From the above narrative from interview 7, we find that time is a barrier to ART adherence as most of the employed patients are not allowed time off work to come to the hospital to collect their medication. There is a great demand for an after-hour service to be provided to working patients to ensure that even after work they can still collect their ARVs. This result of the study is in support of the quantitative result in Chapter 4 that has revealed that employed people are more likely to default ART compared to unemployed people. From the qualitative interviews, we have been able to ascertain the reasons why employed people default treatment.

Employed patients who have defaulted ART have reported serious concerns with regard to staffing at Piet Retief Wellness Centre. Inadequate staffing result in patients being demotivated to go to the wellness centre to collect their ARVs as they will be prone to lose a day's salary while waiting to be attended to at the wellness centre. This quote supports the perceived barrier component of the HBM which explains why employed patients at Piet Retief default treatment. The findings of the study corroborate other studies whereby factors related to the health facility such as insufficient staffing of health workers, long waiting times and limited clinic hours have been reported to affect the quality of ART service delivery, particularly for working people who need time off work to collect medication (E.g. Audu et al., 2014; Hardon et al., 2007; Rasmussen et al., 2013).

In addition to this, patients were also asked about their perspectives with regard to waiting time at the wellness centre before they get attended to by medical personnel. On average, patients emphasized that in the morning hours, the waiting time is short, but they normally face challenges in the afternoon, especially after lunch. This is what some of the patients had to say to show a level of dissatisfaction with regard to waiting time before they are attended to:

> *Waiting time depends on what time you come to the hospital. Sometimes you find that when you arrive late, they have already retrieved your file and you just take it and go see the doctor. You never go back home without being attended to. If we are here by 07:00 am like today, we normally do not wait for long. But I have to come to Piet Retief a day before for my appointment and spend the night with my cousin as there is a problem with transport in the farms where I stay. You see, today they started a bit late and that is why there is a long que like this. I do not know what they were busy with. We were here at 7 am and by now (10 am) we are supposed to be gone home a long time ago. During morning hours, waiting time is not that long, they are usually fast. The problem is in the afternoon. (Interview 4:Non-defaulter, Female, 41 Years, Unemployed, rural residence).*

The above quotation shows that time is one of the reasons why rural people default ART as indicated on the transcript that if patients arrive at the clinic around 07:00 am, the waiting time is okay and bearable. However, if they arrive after 1:00 pm then they wait longer. This could be due to the fact that hospital staff members break for lunch between 12:00 mid-day and return between 1:00 pm and 2:00 pm. On the other hand, urban patients are able to arrive at the hospital as early as 07:00 am because they are closer to the Wellness Centre, especially the unemployed as they have all the time on that day compared to the employed who still have to start at work. Time here acts as a barrier to ART adherence for rural patients who also struggle with reliable transport from the farms to the Wellness Centre. In terms of the HBM, the perceived barrier component of the model is evident here. Interventions need to be put in place for patients' friendly services, whereby hospital staff can be available to provide ART services after hours and on weekend to accommodate both rural and urban employed patients. The following is what patients have to say:

> *The waiting time is okay, especially if you are here by 07:00 am. The only time when we wait for long hours is at the pharmacy where we have to receive the medication. The pharmacy staff is understaffed as currently there are only two staff members serving more than 100 people a day. That has resulted to long waiting times before we can be given our medication (Interview 2: defaulter, female, Unemployed, 46 Years, and Urban Residence)*

The above quote from the patient is in support of the perceived barriers of the HBM. While the patients have not defaulted ART, he has made observations of the concerns with regard to waiting times at the pharmacy when they usually collect medication. Therefore there is a great need for the hospital management to recommend for more staff members to be recruited to join this department of the ART services. Further to the above report, another patient said the following with regard to long waiting times:

> *If for some reasons you have defaulted because you could not get time off at work since my employer uses the no-work no-pay rule, then when you come to the hospital on another day, they will make you wait for the whole day until all the people who were supposed to be attended for that day are finished and then they attend to you after this. This is a quite a challenge because you lose a whole day's pay at work, you get very hungry and end up getting home very late. (Interview 10: Defaulter, 57 Years, Male, Employed, Urban Residence)*

This finding from the study that this patient has defaulted ART due the inability to get time off work to come to the hospital to collect his medication supports the HBM. In fact, the perceived barrier component of the HBM is supported by this finding. On that same note, long waiting hours act as a barrier to ART adherence particularly for employed patients who do not have the time to come and wait at the hospital for long hours. The result from this analysis supports the quantitative analysis of the study where employed people, residing in urban areas have a higher hazard of treatment default compared to unemployed, rural residence people. While the quantitative aspect of the analysis have been able to provide us with a picture in terms of the numbers of those who have defaulted treatment, the qualitative aspect has provided us with the reasons why patients are defaulting treatment. For example, with the above patient, one gets to understand that challenges with time off work has resulted in him defaulting treatment. The results of the study support findings from other studies that revealed that non-adherence was a result of poor service quality emanating from challenges such as long waiting hours for ART services and staff shortages in hospitals (Bezabhe et al., 2014; Jaquet et al., 2010; Penn et al., 2011; Sanjobo et al., 2008; Skovdal et al., 2011).

5.2.2 Patients Perspectives on the attitude of service providers at Piet Retief Wellness Centre

The question on the attitude of service providers had an aim of testing the perceived barriers component of the HBM to ART adherence at Piet Retief Wellness Centre. This question aimed at ascertaining if patients are responsible for defaulting or they are caused by the way service providers treat them. With regard to the attitude of service providers, generally patients reported that that service providers at Piet Retief Wellness Centre have a positive attitude towards them, they are caring and very helpful in terms of supporting them to adhere to treatment to ART. This is a narrative of one of the patients at the Wellness Centre:

> *The nurses and doctors treat us well. They have a very good attitude towards us, they always encourage us to take care of ourselves. They treat us well. Even today, I told them that I am rushing to work and they understood and quickly retrieved my file. The health workers respect our rights too, which is why I am still taking treatment in this wellness centre. Since I started taking treatment here, I have never changed the hospital because of the way they treat us well. They actually made me to stay. They even encourage us to take the treatment faithfully. (Interview 2: Non-defaulter, Male, 46 Years old, Urban Residence)*

> *My sister, I can say that the nurses and doctors are very nice to us. They treat us well. They have a good attitude towards us. They do not discriminate us and they always chat with us and smile with us. They talk nicely with us. (Interview 10: Non-defaulter, Female, 38 Years, Unemployed, Urban Residence)*

> *They treat us well, they are fine. The only challenge is that sometimes they refuse that I assign someone else to come and collect my treatment. In my case, the person that I had initially assigned passed away and they refused to let someone else collect the medication for me because I do not get time at work to come and collect my medication. Since I am here today (July), I will have to come again in August and I am not allowed to assign someone else to collect the medication for me. I hope they will not shout at me when I come back as I will make sure that I come back early on the 4th. (Interview 7: Non-defaulter, Female, Employed, 34 Years, rural residence)*

With regard to the attitude of health care workers at the wellness centre, the findings show that health care workers are very kind, helpful and supportive to them. One of the patients went on to report that one of the reasons why she still collects medication at the wellness centre is because of the support she has received from the health workers. The result of the study is in support of findings from other studies whereby a positive attitude and a caring heart from health workers result in patients adhering to ART (Bezabhe et al., 2014; Jaquet et al., 2010; Skovdal et al., 2011).

Based on the above quotes from non-defaulters, hospital staff members have been treating patients well and respectfully. However, some of the patients reported that they had experiences whereby service providers had a negative attitude towards them. The majority of these were patients who had previously defaulted treatment. This is a narrative one of the patients had to relate:

> *They do not treat us well. This is a challenge for us because this place is where we should be running to in order get some help but the way they mistreat us! They do not even ask questions why you defaulted, my sister, there are challenges in life that we face out there. You get into circumstances whereby you cannot afford even transport money to come and collect medication. It is not like you do not want to come. When you arrive here, you get shouted at.*

> *This has resulted to other patients deciding rather to die at home than to come here and get mistreated. (Interview 3: Defaulter, Male, 30 Years old, Unemployed, Urban residence).*
>
> *My sister, there are times where I have received a very negative attitude from one nurse. We argued that I was not taking the medication correctly, and I know I was talking my medication as recommended. Then he insulted me and said; the only thing you know is a condom, since I always ask for condoms when I come to the wellness centre to make sure that I protect others from HIV. I got very upset with him! It is only a few of the nurses that do not treat us well, it is not all of them. (Interview 9: Defaulter, Female, 42 Years, rural residence).*
>
> *One time I could not make it on the assigned date to come and collect medication because I was too weak. When I came to the hospital after my date, they shouted at me. I did not like the way they treated at me. Generally, I can say that the hospital staff have a good attitude towards us and they treat us well. But they always shout at us when we miss our dates of collecting treatment and when we arrive late. (Interview 5: Defaulter, Female, 23 Years old, Employed, Urban)*

The question asked on the attitude of service providers had an aim of investigating perceived barriers of HBM. A negative report with regard to the attitude of service providers was received from those patients who have defaulted treatment. Most of them have reported being shouted at by health workers, being reminded that they have defaulted previously each time they come to collect their medication and being made to wait the whole day without being attended to after missing their date of collecting medication. The result of the study is similar to the findings of other studies that concluded that that lack of support from hospital staff contributed to patients defaulting ART (Audu et al., 2014; Boyer et al., 2011; Lymo et al., 2012; Maquthu et al., 2010).

In general, where defaulters reported that healthcare providers did not treat them well, adherents reported that the attitude of service providers was good, welcoming and very supportive. This could be due to the fact that defaulters rationalize their behaviour of not adhering to ART by blaming service providers.

5.2.3 Perspectives on clear instructions for taking medication at Piet Retief Wellness Centre

This question of whether patients were given clear instructions on how to take their ART aimed at testing perceived barriers and perceived threats of the HBM. In as far as instructions given to patients for taking medication is concerned, patients were very much appreciative that service providers gave them clear instructions on how to take medication. The following are some of the narratives from the patients:

> *I was given clear instructions on how to take my medication. There was this lady who explained everything to me, I don't know if the lady is still here. I asked her questions and she explained everything to me that I am HIV positive now, I should take care of myself and take my ARVs daily as it is my life now. We were taught that we have to respect the time that we have chosen to take the medication because this is our life. (Interview 4: Non-defaulter, Female, 41 Years, Unemployed, Rural residence)*

> *Yes, I was provided with counselling and I was taught exactly how I should take my medication. They also told me the importance of the treatment. The only reason why I defaulted treatment is because I did not get time off work to come to take my medication. My employer says no-work, no-pay. By the time I come back from work the hospital would be closed. I think if we could have another place besides the clinic where we can collect our treatment after work, then a lot of people would adhere to ART. (Interview 5: Defaulter, Female, 23 Years, Employed, Urban Residence)*

The report from these interviews shows that patients are given clear instructions on how to take their medication. In terms of HBM, Healthcare providers are not a reason why patients have defaulted ART. Further, defaulter 5 stated that the reason why she defaulted ART is because she did not get time off work to come and collect her medication. Interventions need to be put in place whereby employers are involved in supporting patients who are on ART in terms giving them leave days and financial support to come to the Wellness Centre to collect ARVs. This finding also supports the results of the quantitative analysis which revealed that employed patients and urban residents default more compared to unemployed patients and rural residents. Further, more reports from other patients supported this one:

> *Yes the nurses did provide us with counselling and they taught us how to take treatment. In fact, they even mentioned the different types of side effects that we might experience such as rash, headaches, dizziness when we start the treatment. This helped us a lot because when we started experiencing those conditions, we knew that were should not stop taking treatment, but we should continue as with time our bodies will adjust to the treatment. (Interview 1: Non-defaulter, Male, 41 Years, Unemployed, Urban residence)*

> *The nurses and doctors did teach us on how to take the treatment correctly. They told us that we should have a specific time when you take the treatment and we should not change it. They also taught us that we should make sure that we eat food before we take the treatment. The reasons why I defaulted is because I did not have money to buy food. These ARV's make one to be very*

> *hungry and I cannot take it on an empty stomach. Since I am currently unemployed, I have nobody who is supporting me. When I do not have food in the house, I cannot take my ARV's. (Interview 3: Non-defaulter, Male, 30 Years, Unemployed, Urban)*

In terms of the instructions given to patients concerning their medication, the study found that health workers provided clear instructions on how to take medication. In fact, the majority of the patients indicated that health workers were helpful in terms of supporting and encouraging them to adhere to ART. In terms of the HBM, this question aimed at testing the perceived barrier component of the HBM. The results of the study support the findings of Kalichman and Simbayi (2004) that concluded that health literacy positively affected adherence to ART medication. This means that the more informed the patients are with regard to the importance of taking their medication, and the dangers of defaulting treatment, the less likely will they default on treatment.

5.2.4 Benefits of adhering to ART

The study took a step to investigate if patients understand the benefits and the importance of adhering to ART generally. All the respondents of this study have indicated that it is very important for one to adhere to ART. Some of the narratives expressed by the patients are as follows:

> *It is important to take your ARV's if you want to live and if you want to die, then you can stop taking them. Taking treatment faithfully makes you to be healthy and your body weight improves. I was so thin and I had lost a lot of weight before I started taking my treatment. Look at me right now! The pills have help me a lot. My body weight has improved a lot and I am healthy now. (Interview 9: Non-defaulter, Female, 29 Years Old, unemployed, rural residence).*

This finding is in support of the HBM, perceived benefits component and it shows that patients are aware of the dangers of not adhering to ART as non-defaulter 9 specifies that if one want to live, they should be adherent to ART and if they want to die, then they can choose not to adhere to ART. This fact is very important because it shows how informed the patients are in terms of being adherent to ART. This also shows how effective the ART counselling sessions received by patients at this wellness centre have been.

> *Taking your ARVs everyday gives you life. I once defaulted and became very sick, after I took my ARVs again I became well. My sister, what I can tell you is that ARVs are my life, they are like my porridge, and they keep me healthy. (Interview 2: Defaulter, Female, 46 Years Old, unemployed, urban residence)*

> *ARVs have given us a second chance in life. They make us to be healthy. At home I shout at my children to bring my treatment and I leave everything that I am doing to make sure that I take my treatment. They even say I am very proud*

> *of my ARVs at home and I tell them, this is my life! The treatment helps you to stay healthy because the treatment fights the HIV virus in your body. (Interview 4: Non-defaulter, Female, 41 Years, Unemployed, rural residence)*

The quotations from both defaulted and non-defaulted patients show that they have a clear understanding of the benefits of faithfully taking their medication. In terms of the instructions given to patients concerning their medication, the study found that health workers provided clear instructions on how to take medication. In fact, the majority of the patients expressed how helpful health workers have been in terms of supporting and encouraging them to adhere to ART. The perceived barrier component of the HBM was being tested using the question of whether clear instructions were provided to patients or not. It is very encouraging to learn that Patients are fully aware of the benefits brought about by being adherent to ART. The results of the study support the findings of Kalichman and Simbayi (2004) that concluded that health literacy positively affected adherence to ART medication. This means that the more informed the patients are with regard to the importance of taking their medication, and the dangers of defaulting treatment, the less likely will they default on treatment.

5.2.5 Dangers of defaulting treatment

With regard to the patients' perspectives on the dangers of defaulting treatment, responses from all the patients indicated good understanding of the dangers of defaulting treatment. The aim of this question was to test the perceived susceptibility of the HBM. The following are the narratives from respondents who were interviewed at the Wellness Centre:

> *My sister, defaulting treatment is very, very, dangerous. When I look at my friends who become HIV positive earlier than me and defaulted treatment, all of them are dead now because after defaulting they were too weak to come to the hospital to get help. But I was lucky because after defaulting, I was able to come back to the hospital and I got some help on time. I also asked for forgiveness from the health providers for not coming back to take my treatment. Then they allowed me to get back into treatment again. (Interview 3: Defaulter, Male, 30 Years, Unemployed, Urban residence).*

> *Defaulting is dangerous. It makes you to lose weight and feel week. It makes you to be very sick. Defaulting is not good. My friend defaulted and started smoking weed, within two weeks he became sick and passed away. My sister, you know my friend deceived all of us because we were thinking that he was taking his ARVs. But we discovered that he used to put them under the bed and he ended up dead. People should never default from treatment. (Interview 9: Non-defaulter, Female, 29 Years Old, unemployed, rural residence)*

> *After defaulting my ARVs, I nearly died. Stopping ARVs is very dangerous because you end up becoming ill and dying. Look here my sister, I have a small child and right now I cannot default again because I will die and leave my child an orphan. (Interview 2: Defaulter, Female, 46 Years, Unemployed, Urban Residence).*

The quotes from the above patients are clear without any doubts of how knowledgeable the patients are in terms of the dangers of defaulting ART. The patients experiences of witnessing some of their friends passing away because of defaulting ART has also contributed to their behaviour of choosing to adhere to ART because they understand that they are susceptible to falling sick and dying from HIV and AIDS. Further, the quotes showing that some of the respondents who are defaulters are from urban residence is in support of the quantitative results that indicated that urban residents' patients are more likely to default ART compared to urban residence.

In addition to this, a patient who previously saw defaulters dying had the following to say with regard to the dangers of defaulting:

> *It is very dangerous to default treatment especially when you already know your HIV status. I am so scared to default again because I have seen many people dying, including my relatives and my two neighbours. One passed away last year. I defaulted because I did not get time at work to come and collect my medication. Each time I come after work (5:00pm) the wellness centre would be already closed. Once you default, your life becomes affected, you become a sickly person and you cause pain to both your family and love since they can observe your body deteriorating and you are putting your life into danger. (Interview 7: Defaulter, Male, 28 Years, Employed, Urban residence).*

The quote from this patient shows that experiencing another person deteriorating because of defaulting to ART has also contributed to some patients not defaulting to ART. The finding from this report also shows that time has been acting as a barrier to ART adherence as this patient defaulted because his employer could not allow him to come to the hospital to collect his medicine. In terms of HBM, the perceived barrier component is revealed by this finding whereby being employed acts as a barrier to ART adherence. This finding supports the quantitative analysis finding in Chapter 4 whereby employed people were more likely to default ART compared to their unemployed counterpart. Employment acts as a barrier to ART adherence. Interventions should be put in place to ensure that employers also support their employees in terms of ART adherence. There is also a need for the Wellness Centre Management to forge strategies to ensure that ARVs are accessible to patients even after working workers.

The findings from the study show that patients at Piet Retief Wellness Centre are knowledgeable of the dangers of defaulting treatment. It is quite interesting to learn that even those who defaulted before know the dangers of defaulting and they have learnt their lesson not to default again. In terms of the HBM, this report supports the perceived susceptibility component of the model. Both defaulters and non-defaulters have come to an understanding that they are susceptible to falling sick and dying from HIV and AIDS if they default ART.

With regard to the perspectives of patients on the benefits of adhering to ART, all the patients showed understanding of the benefits of taking their medication faithfully. The study found that patients value the great work done by health workers in terms of encouraging them to adhere to ART. This is through the counselling which patients received at the time when they were initiated into treatment and the discussion that patients normally have with service providers during their monthly check up. The results of the study corroborates other studies that concluded that knowledge about HIV and AIDS positively influence the uptake of ART (Martin et al., 2013; Memiah et al., 2013; Ross et al., 2011)

5.3 Summary and Discussion

Chapter five presented some aspects of the qualitative section of the study. Specifically, this chapter assessed the perception of patients on the quality of service and how such perceptions affect ART default at the Piet Retief Wellness Centre. As far as the health workers staffing is concerned, the findings of the study have revealed that there is a shortage of health workers resulting in patients waiting for longer hours to be attended. This situation in turn contributes to the tendency of patients defaulting on ART treatment. The study also found that waiting time is longer, especially in the afternoon. This results in a situation where the very few nurses and one doctor break for lunch and tea breaks, leaving patients unattended.

The findings of the study corroborate other studies whereby factors related to the health facility such as insufficient staffing of health workers, long waiting times and limited clinic hours have been reported to affect the quality of ART service delivery, particularly for working people who need time off work to collect medication (E.g. Audu et al., 2014; Bezabhe et al., 2014; Hardon et al., 2007; Jaquet et al., 2010; Penn et al., 2011; Rasmussen et al., 2013; Sanjobo et al., 2008; Skovdal et al., 2011).

With regard to the attitude of health care workers at the wellness centre, patients generally reported that health care workers are very kind, helpful and supportive to them. One of the patients went on to report that one of the reasons why she still collect medication at the wellness centre is because of the support she has received from the health workers. The result of the study is in support of findings from other studies whereby a positive attitude and a caring heart from health workers result in patients adhering to ART (Bezabhe et al., 2014; Jaquet et al., 2010; Skovdal et al., 2011).

On the other hand, a negative report with regard to the attitude of service providers was received from those patients who have defaulted treatment. Most of them have reported being shouted at by health workers, being reminded that they have defaulted previously each time they come to collect their medication and being made to wait longer hours before getting attended to should they come to the Wellness Centre after they had missed their appointment date. The reports from defaulted patients show that these patients rationalize their behaviour of defaulting ART by blaming clinic staff. It is actually the responsibility of hospital staff to remind defaulters how critical it is to adhere to ART as this determines how long they will live before they die from HIV and AIDS. The result of the study is similar to the findings of other studies that concluded that that lack of support from hospital staff contributed to patients defaulting ART (Aude et al., 2014; Boyer et al., 2011; Lymo et al., 2012; Maquthu et al., 2010).

In terms of the instructions given to patients concerning their medication, the study found that health workers provided clear instructions on how to take medication. In fact, the majority of the patients expressed how helpful health workers have been in terms of supporting and encouraging them to adhere to ART. The results of the study support the findings of Kalichman and Simbayi (2004) that concluded that health literacy positively affected adherence to ART medication. This means that the more informed the patients are with regard to the importance of taking their medication, and the dangers of defaulting treatment, the less likely will they default on treatment.

With regard to the perspectives of patients on the benefits of adhering to ART, all the patients showed understanding of the benefits of taking their medication faithfully. The study found that patients value the great work done by health workers in terms of encouraging them to adhere to ART. This is through the counselling which patients received at the time when they were initiated into treatment and the discussion that patients normally have with service providers during their monthly check up. The results of the study corroborates other studies that concluded that knowledge about HIV and AIDS positively influence the uptake of ART (Martin et al., 2013; Memiah et al., 2013; Ross et al., 2011).

Finally, in as far as patients' understanding of the dangers on non-adherence to ART go, the study has shown that patients understand the dangers of defaulting treatment. Patients have an understanding that ARV's are now part of their daily lives and without which they understand the consequences of not adherence which is falling sick and dying. All reports received from patients with regard to their understanding of non-adherence to ART show that they are aware and knowledgeable of the dangers of non-adherence to ART. The results of the study support findings from other studies that concluded that knowledge about HIV positively influence adherence to ART (Kalichman & Simbayi 2004; Martin et al., 2013).

5.4 Conclusion

In conclusion, the findings of the present study have provided empirical evidence to support not only the usefulness of the HBM as a framework for understanding of individuals' health-related decision-making, but more importantly the role of good service quality in ensuring the uptake of ART in a Wellness Centre in South Africa.

CHAPTER 6: PERSPECTIVES OF PATIENTS ON THE ADVERSE EFFECTS OF ART ON THE INDIVIDUAL: THE EFFECT ON THE UPTAKE OF ART

6.1 Introduction

The management of Antiretroviral Treatment (ART) adverse effects is key to the success of HIV and AIDS treatment as this impact on the quality of life for those living with the disease. Van Dyke (2013) argues that among the most important factors in the success of treatment is how well a patient tolerates the ARV's drugs. Treatment adherence is sustaining the continuity in taking the treatment to avoid defaulting (Van Dyke, 2013). This chapter presents the second part of the qualitative data and looks at the perspectives of patients on the adverse effects of ART on the individual and the possible influence on the uptake of ART. Specifically, the chapter examines patients' experiences with regard to the bodily changes (side effects) and changes in their lifestyles (food preferences) resulting from being on ART.

The questions asked during the interviews seek to tap more information on patients' experiences while on ART from initiation stage to date in terms of; bodily strength, weaknesses, likelihood to prefer certain types of food, challenges in accessing ART in a timely way, ART emotional effects and ART side effects. Further, patients were also asked questions about their experiences with regard to disclosing their HIV status to their family members and friends. These questions involved tapping on the following issues; reaction of the person they disclosed to, if peers knew where they keep their ARV's at home, if they use ARV's openly, if they tell a peer to remind them to take their dose and to keep their hospital appointment for ARV's refill.

The aim of these questions was to collect data that will enable us to understand the reasons why HIV and AIDS infected Patients default from antiretroviral treatment and establish the contribution made by the HBM in explaining why patients choose not to engage in health seeking behaviours which is the uptake of ART in this context. We sought to measure the following aspects of the HBM with these questions: perceived barrier and perceived threat (impact of ART on bodily strength, ART emotional effects, ART side effects), likelihood to prefer certain types of food due to ART (perceived barriers). Further, the questions asked of patients with regard to disclosing their HIV status to family members and friends aimed to test the following components of the HBM and these are; reaction of the person you disclose to (perceived threat), if peers know where you keep your ARVs at home (perceived threat), if you use ARV's openly (perceived benefits), if you tell a peer to remind you to take your dose and to keep your hospital appointment for ARV's refill (self-efficacy and cues to action).

Table 6-1: Themes and sub-themes from the in-depth interviews on Patients' experiences of ART adverse effects

Theme	Sub-theme
Patients experiences of ART from the time of initiation to date	- Impact of ART on bodily strength - Impact of ART on bodily weaknesses - Likelihood to prefer certain types of food due to ART.
Patient HIV Status Disclosure to Family Members and Peers	- Reaction of the person you disclose to - If peers know where you keep your ARVs at home; - If you use ARVs openly. - If you tell a peer to remind you to take your dose and to keep your hospital appointment for ARV's refill.

6.2 Results

Four themes emerged from the discussions with the respondents: (i) Side effects from ART uptake (ii) Food preferences resulting from ART usage (iii) ART disclosure and (iv) ART individual reminders.

6.2.1 Perspectives on ART side effects on the body of the patients

With regard to the side effects experienced by respondents as a result of ART, generally all respondents (both defaulters and non-defaulters) had experienced some side effects. The respondents reported that upon being initiated to ART, their energy levels declined, they experienced dizziness, they had rash, bad dreams and they experienced severe headaches as well. This question on the perspectives of patients on ART side effects was aiming at testing the perceived barrier component of the HBM (the potential negative consequences that may result from being on ART) for those patients who have already defaulted. The quote below illustrates some of the experiences of ART patients:

> *I had quite a number of side effects from ART. Firstly, my energy levels declined drastically and I became sleepy every day after taking the treatment even though I was taking my medication in the morning. My body felt tired most of the time. I also had diarrhoea which I believe largely contributed to my weight loss. I also had rash all over the body and severe headaches. I was in pain, my body limbs were aching and I could not walk properly. This is one of the reasons why I defaulted initially as I could not bear being sickly every day. I could not even afford to buy painkillers as I am unemployed. At the hospital they warned me that I might experience different forms of side effects, but I did not think it would*

> *be this terrible. After I got introduced again into ART, I was able to tolerate the side effects. My energy levels went up and I think the treatment works because when I started taking the treatment, my CD4 count was 84 and now my CD4 count is 700. (Interviewer 1: Defaulter, Male, 60 Years, Unemployed and Rural resident)*
>
> *When I started taking ARVs, my energy levels declined and even my body weight went down for about a month. I became very weak. I could not walk more than two steps without feeling very tired. I felt very sleepy all the time. My whole body ached. There was no part on my body that did not ache. I was in total pain and as I such I stopped treatment.. Although at the hospital they had advised us not to stop our treatment when we experience any side effects, I did not think it was going to be so serious. I was hoping that once I stop taking my ARVs I will become much better. However, I became even more sick and when I went to the hospital again, they gave me counselling and I was re-introduced to ART. (Interviewer 6: Defaulter, Female, 49 Years, Employed, Urban Resident)*

The quotations from these patients show that side effects from ART are one of the factors affecting patients' adherence to ART. In fact, these patients reported that the reason why the defaulted treatment is because he could not tolerate side effects anymore. Both patients (defaulter 1 and 6) had multiple side effects ranging from decline in energy levels, bodily pain, feeling sleepy, rash all over the body and severe headaches among others. To make matters worse, defaulter 1 is unemployed and as such, he did not have money to buy painkillers to try and manage these side effects. This finding therefore supports the perceived barrier component of the HBM and in this case, side effects as experienced by this patient act as a barrier to ART adherence.

The report received from the patients who defaulted treatment show that they did experience side effects while on ART and they defaulted partly due to the side effects that were unbearable. This shows that side effects contributed to patients defaulting ART. In terms of the HBM, this is a perceived barrier to patient not taking their medication. The influx of more than one side effect on the patients when they started their ARV's hugely contributed to ART default. For example, the patients reported among the side effects they experienced was reduction in their energy levels, they experienced severe headaches and had body rash. It also worth noting that as these patients defaulted ART previously, later they got re-initiated into ART and they were provided with counselling again and encouraged to remain in treatment in spite of the side effects.

Where a patients is unemployed and get to experience these side effects, it becomes even more challenging for these as finances is needed for these patients to get pain medication and antibiotics to deal with these ailments. Therefore, in terms of the HBM, this finding supports the perceived barrier component of the HBM. On the other hand, for those patients who have not defaulted from treatment, their report shows that they have also experienced side effects, however, the side effects did not cause them to default treatment as they could manage it.

These findings are similar to that of other studies conducted around the world where side effects such as diarrhoea, rash, headaches and body shaping effects was discovered to be associated with ART non-adherence (e.g. Afolabi, et al., 2009; Elul et al., 2013; Groh et al., 2011; Kip et al., 2009; Mahlangu et al., 2008; Penn et al., 2011; Sanjobo et al., 2008; Skodval et al., 2011).

In terms of the HBM, the question on perceived side effects experienced by the patients who have not defaulted treatment aim to test the perceived threat component of the HBM (the perception of the seriousness associated with leaving a disease untreated, which is defaulting ART). Interviews with patients who have experienced side effects and have not defaulted revealed that where patients are employed and receiving a salary, they are in a better position to manage side effects as they are able to purchase pain killers and antibiotics for managing pain The following is some of the narratives received from some of the patients who have not defaulted treatment:

> *When I started the treatment, I developed side effects such as insomnia, rash, terrible headaches and my energy levels went down for a month. I could not cook and do household chores by myself, all I wanted to do was to sleep throughout the time. However, some of the side effects were manageable as I could go to my pharmacist and request for painkillers and medication to help me sleep. Then I continued with the medication, after a month, my energy levels went back to normal and I was able to do basic household chores like cleaning the house, washing clothes and cooking which I could not do when my energy levels was down. I felt like my life is getting back to normal. (Interviewer 5: Non-defaulter, Female, 22, Employed, rural residence)*
>
> *My sister, when I started the treatment my energy level dropped a lot, I lost appetite for food and I had a terrible rash. I was weak and could not see properly. Since my salary is too little because I work as a house helper, my daughter who is working was able to buy medication for me to help cure the side effects. The hospital staff also did warn us that side effects will be part of the treatment but we should not stop when we experience these symptoms. As times went on, all these side effects stopped, from about 6 months after I had started taking the treatment. (Non-defaulter 2, Male, 46 Years, Employed, rural residence)*

The quotations from these patients show that employed and unemployed patients manage ART side effects differently. These quotations show that employed people are able to better manage side effects better compared to their unemployed counterparts as they can access medication for pain and other necessary medication as they have a salary. This finding supports the quantitative finding of the study in Chapter 4 that showed that patients who reside in rural areas are less likely to default compared to those residing in urban areas. Similarly, the reports from the respondents who have not defaulted treatment also indicate that side effects pose as a challenge for ART adherence. However, where patients are employed and receiving a salary, they are in a better position to manage these side effects as they are able to purchase painkillers and antibiotics for managing pain. However, for the unemployed who is experiencing these side effects, as the pain experienced become unbearable, they default. For the defaulted patients, the component of the HMB that is tested is perceived threat (the perception of the seriousness associated with leaving a disease untreated, which is defaulting ART). This means that side effects in the form of headaches, rash, declining body energy and other side effects are a threat to patients' adherence to ART.

The results of the study support findings from other studies conducted from other parts of the world that revealed that adverse side effects from ART such as diarrhoea, rash and headaches is associated with ART non-adherence (e.g. Afolabi et al., 2009; Elul et al., 2013; Groh et al., 2011; Kip et al., 2009; Mahlangu et al., 2008; Penn et al., 2011; Sanjobo et al., 2008; Skodval et al., 2011).

Further, a study that was conducted by Ayalu et al. (2011) in Africa with the aim of identifying the medication side effects associated with ART revealed that ART adverse effects contributes to ART non-adherence. Symptoms such as skin rash, vomiting and dizziness were identified to be contributory factors to ART non-adherence. Further, Bhengu et al. (2008) conducted a study on the side effects experienced by HIV infected individuals who were on ART therapy in KwaZulu-Natal Province, South Africa. The study found that from the all patients that were interviewed, they had experienced one or more of the following medication side effects; fatigue and tiredness, rashes, headaches and insomnia. Other side effects reported included sadness, disturbing dreams, numbness and pain. This study concluded that medication side effects are associated ART non-adherence.

6.2.2 Food preferences resulting from ART usage

With regard to food preferences experienced by respondents as a result of ART, generally all respondents experienced some preferences for certain food types. However, the main challenge for most respondents, particularly the unemployed, was the lack of finances to purchase the food that they preferred. The aim for asking this question on food preferences was to test the perceived barrier component of the HBM (the potential negative consequences that may result from being on ART). Based on the narratives from the interviews of both defaulted and non-defaulted respondents, being on ART resulted in certain food preferences which they could sometimes not afford to buy, as the majority of the respondents are unemployed. The following are some of the narratives from the respondents who have defaulted ART:

> *My child, what happened is that I grew to like food more, and most of the food which I could not afford. I began to eat many plates of food a day yet I did not have enough money to buy adequate food because I was the only one working in this house. I wish I could have pizza, apples, sour-milk and red meat but the money that I earn is too little, it only allows me to buy the basics. Most of the time, the pills make me crave food that I cannot afford. Just yesterday, I was counting that I have more than a month not eating an apple***.** *(Defaulter 9: Female, 42 years, Employed, Rural Resident)*
>
> *My child, since I started taking treatment, I now love to eat meat and green vegetables very much. I began to love food and I still do even now. The problem is that I do not have enough food and my heart sometimes sinks when I cannot get the food that I like." The grant money that I receive is too little to cover all my food requirements. (Defaulter 1: Male, 60, Unemployed, Rural)*
>
> *ARV's make me very hungry, I eat more now that I am on treatment and sometimes I do not have food in this house which was one of the reasons I defaulted. There is no ways you can put those pills in your mouth if you have not eaten anything, they make you very dizzy and you lose a lot of energy. After being introduced into ART, I began to like chicken meat a lot and I also liked butternut. But I did not have enough money to buy chicken and butternut everyday as I am not employed. I also liked to have avocadoes with every meal. I made sure that I always have it because we have them in my area. I also liked grilled beef. But unfortunately, since I am unemployed, I could not afford all the food that I like right now that I am on treatment. (Defaulter 2: Female, 46 years, Unemployed, Urban Resident).*
>
> *Yes, that definitely happens that you lose your appetite for most food types and start preferring to like certain food. I like spinach so much, meat and tin fish. If I do not get the food that crave on that particular day, I end up not eating anything and this becomes a challenge because ARV's make people to be very hungry. Sometimes you cook certain types of food (different from the one you prefer eating), and then you feel like you don't want to eat anymore. (Defaulter 8: Male, 35 Years, Employed, Urban Residence)*

The quotations received from the above patients' show that patients on ART have food preferences, and in the majority of cases it is expensive food which they cannot afford. Further, the quotes show that when patients are unable to get their preferred food, they tend to default. The quotes from defaulter 2 and defaulter 8 show that ARV's intake increases the demand for food as it makes patients to be hungry and as such one cannot take them on an empty stomach.

In addition to higher demand for food, ARV's also increase the preference for certain type of food which might be not even be affordable to patients. For example, this patient often craves chicken, beef and butternut. With escalating food prices currently, it is a given that when these patients cannot access food adequately, the chances of defaulting ART becomes high. Unavailability of food resulting from being unemployed contribute to ART default.

This finding is similar to the results obtained in the quantitative analysis where employed people were found to be more likely to default compared to unemployed people. The situation is much harder for patients who are unemployed and yet still have to take ARV's daily. In terms of the HBM, the perceived barrier component of the model is assessed with this question. The inability to access the food preferred by the patient can demotivate them to remain in ART. The results of the study are similar to other studies that concluded that the in availability of food resulted to patients defaulting ART. In other studies conducted around the world, financial challenges leading to food unavailability were associated with non-adherence (E.g Bezabhe et al., 2014; Nyanzi-Wakholi, et al., 2009; Penn et al., 2011; Rasmussen et al., 2013; Skovdal et al., 2011; Talam, et al., 2008). Non-defaulters have also reported serious challenges with regard to food preferences as the financially, they are not in a position to meet these food demand. The following are some of the narratives from non-defaulters:

> *When you start taking treatment, you feel like you can eat meat every day. You turn to have less appetite for other things such as potatoes and beans. My food preferences right now is meat, chicken and eggs. Since I am unemployed, I cannot afford to have meat every day in my meals. Most of the time I borrow money from my neighbour to buy food and when she wants it back, I would offer to clean for her or wash her clothes as a way of paying back her money. This makes life hard for me. I hardly have access to this kind of food. Being on ARVs when one is not employed is the hardest thing ever. (Non-defaulter 3: Female, 46 Years, Unemployed, rural residence)*

Although Respondent 3 has not defaulted ART, it is a bit worrying that she is not employed and she has not yet reached the age for getting paid the old age grant. As such, she literally has no source of income. Her food preference is meat, eggs and chicken, which is very expensive to have daily in her meals. Unavailability of adequate food resulting from being unemployed act as a barrier to ART adherence. The HMB perceived barrier component (the potential negative consequences that may result from being on ART) is supported by this finding.

> *When I started taking treatment, I started to like beans but I did not have money to buy them as I am not working and I only depend on my child's grant. I hated*

> *food with fats and sweet. (Non-defaulter 9: Female, 29 Years, Unemployed, Rural resident).*
>
> *Yes, I did have food preferences. I started to like eggs meat and spinach. My favourite was eggs though. Although I am unemployed, two of my children are receiving the child's grant which is the only source of income in this house. The grant is too little to support me to buy the food that I need for the whole month. (Non-Defaulter 4, Female, 41 Years, Unemployed, Rural Resident)*

The quotations from the respondents reveal that even though all the patients had preferences for certain food when they started on ART especially meat, chicken, beans and spinach which all comes at a cost, mostly those respondents who had a form of support either from grant or from a family member were able to meet their needs for food. However, the main challenge for most respondents, particularly the unemployed, was the lack of finances to purchase the food that they preferred taking.

Based on the narratives from the interviews of both defaulted and non-defaulted respondents, being on ART resulted in certain food preferences which they could sometimes not afford to buy, as some of these respondents are unemployed. Even the employed could not afford to sustain themselves throughout the month in terms of food preferences due to limited salaries which resulted in treatment default. Even the employed, as the wages that they received is very limited; this could not support them throughout the month to purchase their food preferences. This is in support of the quantitative results of the study that revealed that the employed are more likely to default treatment compared to the unemployed. Further, the HBM component, perceived barrier, is useful in explaining why patients default from ART as a result of unmet need for food preference.

This finding of the study is similar to the findings of other studies that concluded that the in availability of food is one of the reasons why patients default ART. In other studies conducted around the world, financial challenges leading to food unavailability were associated with non-adherence (E.g. Bezabhe et al., 2014; Nyanzi-Wakholi et al., 2009; Penn et al., 2011; Rasmussen et al., 2013; Skovdal et al., 2011; Talam, et al., 2008). Further, in a study that was conducted by Grierson et al. (2000), unemployment was mentioned as one of the reasons for high non-adherence to ART. According to these researchers, poverty increased the levels of non-adherence to patients on ART. This therefore means that where an individual patient does not have the means to buy food as per the treatment demand, the likelihood of non-adherence for such a patient were escalated. Further, a survey of 924 Australian HIV positive people revealed that lack of employment negatively affected ART adherence, as patients could not afford the money to buy food and for clinic visits for medication refill (Katabira, 2002).

6.2.3 HIV Status disclosure ART non-adherence

In terms of disclosure for one's HIV status, the majority of the respondents reported that they had disclosed their status to either a spouse, family member or their friends. The question on HIV status disclosure was asked to test the perceived threat component of the HBM (the perception of the seriousness associated with leaving a disease untreated, which is defaulting ART) for both respondents who defaulted and those who have not defaulted ART. Disclosing one's HIV status ensures that support is provided to the HIV person, while on the other hand, non-disclosure poses a threat to ART adherence. The following are some of the narratives made by the respondents in terms of disclosing their HIV status:

> *Yes, when I discovered that I was HIV positive I did disclose my status to my girlfriend. She is the same person who encouraged me to start on ARVs. She has been very supportive ever since she discovered that I was on treatment. However, I could not get time at work to go collect my medication because my employer applies the no-work-no-pay policy. (Defaulter 8: Male, 35 Years, Employed. Urban resident).*

Having disclosed his HIV status to his girlfriend, defaulter 8 received support from his girlfriend who encouraged him to take his ARVs. It is significant to note that defaulter 8 missed his hospital appointment, not because of non-disclosure, but because the unavailability of time to go to the hospital to collect his ARVs. The following narratives are from non-defaulters who have also disclosed their HIV status to their family members:

> *When I discovered that I was HIV positive, I told my husband and all of my grandchildren. Then I encouraged my husband to come and check his HIV status, I think he was also here wearing a green top. The whole family has been very supportive in terms encouraging me to remain positive as people who are HIV positive now have ART to keep them alive. Even at the hospital, they taught us to disclose our HIV status so that we can receive support from our family members. (Non-defaulter 5: Female, 22 Years, Employed, rural residence)*

> *Yes I did disclose my HIV status. I told my friends and they were more supportive that I had anticipated. I was scared to tell them because I thought they would leave me. One of my friend is like me now, he is HIV positive and he told all of us. We are both taking treatment now and we support each other. (Non-Defaulter 10: Female, 38 Years, Unemployed).*

The quotations from non-defaulter 5 and non-defaulter 10 show that disclosing one's HIV status to family members provide a support system in terms of encouraging one to adhere to ART. This further provides an opportunity for the people around you as a patient to trust you have enough in terms of disclosing their HIV status. Therefore, disclosing one's HIV is for the benefit of the patient.

On a different note, a small percentage of the respondents reported that they had not disclosed their HIV status since they were afraid that their spouses would leave them or they would be discriminated against because of their HIV status by their family members and friends. Here are some of the reports received from those patients who had not disclosed their HIV status:

> *No I did not disclose to anyone. This is because the father of my child was threatening me that that if he was to discover that he is HIV positive, that would mean I have infected him with HIV and he would kill me. That was even before I knew my HIV status. Therefore he only got to know about my HIV status after he fell sick, and I advised him to go and check his HIV status in the hospital. That was after a year of discovering that I was HIV positive and started treatment. When he discovered that he was HIV positive, he was very apologetic and asked me not to leave. This is when I also informed him that I was also HIV positive and we are okay now. (Defaulter 4, Female, 27 Years, Employed, Urban Residence)*

> *No, I did not disclose my HIV status to my spouse because he is a player and he was going to leave me if I told him. I was hiding it from him all this time, then he asked me if at the hospital they check our HIV status when we are pregnant. I said they do check our HIV status. He asked me if I was not infected and I said yes. It happened that he got sick then I told him to go to the hospital to check his status because I had the guilt conscious in me and I knew that I am taking treatment and he doesn't like us to use a condom. He went to the hospital and then he found out that he was HIV positive. By then he was very sick, then he started taking treatment. (Defaulter 2: Female, 46 Years, Unemployed, Urban Residence).*

The above patients who have not disclosed their HIV status have also defaulted ART. Any single case of HIV non-disclosure among sexual partners is a serious concern in terms of passing the HI-virus to the next person who otherwise might be not infected at the time. Support from family members, including spouses to the HIV infected person plays a critical role in ensuring that the patient adheres to ART. This is consistent with the perceived threat component of the HBM. This means that by disclosing her HIV status to the father of her child, defaulter 4 would suffer the consequence of being blamed that she has infected her boyfriend with HIV and worse still, she is at risk of being killed by her boyfriend.

The narrative from defaulter 4 above who has not disclosed her HIV status and has defaulted ART indicates that the one main reason why she has not disclosed her HIV status to her spouse is because she is afraid he would leave her. Similarly, defaulter 2 has not disclosed her HIV status to her partner because she accuses him to be a womanizer. Research has shown that patients who have disclosed their HIV-status are less likely to default ART compared to those who have not disclosed to anyone. This finding is similar to the reported findings of the study by Arrey et al., (2015) that reported that women did not disclose their HIV status to their spouses in fear that men disappear once their know their status. This kind of behaviour contributes to the high HIV incidence rate. Patients on ART still need to be taught how critical it is for one to disclose his / her HIV status. In terms of the HBM, the perceived threat and perceived barrier component is being assessed.

The result of the study corroborates other studies that have indicated that disclosure of one's HIV status is one of the factors influencing adherence to ART whereby patients who disclosed their HIV status were found to be more likely to adhere to ART compared to those who have not disclosed their HIV status (E.g. Alemu et al., 2011; Bajunirwe et al., 2009; Chi et al., 2009; Muya et al., 2015; Olowookere et al., 2008; Phiri et al., 2010; Roux et al., 2011). Further to this, where an HIV positive person has disclosed their status to their spouses, children and other family members, that was seen as a predictor of receiving support and observed to be associated with adherence (Goudge et al., 2011; Lyimo et al., 2012; Nachega et al., 2006; Penn et al., 2011; Ramadhani, et al., 2007; Ross et al., 2011; Skovdal et al., 2011; Van Oosterhout et al., 2005; Weiser et al., 2003).

6.2.4 ART individual reminders

With regard to ART individual reminders, the majority of the respondents reported that they make use of ART reminders. This refers to someone or something (family member, cell phone or TV programmes) that remind them to take their medication and collecting medication on their allocated dates at the Wellness Centre. The question on ART individual reminders was asked to test the cues to action component of the HBM (which refers to individual strategies to activate readiness, and these occur when an individual feels the desire to take the necessary action after believing that he/she has the capacity to do so) for both defaulters and non-defaulters. Individual reminders for ART helps in insuring that support is provided to the individual who is on ART in terms of being reminded to take his/ her medication timeously. Obviously, where an individual has not disclosed their HIV status to family members, reminders from a person would not be possible and as such, chances of ART non-adherence would be heightened. The following are some of the narratives made by the respondents in terms of making use of individual treatment reminders as part of the ART uptake:

> *Since I started on ART, my girlfriend has been reminding me to take my medication every day. She set an alarm on her phone for seven o'clock in the evening to remind me to take my ARV's. (Non-defaulter 6: Male, 25 Years, Employed, Urban Resident)*

> *Since we are both HIV positive with my boyfriend, we support one another, and we remind each other of the time to take our treatment which is always 21:00 and we set an alarm (reminder) on our phones. We take our treatment late at night usually by that time I am sleepy, and he normally wakes me up. It is very important to have someone who will remind you to take your treatment to avoid ART default because sometimes they give you ARVs to last a period of two months, so you can easily forget to go to the Wellness Centre to collect your medication. (Non-defaulter 7: Female. 34 Years, Employed, rural residence)*

> *My grandchildren always remind me that I should take my treatment. After I discovered that I was HIV positive, I explained my situation to my family and requested for their support in terms of reminding me to take treatment, I discussed this issue with my family and thus I also requested my grandchildren to remind me when the news start to take my treatment. (Non-defaulter 3: Female, 46 Years, Unemployed, Rural residence)*

The quotation above from both defaulter and non-defaulters who have been using treatment reminders from the time they started ART show that treatment reminders play a crucial role in ART adherence. The cues-to-action component of the HBM is assessed by the question. The quotations above show that the respondent have disclosed their HIV status to their spouses which helps to protect him from new infections and re-infections of the HIV positive person.

Specifically, the quotation from non-defaulter 6 shows that he is relying on individual treatment reminders to adhere to ART and these have been working well for him as he has not defaulted from the time he was initiated into ART. For this individual, treatment reminders in the form of a person (his girlfriend) and technology (cell-phone alarm) act as a support system in ensuring that he adhere to ART. Therefore, the use of a person to remind this patient and the use of a cell-phone alarm act as a reminder for ART uptake (cues to action). Research conducted by different scholars have shown that family support ensures that individuals are adherent to ART. For instance, a study that was conducted by Zuurmond (2008) found that a strong supportive family and support group meetings for people living with HIV and AIDS are some of the factors that can influence adherence to ART. In addition to this, the quote from non-defaulter 7 shows the role of teamwork between spouses in ensuring adherence to ART. This patient is relying on individual treatment reminders in the form of her husband to adhere to ART and this has been working well for her, as she has not defaulted from the time she was initiated into ART. For this individual, treatment reminders in the form of a person (her husband) and technology (calls on the cell phone) act as a support system in ensuring that he adhere to ART.

Further, the quotation from patient 3, who is a non-defaulter, shows how important is it to have treatment reminders in the form of a supportive family. Generally, this study discovered that quite a number of the respondents, especially those above 40 years have even resorted to involve their children and grandchildren in reminding them to take their ARVs. For example, non-defaulter 3 uses her grandchildren to remind her to take her ARVs. While in the majority of cases these children would not have an idea of what the medication is for, but they still would remind their family members to take their treatment.

This study found that individuals who have used treatment reminders from the time they were introduced to ART to date have not defaulted to ART. This is explained by the fact that treatment reminders is seen as an indication that the individual has disclosed his / her HIV status to family and friends which also provide a platform for support either financially or otherwise for that particular person. Studies conducted around the world have indicated a positive relationship between disclosure of one’s HIV status and social support from family members (Goudge et al., 2011; Lyimo et al., 2012; Nachega et al., 2006; Penn et al., 2011; Ramadhani, et al., 2007; Ross et al., 2011; Skovdal et al., 2011; Van Oosterhout et al., 2005; Weiser et al., 2003).

Therefore, the use of a person to remind this patient and the use of a cell-phone alarm act as a reminder for ART uptake (cues to action). Research conducted by different scholars have shown that family support ensures that individuals are adherent to ART. For instance, a study that was conducted by Zuurmond (2008) found that a strong supportive family and support group meetings for people living with HIV and AIDS are some of the factors that can influence adherence to ART. On this same note, it is quite encouraging to learn that even those patients who have once defaulted ART have discovered the value brought about individual treatment reminders to assist patients to adhere to ART as the quote below illustrates:

> *When I started taking treatment for the very first, I never had anybody to remind me to take my medication because I did not disclose my HIV status in fear of stigma and discrimination from my family and friends. That is one of the reasons I ended up defaulting the first time because I was hiding my ARVs and would not take them around family and friends. After I got re-initiated into treatment, I spoke to my son to remind me to take my treatment as my husband passed away. Since that day, I get to be reminded by my son to take my ARV’s. He*

> *always makes sure that when generations start on SABC 1 (20:00) he runs to me and tell me to take my ARV's. This has helped me to continue with my ARV's because of the support that my family has provided me. Although he does not know what the treatment I am taking is for, but he always remind me to take it. Sometime he even ask me questions why I am always taking this treatment and I haven't answered him. It is very important to have treatment reminders because when you forget to take the treatment, they can remind you. (Defaulter 9: Female, 42 Years, Employed, Rural Resident)*

While defaulter 9 initially did not disclose her HIV status to family members and was hiding her medication, she ended up defaulting ART (Self-efficacy). This finding supports other studies that revealed that when people living with HIV and AIDS hid and skipped their medicine to avoid disclosure, non-adherence was observed (E.g. Alemu et al., 2011; Bajunirwe et al., 2009; Chi et al., 2009; Muya et al., 2015; Olowookere et al., 2008; Phiri et al., 2010; Roux et al., 2011).

The quotation from the above patient also shows how important it is to have treatment reminders in the form of a supportive family. We found that quite a number of the respondents, especially those above 40 years, have even resorted to involving their children and grandchildren in reminding them to take their ARVs. For example, defaulter 9 uses her son to remind her to take her ARV's. In the majority of cases these children would not have an idea what the medication is for, but they still would remind their family members to take their treatment. For instance, defaulter 9 is using her son to remind her to take her ARVs every day at 20:00 when Generations begins on SABC 1. This patient uses both a person and technology as a reminder for ART uptake. In terms of the HBM, the cues-to-action component of the model is assessed with this question, and self-efficacy component.

Since she started involving her family members in the uptake of ART, she has been taking ART faithfully so. The finding from the study which shows the significant role played by treatment supporters is similar to the findings of other studies that revealed treatment supporters for patients could improve ART adherence (e.g. Goudge & Ngoma, 2011; LaKey et al., 1997; Dlomo et al*.,* 2010; Yoder et al., 2009).

Further, the cues-to-action component of the HBM is assessed. Cues to action refers to strategies to activate readiness and occurs when an individual feel the desire to take the necessary action after believing that he/ she has the capacity to do so **(**Hayden, 2009**).** In this study this is seen whereby patients who are on ART are not confident enough to take ART by themselves as all of them, both defaulters and non-defaulters have reported that they have people, friends and family members who have been reminding them to take their medication (cues to action). Being reminded to take ART provides the necessary support to avoid defaulting ART. On a different note, a small percentage of patients reported that when they first got introduced to ART, they did not have treatment reminders as the quote below illustrate:

> *No, there is no one and there is nothing that reminds me to take my ARV's because I know that this is my life and if I miss them then I miss my life. I am supposed to be the one who thinks and take care of myself. I am the only one who knows my date. When it comes to defaulting, I defaulted once because I forgot to take medication. That is when I decided to set alarm on my phone to remind me to take my ARVs. Now I know that when it is 9 pm, I have to take my treatment and my cell-phone alarm helps me with that. (Defaulter 4: Female, 27 Years, Employed, Rural Resident)*

The quotation from defaulter 4 shows that where a patient has no treatment reminders (cues to action), chances of defaulting ART are high as patients turn to forget to take medication. The result of the study shows that defaulters generally would not have treatment reminders until their first ART default from which they recognize the need to involve either a person or technology (Cell phones, Television set) to act as treatment reminders. On the other hand, non-defaulters involve individual treatment reminders from the very first time they are introduced into ART to ensure support. The result of the study also support findings from other studies conducted around the world that found that treatment supporters for patients on ART could improve ART adherence (e.g. Goudge & Ngoma, 2011; LaKey et al., 1997; Dlomo et al., 2010; Yoder et al., 2009; Zuurmond, 2008). Further, from study findings, the result show that that it is very important to have treatment reminders to act as a form of support to people who are on ARVs. The HBM is very useful in explaining why patients who are on ART default treatment. Moreover, Bearman and LaGreca (2002) found that emotional support from friends, family and community was a strong predictor of adherence.

6.3 Summary and Discussion

This chapter analysed the perspectives of patients on the adverse effects of ART on the individual and its effect on the uptake as predicted by the HBM. Specifically, the chapter presented the findings of the study under the following themes; the perspectives of patients on ART side effects, perspectives of patients on food preferences resulting from ART usage, perspectives of patients on HIV disclosure and non-adherence to ART and finally, perspectives of patients on ART individual reminders. Firstly, with regard to patients' perspectives on the adverse effects resulting from ART usage, all patients reported experiencing adverse effects. However, unemployed patients were the most affected by side effects, as they could not afford to access painkillers and other medication to manage these side effects. As such, they defaulted ART.

Secondly, with regard to patients' perspectives on food preferences resulting from ART uptake, all patients who were on ART had preferences for food and the demand for food generally increased. Mostly, patients preferred to have meat, chicken, eggs and vegetables in their diet which pose a great challenge for all patients particularly due to the high food prices. This situation is even worse for those patients who are currently unemployed and have no source of income.

Thirdly, with regard to the perspectives of patients on HIV status disclosure and non-adherence, the study found that all patients who had not defaulted ART had disclosed their HIV status to their family members and friends and as such, they got supported in the uptake of ART. However, all patients who had defaulted ART had not disclosed their HIV status to their family members and friends.

Finally, patients' perspectives on ART individual reminders revealed that generally those patients who had never defaulted ART had individual treatment reminders in the form of a person and technology. On the other hand, at the inception of ART, defaulted patients did not have individual reminders. However, after defaulting and getting re-initiated into ART, they realized the value of having individual reminders and they are currently using them.

6.4 Conclusion

In conclusion therefore, the HBM has been helpful explaining why patients decide not to adhere to ART. The findings of the present study have provided empirical evidence to support not only the usefulness of the HBM as a framework for the understanding of individuals' health-related decision-making, but more importantly the influence of adverse effects on the individual and its influence on ART uptake.

CHAPTER 7: THE PERSPECTIVES OF PATIENTS ON THE BARRIERS TO ART ADHERENCE: THE EFFECT ON THE UPTAKE OF ART

7.1 Introduction

In order for patients to benefit fully from antiretroviral treatment (ART), an adherence level of at least 90% is needed to suppress the HIV virus efficiently and prevent the development of drug resistant strains and drug failure (Van Dyke, 2013). Constant adherence to ART is a complex and dynamic process as there are several barriers that the patient has to overcome to be successfully adherent to ART (Azia et al., 2016). Barriers to ART adherence refer to the potential negative consequences that may result from taking particular health actions, and these factors include; financial, physical and psychological costs, the inability to access resources to take specific actions, or the belief that the threat does not exist for a particular individual, group or region for specific reasons (Van Dyke, 2013).

This chapter looks at the perspectives of patients on the challenges/ barriers to ART adherence at Piet Retief Wellness Centre. In-depth interviews (individual) were used to obtain information from patients who have defaulted treatment and those who have not defaulted treatment. Respondents were asked questions on the barriers affecting ART adherence at the individual, household and community levels. Specifically, respondents were asked the following questions; if they had ever experienced the following barriers to ART adherence: stigma and discrimination, communication barrier, financial barrier, service barrier, material barrier, pressure from friends, cultural and religious barriers. These questions were aimed at testing the following aspects of the HBM; perceived threat (stigma and discrimination experienced because of HIV status; and perceived barriers to ART adherence; communication, financial, service, material, peers, cultural and religious barriers) and perceived susceptibility (inability to access ART due to gender, culture and age).

Table 7-1: Themes from the in-depth interviews on Patients perspectives on barriers to ART adherence

Theme	Sub-theme
Stigma and Discrimination due to HIV Status	- Have you ever had any experience of being treated differently because of your HIV status by your family, clinic, church, work place and community?
Perceived barriers (problems) and possible solutions of taking ART	- What do you perceive to be the biggest problem regarding taking ARV treatment? - Communication barrier, Financial, Service, - Material, Peers, Cultural and Religious, Support System

7.2 Results

From the analysis, three themes emerged: (i) Patients' experiences on stigma and discrimination (ii) Patients' experiences on social support at home and church iii) Challenges to accessing ART.

7.2.1 Perspectives of patients on ART stigma and discrimination

Globally, persisting HIV/AIDS stigma and discrimination has been identified as a major obstacle to the success of programmes aiming at curbing the HI-virus. Further, stigma and discrimination has been identified is one of the major barriers to ART adherence. In a study that was conducted by Okoronkwo et al. (2013) in Nigeria, non-adherence accounted for 85.1% and stigma and discrimination was identified as one of the major factors contributing to ART non-adherence. With regard to patients' perspectives of their experiences of ART stigma and discrimination at Piet Retief Wellness Centre, all respondents stated that they have experienced stigma and discrimination both at home and in the communities. The respondents reported that upon informing family members and friends and their communities about their HIV status, people started treating them differently and they began to feel discriminated against, isolated and lonely. Patients were asked the following question: have you ever had any experience of being treated differently because of your HIV status? This question on the perspectives of patients on HIV stigma and discrimination was investigated to assess perceived barrier component of the HBM (the potential negative consequences that may result from being on ART).The following is what most patients had to say:

The findings from this study are similar to a study that was conducted by Okoronkwo et al. (2013) in Nigeria, non-adherence accounted for 85.1% and stigma and discrimination was identified as one of the major factors contributing to ART non-adherence. Interviews from both defaulted and non-defaulted patients at Piet Retief Wellness Centre have revealed that stigma and discrimination are also some of the barriers to ART adherence at Piet Retief Wellness Centre. The following are some of the quotes from patients:

> *Yes, at home, they do not drink in the same cup that I have used. They bought paper cups so that when we drink cool drink they can be thrown away to make sure that they do not drink on the same glass that I have used. Because of the way that they treated me when they discovered my HIV status, I decided that I will never take my ARV's in their presence and that led to me defaulting because there would be time when we will be together as a family. That led to me defaulting ARV's. Now when we sleep, I sleep alone yet I used to sleep with my sister before she knew my HIV status. That makes me feel discriminated. (Defaulter 4: Female, 27 Years, Employed, and rural residence).*

> *After I disclosed my HIV status to my family, they started discriminating me. My plate, cups and cutlery were separated from theirs. Then when I cook food for the whole family, they would tell me to stop cooking and let them continue because I am sick and they said I might cut myself and infect them. Because of the negative attitude towards me after they learnt about my HIV status, I lost self-confidence and trust on my family. That led to me defaulting ARV's because I felt all alone, segregated and isolated. I could not take my ARV's before them as they were negative to me. That made me feel very sad and isolated by my own family which is supposed to be very supportive to me. (Defaulter 2: Female, 46 Years, Unemployed, Urban Residence).*

While patients who are on ART are highly encouraged to disclose their HIV status to family and friends so that they can receive support, patients have reported that they have experienced stigma and discrimination after disclosing their status. Stigma and discrimination at the family level have negatively influenced ART adherence. The quotes from defaulter 2 and defaulter 4 show that family members changed their attitude towards the patients who were on ARVs upon discovering that they were HIV positive. They were segregated whereby their cups, plates and cutlery were separated from the rest don the family. This finding supports the perceived barrier component of the HBM. The HBM perceived barrier refers to the potential negative consequences that may result from being on ART. This includes financial, physical and psychological factors. Further, the inability to access resources (ARVs) or the time to take specific actions (adhering to ART) also contribute to the perceived barrier.

Patients who have not defaulted ART have also experienced stigma and discrimination at the family level. This difference is explained by the perceived susceptibility component of the HBM which refers to one's own opinion of how serious a condition is, and what its consequences are. When one recognizes that they are susceptible to getting a certain problem or condition, it does not really motivate them to take the necessary action until they appreciate that getting the condition would have serious physical, psychological and social implications (Hayden, 2009). However, this perception is influenced by various factors as age, gender or cultural beliefs. This is in particular with regard to women where they do not have decision-making powers or authority when it comes to sex, they may feel helpless and susceptible. The following quote is from some of the patients who have not defaulted ART:

> *I have also experienced stigma and discrimination at home. And this is still going on and I don't think it will end any time soon. What normally happens at home is that, since they all know my HIV status as the hospital staff advised us to disclose our HIV status to family members, so I did. But, I have a serious challenge with my family right now. For instance, just the other day, I was in an argument with my sister and she mentioned that since I am HIV positive, I cannot say a thing that she will listen to. I told her that since she hasn't checked herself, she as good as someone who is HIV positive too. Then she got sick and they said she was bewitched. She only survived because when she was sick she listened to my advice to go to the hospital and get tested for HIV. After she learnt that she was HIV positive, then I told her that everything you do, you do it for yourself. (Non-Defaulter 1: Male, 41 Years, Unemployed, Urban Residence).*

Patients who have not defaulted ART have also experienced stigma and discrimination at the family level. Although non-defaulter 1 has also experienced stigma and discrimination at home whereby he is undermined due to his HIV status, he has not defaulted ART. This means that people who are on ART respond to stigma and discrimination differently due to varying socio-economic background. This difference is explained by the perceived susceptibility component of the HBM. When one recognizes that they are susceptible to getting a certain problem or condition, it does not really motivate them to take the necessary action until they appreciate that getting the condition would have serious physical, psychological and social implications (Hayden, 2009). However, this perception is influenced by various factors as age, gender or cultural beliefs. This is in particular with regard to women where they do not have decision-making powers or authority when it comes to sex, they may feel helpless and susceptible. This is the case with non-defaulter 1 who is a male and has experienced stigma and discrimination at the family level and yet has not defaulted ART so far.

Further interviews with patients on ART have also revealed that stigma and discrimination have also been experienced in communities where patients reside. The disappointing part is that such discrimination comes as a result of gossiping about one's HIV status without patients disclosing to community members. From the interviews, patients revealed that what normally happens is that once one person within the community sees a person being sickly, losing weight and coughing, they quickly jump to conclusions that one is HIV positive. Patients were asked whether they have experienced any form of stigma and discrimination at the communication level and the following is what they had to say:

> *Although I have never told anyone that I am HIV positive, the whole community knows about my HIV status. My family could be the ones who told members of the community because I only disclosed my HIV status to them hoping that they would support me. But since I announced the news that I am now HIV positive, I have been treated differently by the community and I have been called names. Some members of the community even refuse to shake my hand when I great them, I do not know whether they think that one can get HIV by shaking hands. At the time when I defaulted, I felt all alone and isolated. My best friend also left me after I told him of my HIV status on the premise that other community members would think he is also HIV positive because we are friends. Around the community people started calling me names saying I will infect their children. They got me so angry. Personally I do not even think that it is a good idea to disclose one's HIV status because there is a serious stigma and discrimination attached to HIV. They started gossiping about me. They just think that they are better than me. They make look stupid because of this discrimination. (Defaulter 8: Male, 35 Years, Employed, Urban Areas).*

The above quotation shows that at the community level, the stigma and discrimination attached to HIV and AIDS is very intense. Where patients are looking forward to some members of the community such as friends to support them, such does not happen. This has led to this patient defaulting ART as he felt all alone! He was abandoned by everyone, including his best friend who did not want to be associated with him. Further, defaulter 8 has been accused by this very community that since he is HIV positive, he will infect their children (girls). This made him very angry as his character was wrongly judged! There is a need for HIV and AIDS education that has to be done in the forms of educational campaigns in this community to ensure that people are taught how HIV is transmitted from one person to the next. In terms of the HBM, this finding supports the perceived barrier component of the model. This finding is similar to that of Zuurmond, (2008) that revealed that stigma and discrimination resulted in patients defaulting ART.

Interviews conducted with patients who have not defaulted ART also reveal that they have also experienced stigma and discrimination at the community level. However, where patients are employed and have a source of income, they turn out to be adherent. The following is one of the narratives from patients:

> *At the community level I have been discriminated and side-lined because of my HIV status. In community meetings where we get to drink the traditional beer in one jar that has to circulate from one member of the community to the next, after I drink, all the people who are supposed to drink after me refuse to drink. That hurts a lot. The reason why I have not defaulted so far is because I am employed and I do not need to go to someone's house to borrow money for attending clinic appointments. (Non-Defaulter 7: Female, 34 Years, Employed, Urban Residence).*

The above quotation shows even though non-defaulter 7 has been subjected to stigma and discrimination at the community level, he still has not defaulted. Where non-defaulters are involved, mostly those who experience stigma and discrimination are employed and they are able to resist the stigma and discrimination as they can afford travel costs to access medication. In addition to this, whenever an unemployed patient has a supportive family, stigma and discrimination from community members does not result into ART non-adherence. They are able to continue with their ARVs in spite of the stigma and discrimination experienced from the community.

> *When I first discovered that I was HIV positive, it was after I was bedridden and could not walk by myself. The community had already started spreading news about me that I had died of HIV. Knowing that HIV is a killer disease, my family got so frustrated and angry because of the rumours that was going around whilst I was still alive. The reason why I am still alive is because my family have been taking me to the clinics to refill my ARV's. They have been taking good care of me. Although I am unemployed, I have never missed any hospital appointment because they always give me money to travel to the clinic. The community has been calling me names like I am a ghost, I am a dangerous person in the community because I will infect everyone. My sister, this community has really humiliated me and declared me dead whilst still alive because of my HIV status. (Non-Defaulter 4: Female, 41 Years, Unemployed, rural residence).*

While non-defaulter 4 is unemployed, the presence of a supportive family in terms of emotional and financial support has enabled her to be adherent to her ARV's. At the community level, patients have reported that they have experienced stigma and discrimination as well. There is a serious need for communities to be taught more about HIV and AIDS and how a person becomes infected. Community members need to learn that sharing the same cups, plates and glasses will not result in someone getting infected.

7.2.2 Perspectives of patients on social support and ART adherence at home

With regard to perspectives of patients on social support provided by family members and friends, the majority of patients have reported that they have not received support from family members.

Instead they have been side-lined, discriminated and abandoned. The following is some of the things they had to say:

> *No, I have not received any form of support from my family members since they got to know about my HIV status. Instead, they started treating me differently and calling me ugly names from the time they learnt that I am HIV positive. Actually, had they supported me the very same time I told them about my HIV status, I would have never defaulted. But instead, they told me that they did not want anything to do with me because I decided to get infected with HIV. My sister, can you believe that my family said that to me? Can a person choose to be infected with HIV? Well, they told me that I should not make this problem of mine to be their problem! I felt abandoned and all alone! Since our parents passed away, we are living with my two brothers and their wives. Then I fell sick and I could not go to work and they did not help me to go to the hospital to collect my ARVs. The reason I defaulted is because I was too weak to travel to the clinic by myself. Although I informed my family that my ARV's were finished, they did not me help me to go to the hospital for ARVs refill because none of them was prepared to miss work and take me to the clinic. (Defaulter 4: Female, 27 Years, Employed, rural residence).*

The quote from defaulter 4 shows that her family has failed to provide her with the support she needed to adhere to ART. In fact, her family is the reason why she defaulted ART. While she was lying bedridden, and too weak to go to the hospital to refill her ARVs, no family member was willing to take a day off at work to take her to the hospital. Their neighbour was the one who ended up coming to her rescue and took her to the hospital but unfortunately already she had defaulted. This statement from defaulter 4 lends support to the finding in the quantitative analysis that showed that employed people default more compared to the unemployed. In circumstances like this one whereby a patient becomes too weak to travel to the hospital by herself and has no support from family to take her to the clinic, patients end up defaulting ART. This similarly supports the HBM's perceived barrier component in that stigma and discrimination become barriers to ART adherence.

Generally, the findings corroborate other studies that have shown that a strong supportive family positively impacts ART adherence (e.g. Goudge & Ngoma, 2011; LaKey et al., 1997; Dlomo et al*.,* 2010; Yoder et al., 2009). Moreover, Bearman and LaGreca (2002) found that emotional support from friends, family and community was a strong predictor of adherence. In support of this, a study that was conducted by William (2008) found that support groups, food schemes and disability grants are ways of improving ART adherence in communities.

7.2.3 Challenges with a lack of social support at church and ART adherence

The church has a role in ensuring that its members adhere to ART. The question on the role played by the church in encouraging patients to adhere to ART was aiming at assessing the perceived barrier of the HBM (potential negative consequences that may result from being on ART). The following are some of the quotes from patients with regard to the church's participation in the fight against HIV and AIDS:

> *In my church, they have a problem of not talking about our personal lives. Whether we are sick or healthy, that is not discussed in our church. There are other three people here at church who have stopped their ARV's and there is nobody in the church who is encouraging us to do us. At church they have a problem of not opening up they hide their status. They are not free. (Defaulter 5: Female, 23 Years, Employed, Urban Residence).*
>
> *At church, they do not know about my HIV status and other diseases. This is because we do not tell everyone about our HIV status except for those that we meet here in the clinic for our ARV's refill. (Non-Defaulter 3: Female, 46 Years, Unemployed, Rural residence).*
>
> *We never talk about our HIV status at church. We keep it to ourselves and besides, at church we never talk about our HIV status with the believers. They don't want to bury you because you stopped taking your treatment but because of accidents not that you stopped taking treatment. (Defaulter 3: Male, 30 Years, Unemployed, Urban Residence).*

The quotes from non-defaulter 3 and defaulters 5 and 3 show that the church has been too silent where it concerns HIV and AIDS. Generally, church is regarded as a second home to its church members and as such, the church exerts a great influence upon its members. At this time where a lot of people especially those already infected with HIV have lost hope, the church needs to step in and encourage its members to value their lives by taking the necessary health actions expected of them, which is adherence to ART. By encouraging the church members to be responsible for their health, the church will also be putting in a hand in the fight against HIV and AIDS. The above quotations received from defaulters indicate that the church has been indifferent in contributing towards the fight against HIV and AIDS. In fact, the church has been silent and has not been encouraging people to take care of their health.

However, some of the quotations show that HIV is never mentioned in some of the churches, which would contribute to patients not disclosing their HIV status to their friends at church. This in turn would rob the patients the opportunity of getting moral support from the church. There is an urgent need for the church to participate in the fight against HIV and AIDS. Further, campaigns should also be taken to the church where people will be taught the basics about HIV and AID. Within the church, there are a lot of people who are struggling with adherence issues and support from such institutions would go a long way. On a different note, a small percentage of respondents reported that their churches have been encouraging them to know their HIV status and remain on treatment if they have tested HIV positive. The following is what they had to say:

> *My church has been very supportive especially the mothers. They always encourage us to know our HIV status and once we are aware of what is going on, we have to take the necessary actions. The mothers in the church always tell us that there is no reason why people should die because of AIDS because we have access to ARV's now. The mothers in the church are supportive in such a way that they even told us that if we need money to travel to the hospital to collect our ARV's, we should let them know so that they can help us. I am attending church at Zion, the name of my church is Zion Christian. (Non-defaulter 7: Female, 34 Years, Employed, rural residence).*
>
> *Our Pastor at church always tell us to be informed with our health status. That means we should visit the doctor now and again to check for these three killer diseases; HIV, High Blood Pressure and TB. Once we know the status of our health, we have to take the necessary steps towards ensuring good health. At church they tell us that yes, we are a church but when the doctor tells you that you are sick, take your treatment. I am attending The Christian Church of Africa. (Non- defaulter 1: Male, 41 Years, Unemployed, Urban Residence).*

The quotations above show that some churches plays a vital role in the fight against HIV and AIDS. In the absence of community social support groups to encourage and support community members to adhere to ART, the church is the last hope for these patients. The question on the role played by the church in encouraging patients to adhere to ART was aiming at assessing the perceived barrier of the HBM (potential negative consequences that may result from being on ART). There were very few individuals who confirmed that their churches were supportive in ensuring that they adhere in ART. This shows the significant role played by the church as a treatment supporter is similar to the findings of other studies that revealed that treatment supporters for patients could improve ART adherence (e.g. Goudge & Ngoma, 2011; LaKey et al., 1997; Dlomo et al., 2010; Yoder et al., 2009)

7.2.4 Challenges with time off work for medication

Getting time off work for attending hospital appointments for ARV refills has been reported as one of the major challenges to ART adherence. Patients in this study have reported that employers refuse to allow them to go to the clinic as they normally apply the no-work-no-pay policy. Patients then opt to go to the clinic after work only to discover that the HIV clinic will be closed. The following is some of what patients said:

> *My biggest challenge to ART adherence is the in-availability of time for ARV's refill as my employer told me when I disclosed my HIV status to him that I should not interrupt work-time by attending clinic. The no-work, no-pay policy applies work. Personally, I defaulted because at the time when I asked for permission from my employer, he literally declined and told me if I do not present myself at work the following day, I will not receive a pay for that day. Therefore, I defaulted because I could not get time off at work since my employer uses the no-work no-pay rule, then when you come to the hospital on another day, they will make you wait for the whole day until all the people who were supposed to be attended for that day are finished and then they attend to you after this. This is a quite a challenge because you lose a whole day's pay at work, you get very hungry and end up getting home very late. (Interview 10: Defaulter, 57 Years, Male, Employed, Urban Residence).*
>
> *I am work as a security guard. During normal hours, 08:00am till 17:00pm, I am always at work. I do not normally get time to come and get my treatment. (Defaulter 8: Male, 35 Years, Employed, Urban Residence)*
>
> *One of the major challenge facing those people on ART like myself is getting leave days from our employers for medication refill. You know what that means my sister? My employer will not pay me for that day that I spent at the hospital and do nothing in terms of my duties that I was employed for. Do you think I will be in position to lose a whole day's pay from my salary just because I have to come and wait here the whole day? Never! There is therefore a need for the hospitals to engage our employers in the fight against HIV and AIDS. Some of us have to berg our employers to give us some few hours to come and collect our medication. This will then cause some of us to default from treatment because we have to spend the whole day here waiting and to get medication. (Interview 7: Defaulter, Male, 28 years, Employed, Urban).*

Essentially, this patient defaulted ART due his failure to get time off work to come to the hospital to collect his medication supports the perceived barrier component of the HBM. Similarly, long waiting hours at clinics act as a barrier to ART adherence particularly for employed patients who do not have the time to come and wait at the hospital for long hours. This issue supports the quantitative analysis of the study where employed people, residing in urban areas have a higher hazard of treatment default compared to unemployed, rural residence people. While the quantitative aspect of the analysis has been able to provide us with a picture in terms of the numbers of those who have defaulted treatment, the qualitative aspect has provided us with the reasons why patients are defaulting treatment. For example, with the above patient, one gets to understand that challenges with time off work have resulted in him defaulting treatment.

The above quotations from defaulter 7 and defaulter 10 show that that lack of time for medication refill is a major barrier to ART adherence as most of the employed patients are not allowed time off work to come to the hospital to collect their medication. In fact, the problem of time off work to collect medication underscores the huge demand for an after-hour service to be provided to working patients to ensure that even after work they can still collect their ARVs.

Employed patients who have defaulted ART have reported serious concerns with regard to staffing at Piet Retief Wellness Centre. Inadequate staffing results in patients being demotivated to go to the wellness centre to collect their ARVs as they will be prone to lose a day's salary while waiting to be attended to at the wellness centre. This quote supports the perceived barrier component of the HBM which explains why employed patients at Piet Retief default treatment. The findings of the study corroborate other studies whereby factors related to the patient's health such as lack of time for ART refill and limited clinic hours have been reported to affect the ART adherence particularly for working people who need time off work to collect medication (E.g. Audu et al., 2014; Hardon et al., 2007; Rasmussen et al., 2013).

7.2.5 Financial obstacles to ART adherence

Studies conducted in different parts of the world have shown that lack of finances resulting from unemployment acts as a barrier to ART adherence. In a study that was conducted by Grierson et al. (2000), unemployment was mentioned as one of the reasons for high non-adherence to ART. In addition to this, a survey of 924 Australian HIV positive people revealed that lack of employment negatively affected ART adherence, as patients could not afford the money for clinic visits for medication refill (Katabira, 2002). Thus, according to these studies, poverty increases the levels of non-adherence to patients on ART. The quotes below illustrate some of the experiences of ART patients with regard to financial obstacles:

> *My sister, when you are unemployed it becomes very challenging to honour your hospital appointment for ARV's refill. At the time when I defaulted, I did not even have money to buy food, its worse when you think about transport money. Now I cannot starve myself, so I can get money for transport to come get my treatment. Without a job, life is very hard for us who are on ARV's. You see my sister, knowing that you are hungry, and you do not know what you going to eat when you take the tablets. You find that you are not working, and you cannot even get a piece job to get transport for you to get there. Now you end up asking the neighbours for help. They also start calling you names, you know the*

> *community we live, they talk a lot. That is when you give up. When I stopped it was because I did not have transport money to go to the hospital. (Defaulter 2: Female, 46 Years, Unemployed, Urban Residence)*
>
> *The main problem is with finances. My job is not paying much, I am just a garden boy at the location. You cannot walk from the location to the clinic and taxi fare is R30-00 return. Sometimes you find that I do not have money to even buy food. Those are some of the times that I would miss my ARVs because you cannot take them on an empty stomach. They make you to be very dizzy and nauseous. I would even get to the point whereby I will borrow money from my neighbours in order to board a taxi to the clinic and buy food. (Defaulter 10: Male, 57 Years, Employed, Urban Residence).*
>
> *My sister, I am unemployed and I have been searching for a job without success. Now that I am on ARVs, I need to get balanced meals and get transport fees to come to the clinic to collect my ARVs. Lack of finances resulted into my ART default. There is nobody at home who is working and thus I did not have anyone to help me come to the clinic for ARVs refill. We do need help. At least if government was providing a small grant for the unemployed to cover basic needs such as transport fees to the clinic for medication refill. We do not have the financial power to take care of ourselves. (Defaulter 3: Male, 30 Years, Unemployed, Urban Residence).*
>
> *Even though I am employed, my salary is too little to take care of all my needs especially living expenses such as food, shelter and clothing. Shortages of finances results in people defaulting ART. In my case, I missed my medication during the time when I did not have enough money for my hospital visits. The little that we get is used for transport to work, when the date comes for you to go get your treatment, there is no money then you default. (Defaulter 7: Male, 28 Years, Employed, Urban Residence).*
>
> *My parents passed away and I am not employed but my younger sister is employed which is the reason I have not defaulted because she helps me with transport money to collect my medication. The unavailability of transport fees is the main reason why people default ART. I have other two friends who defaulted and passed away as no one in their families was working and thus they missed their hospital appointments multiple times. (Non-defaulter 9: Female, 29 Years, Unemployed, rural residence).*

The quotations above from patients who have defaulted ART shows that financial challenges is a barrier to ART adherence. While defaulter 10 is employed, the salary she receives monthly is too little to cover her expenses including transport costs to the clinic to collect her ARVs. The situation is even worse for patients who are unemployed, as they would struggle to get transport fees to the clinic. Under a circumstance where unemployed person comes from a family with a stable source of income and have disclosed his HIV status to family members, that person receives financial support from family to cover their monthly financial expenditure including hospital visits for ARVs refill. Therefore disclosing one’s HIV status to family members is very important. This confirms the perceived threat component of the HBM whereby although non-defaulter 9 has financial challenges just like other patients who have defaulted ART, she understand the complications brought by one’s non-adherence to ART.

In situations whereby the patient is unemployed and has no relative to help out, then they end up defaulting as reported by defaulter 2 that she defaulted because she did not have transport money to go to the clinic to collect her medication. Further, non-defaulter 9 has specified that two of her friends defaulted ART as they did not have anyone at home to help the with transport money yet this patient still has not defaulted. This observation supports the perceived severity component of the model which refers to the perception of the seriousness associated with leaving a certain illness untreated.

This finding is similar to other studies conducted around the world whereby financial challenges such as transport costs, health facility costs and financial insecurity, arising from unemployment, were associated with non-adherence (e.g Bezabhe et al., 2014; Nyanzi-Wakholi, et al., 2009; Penn et al., 2011; Rasmussen et al., 2013; Skovdal et al., 2011; Talam, et al., 2008).

7.2.6 Suggestions from Patients on how to Improve ART Adherence

In order to address the current barriers to ART adherence experienced by patients at Piet Retief Wellness Centre, the question on what patients think could be done to address these challenges was asked. The aim of the question was to solicit suggestions from the affected patients and ensure that they are involved in developing the interventions that will be put in place. In responding to the question aimed at addressing the existing barriers to ART adherence, there are a lot of community based initiatives that were suggested by patients to make sure the challenges experienced being lack of finances, lack of time off work for ARVs refill, lack of social support from family, community and the church are addressed.

7.2.6.1 Suggestions for dealing with patients financial challenges

The following are some of the suggested interventions by the patients to ensure optimal ART adherence:

> *I would like the government to intervene through finances for those people who are enrolled on ART and are unemployed. It is a fact that we come from different families with varying financial challenges. For example, I come from a family*

> *where no one is working and nobody is earning any grant. If I may ask you this question my sister, since the medication requires that one gets a balanced diet, there is also transport costs to go to the clinic for medication refill which is an addition to other household expenses such as clothing, food and shelter. Basically, how does government expect us to survive? In my situation, I am unemployed and there is no source of income whatsoever, how am I supposed to meet all the daily financial demands? My suggestion is that, the government should raise funds for those who are unemployed and are on ARVs at least for food and transport. Then we can go to the clinic to collect our ARVs. (Interview 2: Defaulter, Female, 46 Years, Unemployed, Urban Residence).*

> *Personally I do have one or two suggestions to ensure that in the future, we have no reason for defaulting ART. Firstly, I would like the government to create job opportunities so that the youth can get jobs and this will help reduce the high crime rates in the country as the youth is always associated with the criminal activities taking place in our country. We should not forget that being on ARVs requires one to at least have a source of income for food, transport costs and some of the medication for controlling side effects such as pain killers and antibiotics. For people, I reside in the rural areas, it becomes very difficult when one is due for the hospital appointment and you literally have nobody to give you money for transport. From here to the clinic, my return fare is R96-00. So since to go there every month, where will I get such a lot of money. If the government can provide us with a source of income such as a grant for the unemployed patients who are on ART, I do believe that the level of non-adherence would be decreased. (Interview 9: Defaulter, Female, 29 Years, Unemployed, rural residence).*

> *I would like to request if the government can provide us with a small grant for food and transport costs to the clinic. Although I am employed, my salary is too little to provide me with daily nutritional meals given the fact that when one is on ARV's, it is very important to get balanced meals. (Interview: Defaulter 5, Female, 23 Years, Employed, Urban Residence).*

The quotations above show that lack of finances is indeed a barrier to ART adherence. For the unemployed such as defaulter 9, it becomes even more challenging for such a person to honour her hospital appointment as she has to travel long distances from rural areas to the clinic. In addition to that, in the absence of a job and the high demand for balanced meals for people on ART, government has to intervene in this situation to ensure good quality of life for the citizens of South Africa. As observed in studies conducted in different parts of the world, lack of finances resulting from unemployment acts as a barrier to ART adherence (Grierson et al., 2000; Katabira, 2002).

7.2.6.2 Suggestions for dealing with time constraints in terms of operating hours

In terms of the challenge facing patients whereby the wellness centre close at 17:00 on Monday to Friday, the patients had the following suggestions aimed at improving ART adherence especially for employed people:

> *Most of the time when I come out of work which is around 6 pm, the hospital will be closed but around town there are pharmacies that close after 7 pm. Strategies should be put to place to assist patients to have access to ARVs even after working hours. This could be through working with pharmacies so that patients can collect ARVs from there. The chemist is better because when you have gone somewhere then you get always go and get them. (Interview 10: Defaulter 10, Male, 57 Years, Employed, Urban Residence)*

> *The operating hours at the hospital which is from 08:00 am till 17:00 pm is a big challenge to me in terms of ART adherence. Since I am working as a security guard, I do not normally get time during working hours to attend my hospital appointment. I would be happy if the government can help us by providing other ART centres like pharmacies where we can collect ARVs after work or even on weekends. (Defaulter 8: Male, 35 Years, Employed, Urban Residence)*

> *My sister, since I am working in the forest industry, I always leave home at 05:30 am and return home around 18:30 pm. During this time the wellness centre will be closed. Operating hours for me pose as a barrier to ART adherence. We should be given a second option where we can collect our ARVs, especially for the employed as we do not get time during the day to come to the wellness centre to refill our ARTVs. (Interview: Defaulter 6, Female, 49 Years. Employed, Urban Residence)*

The quotations above show that interventions should be put in place to ensure that patients have sufficient access to ARVs. The mostly challenged group in terms of the hospital operating hours is the employed ones. Most of them work out of town and by the time they return from work, the wellness centre will be closed. This observation supports the perceived barrier component of the HBM. Operating hours pose as a challenge to ART adherence. Therefore, interventions should be put in place to enable employed patients to access ARVs even after hours.

7.2.6.3 Suggestions for dealing with long hours of waiting for service

Long waiting hours act as a barrier to ART adherence particularly for employed patients who do not have the time to come and wait at the hospital the whole day. The following narratives came from patients with regard to ways of improving long waiting times for medication refill:

> *My sister, the long waiting times actually makes one to think twice whether to honour our hospital appointment for medication refill or not! Given the fact that the only time my employer agreed to free me to come and collect my ARVs is after lunch, I have no option of coming here earlier. My suggestion is that government should take this department very serious and stop treating us like sub-humans. Government should train more nurses and doctors to work in the HIV clinic here in Piet Retief. There is insufficient staff and this result into long queues and long waiting times which negatively affects service quality. (Interview 7: Defaulter, Male, 28 years, Employed, Urban).*

> *There is a need for more nurses and doctors to be employed at Piet Retief Wellness Centre as patients are made to wait long hours before they get attended to. In order to improve to this situation, there is a need for Government to employ more nurses and doctors to work in the wellness centre. This will also improve service quality as more patients will be attended to within a short period of time and then they can be able to return to work promptly. (Interview 1: Non-defaulter, Male, 41 Years, Unemployed, Urban).*

The current prevailing situation whereby patients find themselves waiting long hours to receive the ART services could be a reason why employed patients default more compared to unemployed patients at this Wellness Centre. This shows that there is an urgent need to add more doctors and nurses at the Wellness Centre. Long waiting times demotivates patients from attending their appointment at the wellness centre for medication refill. In terms of HBM, inadequate staff shortages act as a barrier to ART adherence. As such, this finding supports the perceived barrier component of the HBM. The findings of the study corroborate other studies whereby factors related to the health facility such as insufficient staffing of health workers, long waiting times and limited clinic hours have been reported to affect the quality of ART service delivery, particularly for working people who need time off work to collect medication (E.g. Audu et al., 2014; Bezabhe et al., 2014; Hardon et al., 2007; Jaquet et al., 2010; Penn et al., 2011; Rasmussen et al., 2013; Sanjobo et al., 2008; Skovdal et al., 2011).

7.2.6.4 Suggestions for dealing with lack of treatment supporters

Treatment supporters have been identified as a very critical factor in terms of assisting patients in taking their ARVs consistently. The need for treatment supporters underscores the in inadequacy of family support even after patients have disclosed their status. This inadequate family support could be the result of widespread poverty or neglect by the family members due to their own emotional exhaustion with the patients. With regard to treatment supporters, patients suggested that government should help by hiring HIV and AIDS trained personnel to move around the community and train people on treatment on the benefits of adhering to ART and the dangers of non-adherence to ART. The following are some of the suggestions from patients:

> *We need to get assistance from the hospital staff to get treatment supporters through support groups whereby we can chat, call or text each other for emotional support. Currently here in Piet Retief, we do not have any adherence groups. In this group we can also help the beginners (ARV's) and teach them about managing the side effects from ARV's. Support groups help because they tell you that you will continue to live therefore instils hope upon the people. (Interview 9: Non-Defaulter, Female, 29 Years, Unemployed, rural residence."*

> *The Government through the hospital should send people around our communities to train and remind us on the dangers and benefits of adhering to ART. In as much as we are taught this at the hospital, getting more information on this subject at the community level through adherence groups could foster more knowledge and understanding for the people who are on ARV's. (Interview: Non-defaulter 2, Male, 46 Years, Employed, rural residence).*

> *I would love that the government hire people that will go to the community and teach people how they should take their treatment. (Interview: Non-defaulter 6, Male, 25 Years, Employed, Urban Residence)*

The suggestions from these patients show that there is an urgent need within the community to develop treatment support groups. This will assist in ensuring that patients receive both moral and emotional support. Given the fact that the Wellness Centre started operating as long ago as in 2006, one would presume that by this time such support mechanisms would be existing to act as a support structure for both old and new ART patients.

7.3 Summary and Discussion

This chapter analysed the perspectives of patients on the challenges / barriers to ART adherence and its effect on the uptake as predicted by the HBM. Specifically, the chapter presented the findings of the study under the following themes; the perspectives of patients on stigma and discrimination, perspectives of patients on social support and financial challenges and ART adherence. Firstly, with regard to patients' perspectives on stigma and discrimination and its effect on ART uptake, patients reported that they have experienced stigma and discrimination at the community and home level. Secondly, with regard to the perspectives of patients on social support, where patients did not receive social support, they were more likely to default compared to patients who were emotionally supported by their families, at home and at the community level.

Thirdly, with regard to the perspectives of patients on social support at church, where patients had not received social support, they were more likely to default as compared to those whose churches supported them both financially and emotionally.

Finally, patients' perspectives on financial barriers to ART adherence, all patients reported that financial challenges pose as a barrier to ART adherence. While this issue is a problem to the employed receiving the basic minimum wage (maid, security guards), this challenge is even worse to the unemployed who do not even have a single-family member who is employed.

7.4 Conclusion

In conclusion therefore, the HBM has been helpful in explaining why patients decide not to adhere to ART. The perceived barrier, perceived threat and perceived susceptibility components of the model were assessed in this chapter in terms of challenges faced by patients in terms of ART adherence. The findings of the present study therefore have provided empirical evidence to support the usefulness of the HBM as a framework for the understanding of individuals' health-related decision-making and its influence in understanding of the challenges / barriers to ART uptake.

CHAPTER 8: SUMMARY OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

8.1 Introduction

The present study set out to examine the socio-demographic factors affecting patients' adherence to ART in Piet Retief Wellness Centre in the Gert Sibande District of Mpumalanga Province in South Africa. Further, the study investigated the perspectives of patients with regard to service quality influencing ART uptake, perspectives of patients on ART adverse effects and finally, the barriers to ART adherence. The study used both quantitative and qualitative data to achieve its objectives. For the quantitative component, the study utilized the univariate, bivariate and multivariate (survival analysis) approaches to examine the effect of the socio-demographic factors on patients' adherence to ART by HIV patients who are both defaulters and non-defaulters using the Cox proportional hazard regression model.

On the other hand, the study complemented the quantitative findings with qualitative data whereby psychosocial factors were also examined in relation to ART non-adherence. Specifically, the qualitative aspect of the study examined patients' perspectives with regard to the influence of service quality on the uptake of ART, patients' perspectives on ART adverse effects and its impact on ART adherence, and finally, the qualitative data investigated patients' perspectives on the barriers to ART adherence. In terms of service delivery at the wellness centre, it is vital that the voice of the people at whom the service is directed is heard. In this case, these are all patients enrolled on ART. As such, the results of the study are very important in terms of policy and interventions aimed at supporting patients who are already enrolled into ART to maximize the chances of being adherent.

This chapter presents the summary of the study findings, conclusion and recommendations for the study. Further, the chapter discusses policy implications and suggestions for future research based on the findings of the study. This chapter therefore is organized as follows: a summary of the study findings, a brief summary of the quantitative and qualitative findings as presented in the previous chapters is provided. Secondly, the chapter provides the conclusion and its recommendations. Finally, the chapter also identifies the areas requiring future research in relation to ART adherence in similar health situations.

8.2 Theoretical Framework

The study was based on the HBM. The HBM emerged from the research of several social psychologists in the 1950s, who sought to explain why some individuals declined participation in preventive health care programmes such as immunization and tuberculosis screening that could aid with early diagnosis and prevention of the disease (Janz & Becker, 1984).The HBM helps to explain the association between health beliefs and the performance of preventive health behaviours. The major components of the HBM are perceived susceptibility, perceived severity, perceived benefits, perceived barriers, self-efficacy and cues to action (Hayden, 2009; Stanhope & Lancaster, 2000).

According to Janz and Becker (1984) the HBM is based on three assumptions. Firstly, it assumes that a person will take a health-related action if that person feels that a negative health condition can be avoided. Secondly, the HBM also assumes that a person will take action if that person has a positive expectation that by taking a recommended action they will avoid a negative health condition. Finally, the HBM assumes that a person takes a health-related action if the person believes that she/he can successfully take the recommended action.

The present study was based on these assumptions of the HBM as it pertains to patients' adherence to ART after he/she has been introduced to ART. It is assumed that those who adhere to ART: (i) feel that falling sick and dying because of HIV and AIDS infection can be avoided; (ii) believe that adhering to ART will be effective in preventing them from falling sick and finally dying from HIV. The HBM is made up of six key components which are cognitive-based stipulating specific factors that a person who believes himself/herself to be healthy must consider when deciding whether or not to adopt a recommended health behaviour.

These six components of the health belief are operationalized in the present study, namely, perceived susceptibility, perceived severity, perceived threat, perceived benefits, perceived barriers, cues to action and self-efficacy. The findings of the study showed how socio-demographic and psychosocial fact influences the uptake of ART in a wellness centre. Therefore, the findings of the present study have provided empirical evidence to support both the usefulness the HBM as a framework for understanding of individuals' health-related decision-making.

8.3 Summary of the Findings

The study addressed the general question of the factors that affect ART adherence in a wellness centre in South Africa using a quasi-experimental research design utilizing both quantitative and qualitative data. During the period under study which is from 2010 to 2014 non-adherence was recorded at 33% while ART adherence was sitting at 67%. Using both the quantitative and the qualitative data sources, the study has contributed to the body of literature by unearthing and highlighting the factors associated with ART non-adherence in a country utilizing both quantitative and qualitative research approaches

8.3.1 Socio-demographic risk factors associated with antiretroviral therapy non-adherence at Piet Retief Wellness Clinic.

In terms of the socio-demographic risk factors affecting adherence to antiretroviral treatment (ART), this study was limited to analysing the quantitative data. The data were analysed at three levels, namely, univariate, bivariate and multivariate. Among the socio-demographic factors examined were gender, age, education, marital status, employment status, and place of residence. As far as gender is concerned, after adjusting for the effects of all the factors in the model, the relationship between gender and ART default was found to be statistically insignificant. This finding corroborates the results of other studies that show that there is no relationship between gender and treatment default.

As far as age goes, we found that there is a positive association between age and ART default. This finding is corroborated by Okoronkwo et al. study (2013) which showed that in terms of patients' age and non-adherence to ART, patients who were 40-49 years old were more likely to default compared to patients below 40 years. Moreover, Shigdel et al. (2014) found that ART non-adherence increased significantly with increasing age particularly after the age of 50 years. In terms of marital status, the hazard of treatment default shows that there is no difference in treatment default in terms of marital status, a finding which is similar to that of other studies that revealed that there was no statistically significant association between marital status and adherence.

As far as education is concerned, the study found that there is an inverse relationship between educational attainment and ART treatment default. The default rate was 2.0 times higher among respondents who had primary education compared to respondents who had no education.

In terms of employment status, the finding that the hazard of treatment default is higher among employed respondents compared to unemployed respondent is contrary to the findings of some studies that concluded that people who were employed were less likely to default from ART medication compared to those who were unemployed (Pratt et al., 1998; Martinez et al., 1998).

The finding that the hazard risk of treatment default is higher among respondents living in rural areas compared to respondents living in urban areas is supported by Maquthu et al. (2010) study on the impact of the place of residence revealed that as residential status changed from rural to urban, adherence to ART improved as well. Moreover, Pelzer et al. (2010) found in KwaZulu-Natal, South Africa, that ART adherence for urban residents was found to be 3 times greater than that of rural residents.

In terms of area of residence, the hazard of treatment default is 4.5 times higher among respondents residing in urban areas compared to respondents residing in rural areas. Our finding however is contrary to the findings of other studies on the relationship between area of residence and ART default. For example, in India, long travel time by village people to ART centres has been identified as one of the major causes of ART non-adherence (e.g. Cauldbeck et al., 2009; Sarna et al., 2008). This is despite efforts by the country's Ministry of Health of ensuring that ART centres are closer to villages, people still prefer travelling long distances to access ART in pursuit of avoiding being stigmatized in their local communities (Wakibi et al., 2011).

8.3.2 Perspectives of Patients on the quality of service delivery influencing the uptake of ART in Piet Retief Wellness Centre.

In terms of patients' perspectives on the quality of service delivery and its influence on the uptake of ART, the findings of the study revealed that there is a shortage of health workers resulting in patients waiting for longer hours to receive attention. This situation in turn contributes to the tendency of patients defaulting on ART treatment. The study also found that waiting time is longer, especially in the afternoons. This results in a situation whereby the very few nurses and one doctor break for lunch and tea breaks leaving patients unattended.

This concurs with other studies whereby factors related to the health facility such as insufficient staffing of health workers, long waiting times and limited clinic hours have been reported to affect the quality of ART service delivery, particularly for working people who need time off work to collect medication (E.g. Audu et al., 2014; Bezabhe et al., 2014; Hardon et al., 2007; Jaquet et al., 2010; Penn et al., 2011; Rasmussen et al., 2013; Sanjobo et al., 2008; Skovdal et al., 2011).

The study also found that with regard to the attitude of health care workers at the wellness centre, patients generally reported that health care workers are very kind, helpful and supportive to them. The result of the study is in support of findings from other studies whereby a positive attitude and a caring heart from health workers result in patients adhering to ART (Bezabhe et al., 2014; Jaquet et al., 2010; Skovdal et al., 2011).

In terms of the instructions given to patients concerning their medication, the study found that health workers provided clear instructions on how to take medication. In fact, the majority of the patients expressed how helpful health workers have been in terms of supporting and encouraging them to adhere to ART. The results of the study support the findings of Kalichman and Simbayi (2004) that concluded that health literacy positively affected adherence to ART medication. This means that the more informed the patients are with regard to the importance of taking their medication, and the dangers of defaulting treatment, the less likely they will default on treatment.

With regard to the perspectives of patients on the benefits of adhering to ART, all the patients showed understanding of the benefits of taking their medication faithfully. The study found that patients value the great work done by health workers in terms of encouraging them to adhere to ART. This is through the counselling which patients received at the time when they were initiated into treatment and the discussion that patients normally have with service providers during their monthly check up.

Finally, in as far as patients' understanding of the dangers on non-adherence to ART is concerned, the study has shown that patients understand the dangers of defaulting treatment. Patients have an understanding that ARV's are now part of their daily lives and without which they understand the consequences of not adherence which is falling sick and dying. All reports received from patients with regard to their understanding of non-adherence to ART show that they are aware and knowledgeable of the dangers of non-adherence to ART.

8.3.3 Perspectives of patients on the adverse effect of ART on the individual.

The study investigated ART adverse effects under the following themes; the perspectives of patients on ART side effects, perspectives of patients on food preferences resulting from ART usage, perspectives of patients on HIV disclosure and non-adherence to ART and finally, perspectives of patients on ART individual reminders. Firstly, with regard to patients' perspectives on the adverse effects resulting from ART usage, the study discovered that all patients have experienced ART adverse effects. However, unemployed patients were severely affected by adverse effects as they lack the finances to access painkillers and other medication to manage these side effects. As such, they defaulted ART.

Secondly, with regard to patients' perspectives on food preferences resulting from ART uptake, the study found that all patients had preferences for different kinds of food. Mostly, patients preferred to have meat, chicken, eggs and vegetables in their diet which pose a great challenge for all patients particularly due to the high food prices. This situation is even worse for those patients who are currently unemployed and have no source of income. Thirdly, with regard to the perspectives of patients on HIV status disclosure and non-adherence, the study found that all patients who had not defaulted ART had disclosed their HIV status to their family members and friends and as such, they got supported in the uptake of ART. However, all patients who had defaulted ART had not disclosed their HIV status to their family members and friends.

Finally, patients' perspectives on ART individual reminders revealed that generally those patients who had never defaulted ART had individual treatment reminders in the form of a person and technology such as tv, radio, cell-phone alarm. On the other hand, at the inception stage of ART, defaulted patients did not have individual reminders. However, after defaulting and getting re-initiated into ART, they realized the value of having individual reminders and they are currently using them. This finding of the present study have provided empirical evidence to support not only the usefulness of the HBM as a framework for the understanding of individuals' health-related decision-making, but more importantly the influence of adverse effects on the individual and its influence on ART uptake.

8.3.4 Challenges/ barriers to ART adherence in Piet Retief Wellness Centre.

The study explored the perspectives of patients on the challenges / barriers to ART adherence and its effect on the uptake as predicted by the HBM. This investigation was conducted under the following themes; the perspectives of patients on stigma and discrimination, perspectives of patients on social support, perspectives of patients on financial challenges and ART adherence. Firstly, with regard to patients' perspectives on stigma and discrimination and its effect on ART uptake, the study found that patients have experienced stigma and discrimination both at the community and home level. They were mainly stigmatized after disclosing their HIV status to family and friends which is the main reason why some patients did not disclose their HIV status in fear of stigma and discrimination. Secondly, with regard to the perspectives of patients on social support, where patients did not receive social support, they were more likely to default compared to patients who were emotionally supported by their families, at home and at the community level.

Thirdly, with regard to the perspectives of patients on social support at church, the study found that where patients had not received social support, they were more likely to default compared to those whose churches supported both financially and emotionally. Finally, in terms of patients' perspectives on financial barriers to ART adherence, all patients reported that financial challenges pose as a barrier to ART adherence. While this issue is a problem to the employed receiving the basic minimum wage (maid, security guards, petrol attendants), this challenge is even worse to the unemployed who do not even have a single-family member who is employed.

8.4 Limitations of the Study

The study has shed light on the socio-demographic and psychosocial factors impacting ART adherence in a wellness Centre in South Africa. However, the study has one major limitation being that since it was conducted within one province of the country which is Mpumalanga province, the findings of the study therefore cannot be generalized to the whole of South Africa.

Secondly, we did not test the entire model (HBM) as this was not the aim of the study. Had this been the study aim, we would have operationalized each component of the model and test them with a statistical technique such as path analysis to establish the direct and indirect influences of the components of the model.

8.5 Conclusion

The HBM has been helpful in explaining the challenges faced by patients which in turn affect ART adherence. The findings of the study from the quantitative analysis revealed that socio-demographic factors influence ART non-adherence (age, education level, area of residence either urban or rural and employment Status). Subsequently, the findings from the qualitative analysis revealed that poor service quality negatively influence ART uptake, adverse effects from ART negatively affects ART uptake and barriers/ challenges to ART uptake as faced by patients such as financial, psychological and physical barriers negatively affect the uptake of ART. Interventions aiming at dealing with these issues as identified and discussed in the study have to be developed and put in place to ensure success in the administration of ART in Mpumalanga province of South Africa. Thus, the findings of the present study have provided empirical evidence to support the usefulness of the HBM as a framework for the understanding of individuals' health-related decision-making and its influence in understanding of the challenges / barriers to ART uptake.

8.6 Recommendations

There is a need for policy makers to understand that the ARVs availability is not the only determining factor enhancing adherence ART. There are a number of other factors that need to be addressed including patients' background factors. As such, the following recommendations are suggested:

In view of patients with secondary education and above being more adherent to ART compared to their lower educated counterparts, there is a need for government to legislate mandatory secondary education for all the citizens of the country to ensure that they are better equipped in in the fight against HIV and AIDS. Not only will this enhance better utilization of ART health services, but it will also help to promote a better-educated nation which in turn will contribute to the country's economy.

There is a need for the government through the Department of Health to educate and emphasize to patients the important role played by treatment reminders in ensuring ART adherence either through technology (cell-phone, radio or TV programme) or family members. This is based on the fact that in Mpumalanga province, the age group 40-49 years are the most defaulters compared to their younger counterparts. This could be due to old age which brings along a lot of commitment as one has to provide for their families and as such they forget to take their medication. It is therefore vital even for health professionals to ensure that during counselling and hospital visits, treatment reminders are emphasized. Further, government' intervention through media such as radio and TV programmes emphasizing the role played by treatment reminders can be useful.

In view of employed people having a high hazard of ART default in Mpumalanga province compared to their unemployed counterpart, there is a need for government to legislate workplace HIV policy in all employment sectors. The presence of an HIV policy will ensure that both employers and employees are well educated about HIV and ART at the organizational level. This will also help in reducing stigma and discrimination at the family, workplace, community and country level as all myths existing on how HIV is transmitted and cured will be dealt with. Employed people also highlighted that sometimes their employers refuse to grant them time off work for medication refill. It is the availability of this same HIV policy at the workplace that will ensure that employers are also educated about the nature of HIV as a disease and as such, patients' rights will be respected in terms of ensuring that they are in good health at all times. That demand that they are granted time off work for medication refill.

Strategies need to be put in place in terms of the wellness centre operating hours to promote ART accessibility to all patients. The mostly challenged group in terms of the hospital operating hours is the employed ones. Most of them work out of town and by the time they return from work, the wellness centre will be closed. There is a need to introduce other centres with longer operating hours (after hour services) to ensure ARVs accessibility to all patients on treatment. Currently the wellness centre is open from 08:00 am until 17:00 and therefore this act as a barrier to ART adherence. For example, the local pharmacy in Piet Retief closes at 21:00 daily and operates 7 days a week.

In view of the current situation whereby patients wait long hours before they receive ART services which has negatively influenced ART adherence especially for employed patients, there is an urgent need for the government through the Department of Health to support the training of more doctors and nurses in HIV and AIDS management and care. These health professionals should come from this same community of Piet Retief to ensure the Wellness Centre receives adequate support in the administration of ART. The government can add a clause on their training contract that upon completion of training, they will work for the province of Mpumalanga for a set number of years.

While patients have been highly encouraged to disclose their HIV status to family members, there have been reports of stigma and discrimination both at the family and community level after such disclosure. There is therefore an urgent need for HIV education both at the family, community and national level. In fact, HIV education is recommended from as low as early primary levels Grade 4 and above) given the fact that primary school children have been reported to be already engaging in unprotected sexual activities. Further, HIV programmes aimed at educating the nation on the importance of family support for the patients on ART are further recommended, both on radio and TV. Such programmes will also aim at discouraging stigma and discrimination at the family and community level.

The church has a role to play in the fight against HIV and AIDS through providing a supportive environment that will not only foster ART adherence but also spiritual, emotional and financial support for their church members on ART. Patients from Mpumalanga province mainly reported that the church has been indifferent in the fight against HIV and AIDS. In fact, patients have highlighted that the church has been silent towards the issue of HIV and AIDS.

In terms of social support, government should intervene by establishing and developing treatment support groups to act as a support structure for patients who are on ART. HIV and AIDS trained personnel should move around the community and train people on treatment on the benefits of adhering to ART and the dangers of non-adherence to ART The need for treatment supporters underscores the in inadequacy of family support even after patients have disclosed their status. This inadequate family support could be the result of widespread poverty or neglect by the family members due to their own emotional exhaustion with the patients. The availability of treatment supporters will assist in ensuring that patients receive both moral and emotional support. The government, through the hospital should send people around the communities to train and remind patients on the dangers and benefits of adhering to ART. In as much as these are taught at the hospital during counselling, getting more information on this subject at the community level through adherence groups could foster more knowledge and understanding for the people who are on ARVs. Given the fact that the Wellness Centre started operating as far as 2006, one would presume that by this time such support mechanisms would be existing to act as a support structure for both old and new ART patients.

Government’ intervention is needed for patients who are on ART and are unemployed. In view of the financial challenges faced by unemployed patients in terms of consistency in taking their ARVs due to the fact that this medication requires one to at least have a source of income for food, transport costs and some of the medication for controlling side effects such as pain killers and antibiotics. This could be either through a small grant for food and transport for the unemployed and through skills development programmes to ensure that those who are not employed have better chances of employment once they have a general skill such as brick laying and other short courses.

8.7 Policy Directions

The National Strategic Plan (NSP) 2017-2022 is the country's master plan that outlines the country's response in the fight against HIV and AIDS, STI's and TB in terms of prevention, treatment and care for the next five years. The aim of the NSP is to promote a healthy life, increase life expectancy and reduce the burden of disease among all those who live in South Africa inclusive of migrant populations. The study findings from both quantitative and qualitative analysis have quite a number of implications for policy. Antiretroviral Treatment demand a number of adjustments on the part of the patient and their mere availability at the clinic is not a guarantee that the patient will successfully adhere to them. There is therefore an urgent need for the country to consider the following in terms of policy direction:

Firstly, there is a need for the country to make it mandatory for all organizations both private and public and small, medium and large enterprises to develop an HIV and AIDS workplace policy which will ensure that employees who are infected with HIV and AIDS are not unfairly treated. Such a policy will cover issues of prevention, care and non-discrimination. Further, the policy should include practical strategies for management, workplace principles and workplace programme which will have a universal buy-in from employees. The availability of such a policy will also enhance HIV education and knowledge for all employees. As such, HIV stigma and discrimination will be reduced. The findings from this study have shown that employed patients default more compared to their unemployed counterparts. The results from the interviews indicated that one of the reasons patients default is because they do not get time off work to go to the clinic to refill their ARVs. In addition to this, where employers have agreed to employees to attend clinic, it will be on a "No-work no-pay policy". Therefore, it is mandatory that such a policy be put in place.

The findings of the study have shown that the poor quality of care for ART services at the wellness centre particularly with regard to staff shortages and turn-around time for ART services require an urgent attention. The NSP (2017-2022) Goal 7 advocates for addressing the social and structural drivers of HIV, TB and STIs and link these efforts to the National Development Plan. Poor service quality acts as a structural driver perpetuating ART non-adherence especially due to shortages of staff workers and long waiting hours for ART services at the wellness centre. Consequently, the Department of Health created the Patients' Rights Charter to highlight their constitutional rights to access quality healthcare. Among the important patients' rights provided by the charter is the right to access healthcare, receive timely emergency care, treatment and rehabilitation (Booysens, 2008). Therefore, there is need to ensure that treatment of high quality is afforded to patients in the wellness centres. Government, through the NDH has to monitor and emphasize the importance of ensuring ART quality services in all HIV clinics around the country to ensure that ART patients remain in treatment for a lifetime. Serious monitoring of ART services should be a priority for all clinics providing ART services. HIV clinics around the country have to ensure that patients are retained especially in terms of turn-around time for ARVs refill to avoid high default rates. In sufficient staff workers resulting in patients waiting for long hours without being attended contribute ART non-adherence.

The findings of the study revealed that ART patients experience stigma and discrimination due to their HIV status both at family and community level. Further, patients have reported lack of social support from family and the community. As part of policy for HIV treatment, management and care, there is a need for government through the different hospitals rendering HIV services to invest in HIV Treatment Support Groups at the community level to act as a support structure for every individual on ART both in rural and urban areas. Within the support groups, different forms of treatment reminders, both person and technological (ICT, for example through sms, calls or other means) should be taught and emphasized to ensure that patients are reminded of their hospital appointment and time to take their ARVs.

The findings from the study that the age group 40-49 years are more prone to ART non-adherence compared to their younger counterparts shows a demand for such support structure as well. Generally this age group would be the breadwinners at home and are always working on a tight schedule which might be contributory factor to the high ART non-adherence rate. It is through this support groups that family involvement in terms of social support will also be enhanced. Patients should be encouraged to bring along their closest family members (who might not necessarily be infected with HIV) to participate in all Treatment Support group activities and in that way the family as a whole would get to be informed better of HIV and AIDS. The involvement of other family members in reminding that the patient takes his medication consistently and attends his hospital appointment is also very important. Family members should be trained on how to support HIV and AIDS patients and this can take place during the Treatment Support groups meetings.

Finally, according to the NSP 2017-2022 goal 3, government has vowed to reach all key and vulnerable populations with customized and targeted interventions to ensure ART adherence for all people. Therefore, there is a need for an intervention in terms of finances to meet the escalating food and transport demand for people on ART to ensure that adherence is for a lifetime. The study findings showed that financial challenges resulting from unemployment strongly contribute to ART non-adherence. All patients interviewed during the study, both employed and unemployed reported finances as a barrier to ART adherence. This is caused by the fact that most of the patients are involved in informal employment receiving the basic minimum wage (forestry, domestic worker, security guards, and petrol attendants). The issue of finances is even worse to the unemployed who are not on grant and who do not even have a single family member who is employed. Further, the study findings have shown that unmet need for food preferences on ART patients and unmet high demand for food in unemployed patients contribute to high default rates. This is based on the fact that ARVs require one to have eaten food before you take them. On an empty stomach, they result in unmanageable side effects such as nausea, dizziness, terrible headaches and other condition.

8.8 Future Research Directions

The study examined socio-demographic and psychosocial factors influencing patients' adherence to ART between 2010 and 2014 in the Mpumalanga Province of South Africa utilizing both quantitative and qualitative data. For quantitative analysis, the study utilized survival analysis while the qualitative data were analysed with the use of the NVIVO software. Therefore, based on this study, the following research areas are suggested.

Further research on socio-demographic and psychosocial factors affecting patients' Adherence to ART utilizing the survival analysis, focusing on all wellness centres in South Africa need to be conducted. Such a study should include both urban and rural areas so that any differentials and opportunities available to these areas can be noted and documented.

More studies, using the mixed methodology need to be conducted to investigate the challenges faced by urban residents resulting in the high default rates. Such a study should also investigate the employment sectors where patients come from and ascertain the availability of an HIV policy in the work places.

Further research on the role played by ART treatment reminders to ensure ART adherence, particularly the use of family members, information technology (cell phones, television programmes and radio) needs to be investigated.

Further, pilot studies on the possibility of financial social support for unemployed patients and those in informal employment sectors in terms of small grant provision needs to be conducted throughout the country. Financial challenges resulting from unemployment strongly contribute to ART non-adherence.

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APPENDIX 1: Clinical Data Collection Form for HIV/AIDS Patients attending a Wellness Centre in South Africa between 2010-2014 from patients files records

1. Gender

1 = Male	
2 = Female	

2. Age in Years...

3. Marital Status:

Married	1
Never married	2
Cohabiting	3
Divorced	4
Widowed	5

4. Highest level of Education:

No School	1
Primary education	2
Secondary education	3
Tertiary education	4

5. Current employment status:

Not employed	1
Still studying (student)	2
Employed with a salary /wages	3
Self employed	4

6. Area of residence:

1= Rural	
2= Urban	

7. Category:

1 = Defaulted	
2 = Not defaulted	

8. Date of Starting Treatment:

Day	Month	Year

9. Date of initial default (if defaulted) :

Day	Month	Year

10. Date last seen at the clinic (for defaulters only)

Day	Month	Year

11.Date the patient died (for those patients who have died already)

Day	Month	Year

12.

Outcome	Mark with an (X)
1= Defaulted	
2=Still in the system without default	
3=Lost to follow-up	
4= Died (HIV related)	
5= Died (other causes)	

Appendix 2: Qualitative Data Logistics: Informed Consent

Informed Consent.

Socio-Demographic Factors Affecting Antiretroviral Treatment Adherence in a Wellness Centre in South Africa.

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My name is…………………………………I am a PhD student from Population Studies Department of North West University, South Africa. I am conducting a research on "Socio-Demographic Factors Affecting ART Adherence in a Wellness Centre in South Africa: A Survival Analysis". The purpose of the study is to understand the reasons why HIV/AIDS infected patients default from Antiretroviral treatment (ART) in South Africa. I will ask questions about your background information and your experiences pertaining the use of ART, your perceptions on the accessibility of Piet Retief Wellness Centre, your perceptions of the services provided by Piet Retief Wellness Centre as well as the reasons for defaulting from ART.

Your participation is voluntary and if you agree to take part in this interview, we might take about 30 minutes. During the interview, you are free to ask any question and even stop the interview altogether. If you decide to quit, then your responses (captured from interview guide) will not be considered for analysis. Therefore, if you consent to the interview, all information given will be treated as confidential and be used for the purpose related to this study.

Consent to Participate in the Survey

Please sign below if you agree to participate in the study.

The above document explaining the purpose of the study on the socio-demographic factors affecting ART adherence in South Africa, Piet Retief Wellness Centre: A Survival Analysis has been read and explained to me. I have been given an opportunity to ask questions about the study and they have been answered/not answered to my best satisfaction. I agree to participate in the study.

Respondent

Signature: ………………………….……… Date:………………………………..

Interviewer

Signature:…………………….......... Date:……………………………........

Appendix 3: Qualitative in-depth interview guide for both ART defaulted and non-defaulted Patients at Piet Retief Wellness Centre

1. Patients Individual physiological Challenges in adhering to ART

1.1 Can you explain your experience with antiretroviral treatment starting from the period you started in terms of;

bodily strength,

weakness (physiological effects of ART),

likelihood to prefer certain types of food,

challenges in accessing ART in a timely way,

side effects,

emotional effects

2. Patient HIV Status Disclosure to Family Members and Peers

Have you disclosed your HIV status to anyone?

Reaction of the person you disclose to

Do your peers know where you keep your Arv’s at home;

Do you use ARV’s openly?

Do you tell a peer to remind you to take your dose and to keep your hospital appointment for ARV’s refill?

3. Stigma and Discrimination due to HIV Status

Have you ever had any experience of being treated differently because of your HIV status?;

Probe:

family,

clinic,

church,

work and community at large

4. ART Service Quality at the Wellness Centre

What are your observation about the quality of service that is offered in this Wellness Centre?

Probe:

waiting time for medication refill,

staffing of medical personnel,

attitude of health care providers

availability of drugs (ART).

5. Knowledge of Patients / Service Providers about ART and openness to discuss the subject matter

Were you provided with counselling (HIV/AIDS and ART education) before you were initiated into treatment?

HIV knowledge of the patient

benefits of adhering to ART as well as dangers of not adhering to ART

given clear instructions on how to take your medication?

health provider inform you of the treatment and side effects

attitude of the health provider on your present state

perspective of throughput of service at the facility

patients' right at the facility is it adhered to

6. Perceived barriers (problems) and possible solutions of taking ART

What do you perceive to be the biggest problem regarding taking ARV treatment?

Communication barrier

Financial

Service

Material

Peers

Cultural

Religious

7. What do you think could be done to improve this?

Do you have any questions for me?

Thank you for your time and cooperation.