

**The experiences of HIV positive patients on antiretroviral drugs  
attending the public service health institutions in the Eastern  
Cape Province: A qualitative study**

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Date: March 2017

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## **ABBREVIATIONS**

AIDS	Acquired Immuno Deficiency Syndrome
ARV	Antiretroviral
AZT	Azidothymidine
HAART	Highly Active Antiretroviral Treatment
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
MDG	Millennium Development Goals
NGO	Non-Governmental Organisation
NHI	National Health Insurance
PEPFAR	The President's Emergency Plan for AIDS Relief
PLWH	People/Person Living With HIV
SDG	Sustainable Development Goals
UN	United Nations
UNAIDS	United Nations programme on AIDS
WHO	World Health Organisation

## **ABSTRACT**

### **Introduction**

In August 2003, a landmark decision was made by the South African government to include the use of antiretroviral drugs in the public health service as part of the comprehensive response to the HIV pandemic. The Eastern Cape Province implemented the decision in May 2004. The aim of this study was to explore the experiences of patients taking antiretroviral (ARV) medication in the public sector of the Eastern Cape Province. The main objective was to explore the personal, health service and contextual related experiences of HIV positive patients on antiretroviral drugs attending the public service health institutions in the Eastern Cape Province with the following specific objectives:

- To explore how patients incorporate the taking of ARVs into their lifestyle.
- To explore the beliefs and feelings of patients regarding their ARVs.
- To explore the positive and negative experiences of patients attending the ARV clinic.
- To explore how others such as family and friends react to their taking of ARVs.
- To explore what they expect of the ARVs.
- To explore what motivates them to take the ARVs.
- To explore the positive and negative forces that affect the patient's ability to adhere to the treatment.
- To understand the social, cultural and contextual issues that impact on the patient's ability to take ARVs.
- To elicit any other unanticipated issues that arise in the patient's context or experience that are important to their ability to take ARVs.

The results of the study will inform the strategies for implementing the antiretroviral programme in the Eastern Cape Province.

### **Methods**

#### **Study design**

A qualitative study design was used. A purposive sample of HIV positive patients on antiretroviral drugs who met the inclusion criteria were selected from HIV Clinics at Lusikisiki, Mthatha, East London and Port Elizabeth. Data on the experiences of the

participants were collected via interviews, from daily narratives in the medicine diaries compiled by the patients, focus groups of patients and patient's treatment supporters/care givers, and participant observation. Data from the individual and focus group interviews were collected until a point of saturation was reached.

### **Analysis**

The data analysis was done using ATLAS-t.i Version 6.2 computer programme for the analysis of qualitative data.

### **Ethical considerations**

Informed consent was obtained from all participants and confidentiality ensured. Ethics Committee approval was obtained from the University of Stellenbosch and Walter Sisulu University. Permission was obtained from the Heads of Clinical Governance of the participating hospitals.

### **Results**

The personal experiences of participants highlighted the importance of the knowledge of one's HIV status through testing, as a gateway to accessing care, although the decision to test was not an easy one due to the fear of stigma and discrimination. Disclosure of HIV status was selective for the same reason. Acceptance of HIV status; use of technology, especially mobile phones; and treatment supporters facilitated adherence to the ARVs. The health benefits of ARVs motivated adherence and outweighed the challenges of the side effects.

Save for a few positive experiences related to the health service, patients had challenging experiences. These included negative health provider attitudes, stigma and discrimination, long waiting times, inadvertent disclosure, lack of person centred care, inequity in access to care, poor infrastructure, overcrowding and unhygienic practices and environment.

The positive contextual experiences related to support from the family and others the participants interacted with. Some family members and others were also responsible for the negative experiences the participants were subjected to, particularly stigma and discrimination. Challenging experiences related to food insecurity and poor socio-economic status featured quite prominently. The socio-cultural experiences mainly related to the effects

of traditional medicine in relation to the ARVs, especially when taken concurrently. The healthcare providers discouraged the practice as it could affect the efficacy of the ARVs.

## **Conclusions**

The conclusions were based on the objectives of the study. The incorporation of ARVs into the lifestyle of the patients was facilitated by the treatment supporters and the use of technology, mainly mobile phones. The patients believed that ARVs saved their life and gave them hope to live long enough to fulfil their aspirations in life, e.g., bringing up of their children. Lack of acceptance of HIV status, and drug and alcohol abuse were considered to be some of the serious challenges to adherence and the health benefits of ARVs. A few but inconsistent positive experiences related to the HIV clinic included some practice of person centred care, availability of ARVs, patient education and sharing of experiences with peers. The negative experiences dominated the experiences at the HIV clinic. These included lack of person centred care, the practice of stigma and discrimination by the health care providers, poor unhygienic infrastructure, and fears about the sustainability of the supply of ARVs in the public service. The positive reaction of the family and others in the form of support contributed to improvement in the health of the patients while the negative reactions, especially stigma and discrimination, compromised support and fuelled ill health for the patients. Socio-cultural and other contextual challenges related to the taking of ARVs were the rampant practice of stigma and discrimination against people living with HIV by families and the society at large, leading to lack of support. Poverty, food insecurity and the use of traditional medicine concurrently with ARVs were also highlighted. Other unanticipated issues raised were the importance of the role of the treatment supporters in the care of the people living with HIV and the need to consider those who have no source of income for some form of remuneration. The emerging rising challenge of drug and alcohol abuse in relation to patients on ARVs was highlighted and is a concern. For all the issues raised above, specific recommendations have been made.

## ABSTRAK

### Inleiding

In Augustus 2003 is 'n besluit geneem deur die Suid-Afrikaanse regering om die gebruik van anti-retrovirale middels in die openbare gesondheidsdiens as deel van die omvattende reaksie op die MIV-pandemie in te sluit. Die Oos-Kaap het die besluit implementeer in Mei 2004. Die doel van die studie was om die ervarings van openbare sektor pasiënte in die Oos-Kaap wat antiretrovirale (ARV) medikasie gebruik, te verken. Die hoofdoelwit was om die persoonlike, gesondheidsdiens en kontekstuele ervarings van MIV-positiewe pasiënte op antiretrovirale middels in die staatsgesondheidsdiens in die Oos-Kaap te verken, met die volgende spesifieke doelwitte:

- Om te verken hoe pasiënte die neem van ARV's in hul lewenstyl inkorporeer.
- Om die oortuigings en gevoelens van pasiënte met betrekking tot hul ARV's te verken.
- Om die positiewe en negatiewe ervarings van pasiënte aangaande bywoning van die ARV-kliniek te verken.
- Om te verken hoe ander soos familie en vriende reageer op hul neem van ARV's.
- Om te verken wat hulle van die ARV's verwag.
- Om te ondersoek wat hulle motiveer om die ARV's neem.
- Om die positiewe en negatiewe kragte wat die pasiënt se vermoë om te voldoen aan die behandeling beïnvloed te verken.
- Om die sosiale, kulturele en kontekstuele kwessies te verstaan wat 'n impak het op die pasiënt se vermoë om ARV's te neem.
- Om enige ander onverwagte kwessies wat ontstaan in die pasiënt se konteks of ervaring wat belangrik is vir hul vermoë om ARV's te neem is ontlok.

Die resultate van die studie sal die strategieë inlig vir die implementering van die anti-retrovirale program in die Oos-Kaap.

### Metodes

#### Studie ontwerp

'n Kwalitatiewe studie ontwerp is gebruik. 'n Doelgerigte steekproef van MIV-positiewe pasiënte op antiretrovirale middels wat voldoen het aan die insluitingskriteria was gekies uit MIV Klinieke in Lusikisiki, Mthatha, Oos-Londen en Port Elizabeth. Data oor die ervarings

van die deelnemers is ingesamel deur onderhoude, uit die daaglikse verhale in die medisyne dagboeke saamgestel deur die pasiënte en fokusgroepe van pasiënte en pasiënte se behandelingsondersteuners / versorgers en direkte waarneming. Data van die individue en fokusgroeponderhoude was ingesamel totdat 'n versadigingspunt bereik was.

### **Ontleding**

Die data-analise is gedoen met behulp van ATLAS-ti, Weergawe 6.2, rekenaarprogram, vir die ontleding van kwalitatiewe data.

### **Etiese oorwegings**

Ingeligte toestemming was verkry vanaf al die deelnemers en vertroulikheid was verseker. Etiese goedkeuring was verkry van die Universiteit van Stellenbosch en Walter Sisulu Universiteit se Etekkomitees. Toestemming was verkry van die hoofde van kliniese bestuur van die deelnemende hospitale.

### **Resultate**

Die persoonlike ervarings het die belangrikheid beklemtoon van die kennis van pasiënte se MIV-status deur middel van toetsing as 'n poort om toegang te verkry tot sorg, al was die besluit om te toets nie 'n maklike een nie, as gevolg van die vrees vir stigma en diskriminasie. Bekendmaking van MIV-status was selektief vir dieselfde rede. Aanvaarding van MIV-status, gebruik van tegnologie, veral selfone, en behandelingsondersteuners het nakoming van die ARVs gefasiliteer. The gesondheidsvoordele van ARV's het nakoming gemotiveer en die uitdagings van die newe-effekte oorskadu.

Behalwe vir 'n paar positiewe ervarings wat verband hou met die gesondheidsdiens, het pasiënte uitdagende ervarings gehad. Dit het ingesluit negatiewe gesondheidsverskaffer houdings, stigma en diskriminasie, 'lang wagtye, onopsetlike openbaarmaking, 'n gebrek aan persoonsentreerde sorg, ongelykheid in toegang tot sorg, swak infrastruktuur, oorbevolking en onhygiëniese praktyke en omgewing.

Die positiewe kontekstuele ervarings het verband gehou met die ondersteuning van die familie en interaksie met ander deelnemers. Sommige familieledes en ander was ook verantwoordelik vir die negatiewe ervarings van die deelnemers, veral stigma en

diskriminasie. Uitdagende ervarings wat verband gehou het met voedselonsekerheid en swak sosio-ekonomiese status was baie prominent. Die sosio-kulturele ervarings het hoofsaaklik verband gehou met die gevolge van tradisionele medisyne met betrekking tot die ARVs, veral wanneer hulle saam geneem was. Gesondheidswerkers het die praktyk ontmoedig, aangesien dit die effektiwiteit van die ARV's kan beïnvloed.

## **Afsluitings**

Die gevolgtrekkings is gebaseer op die doelwitte van die studie. Die inlywing van ARV's in die lewenstyl van die pasiënte was gefasiliteer deur die behandelingsondersteuners en die gebruik van tegnologie, hoofsaaklik selfone. Die pasiënte het geglo dat ARVs hul lewe gered het en het vir hulle hoop gegee om lank genoeg te leef om hul aspirasies in die lewe, bv. die opvoeding van hul kinders, na te kom. Gebrek aan aanvaarding van MIV-status, dwelm- en alkoholmisbruik was beskou as 'n paar van die ernstige uitdagings vir die nakoming en die voordele van gesondheid ten opsigte van ARVs. 'n Paar, maar strydige, positiewe ervarings wat verband gehou het met die MIV-kliniek, was die praktyk van persoon gesentreerde sorg, beskikbaarheid van ARV's, pasiënt onderwys en die deel van ervarings met eweknieë. Die negatiewe ervarings het die MIV-kliniek ervarings oorheers. Dit het ingesluit 'n gebrek aan persoongesentreerde sorg, die praktyk van stigma en diskriminasie deur gesondheidswerkers, swak onhigiëniese infrastruktuur en vrese oor die volhoubaarheid van die verskaffing van ARV's in die staatsdiens. Die positiewe reaksie van die familie en ander in die vorm van ondersteuning het bygedra tot die verbetering van die gesondheid van die pasiënte, terwyl die negatiewe reaksies, veral stigma en diskriminasie, ondersteuning in die gedrang gebring het, en swak gesondheid vir die pasiënte aangevuur het. Sosio-kulturele en ander kontekstuele uitdagings wat verband gehou het met die neem van ARV's was die wye praktyk van stigma en diskriminasie teen mense wat met MIV leef deur families en die samelewing in die algemeen wat gelei het tot 'n gebrek aan ondersteuning. Armoede, voedselonsekerheid en die gelyktydige gebruik van tradisionele medisyne saam met ARV's was ook uitgelig. Ander onverwagte kwessies wat uitgelig was, was die belangrikheid van die rol van die behandeling ondersteuners in die sorg van die mense wat met MIV leef en die behoefte om diegene met geen bron van inkomste met een of ander vorm van vergoeding te oorweeg. Die opkomende stygende uitdaging van dwelm- en alkoholmisbruik in verhouding tot pasiënte op ARV's was uitgelig. Spesifieke aanbevelings is vir al die kwessies wat hierbo uitgelig is, gemaak.

# CHAPTER ONE: INTRODUCTION

## 1.0 Social value of the research

The HIV pandemic has no real equivalent in modern history in terms of its global scale and impact. By the end of 2015 about 7 million were infected worldwide with two million people infected globally in that year. In the same year 1.1 million people have died globally of AIDS related illnesses. Of the 78 million estimated to have been infected, 35 million people have died globally from AIDS related diseases since HIV was first identified in 1981 (UNAIDS, 2016, WHO, 2016a). Sub-Saharan Africa is hardest hit, hosting about 25.8 million infected people. The region also accounts for about 70% of the global total of new HIV infections (UNAIDS, 2015). On the continent as a whole, southern African countries are the most affected with the prevalence ranging from about 12% in South Africa (Shisana, Rehle, & Simbayi, 2014) to 32% in Swaziland (Bicego et al., 2013). Currently South Africa has approximately 7 million people infected with HIV, making it the country with the highest prevalence in the world (UNAIDS, 2015). In the Eastern Cape Province, about 11.6% of the population is infected (Shisana, Rehle, & Simbayi, 2014).

HIV/AIDS was the leading cause of mortality in South Africa until 2011 when it was overtaken by Tuberculosis to date (Bradshaw et al., 2003; Statistics SA, 2015a). Despite it being the fifth cause of mortality in 2014 it still remains a major health problem with serious social implications for the country. It is estimated that 2.1 million children (0-17 years) are orphans as a result of HIV infection, resulting in many child-led families (Shisana, Rehle, & Simbayi, 2014, UNAIDS, 2015). The age group between 15-49 years constitutes 19.2% of the population infected and the are most affected, which has a significant economic impact for the country as this age group contributes considerably to the economy of the country. The infected individuals create a social burden for their families and communities as the disease progresses and results in more dependence on others.

Women are disproportionately infected due to their economic dependency on men, cultural disempowerment in the negotiation of sexual relations, and discrimination in the labour market with fewer opportunities for employment. This also increases their chances of

resorting to risky commercial sex work (Shisana, Rehle, & Simbayi, 2014). A number of biological reasons including the longer contact of the male semen in the vagina following sexual intercourse, sexually transmitted causing vaginitis or cervicitis, injuries in the vaginal mucosa during intercourse and anatomical reasons related to the structure of female genitalia, such as the large surface area of the vaginal mucosa coming into contact with the glans penis in the act of sexual intercourse, also increases their chances of getting infected (Nicolosi *et al.*, 1994; Higgins, Hoffman, & Dworkin, 2010)

Managing HIV has been a scientific challenge since it was first described in 1981. While other viruses which have caused epidemics in the past, such as smallpox, polio, measles and influenza, have been successfully controlled using vaccines; thus far this has not been achieved with HIV. The search for an effective vaccine is still ongoing and is anticipated to continue for several years to come (Dolin, 2009; Rerks-Ngarm *et al.*, 2009). Despite the challenges, the global response to mitigate the HIV pandemic has been phenomenal across ideological, political, geographical and socioeconomic divides. The United Nations (UN), through the World Health Organisation (WHO) and the UNAIDS programme, plays a leading role in co-ordinating the effort. The response to the pandemic is based on the known biomedical and psychosocial dimensions of HIV infection.

Transmission of HIV is mainly through sexual intercourse, heterosexual or homosexual, with the former being the main mode of transmission in South Africa. Other modes of transmission include: contact with contaminated blood and other body fluids, use of contaminated needles for injection of drugs, vertical transmission from mother to child in utero, and transmission through breast milk (Shisana *et al.*, 2005). As there is no known cure for HIV infection at the moment, it can only be controlled.

WHO provides guidelines to inform countries on how to plan their own response to the HIV pandemic. A comprehensive approach to implementing the strategies for mitigating the HIV infection is recommended by WHO as no single strategy on its own has been found to be effective. South Africa has had a phased response to the pandemic. The current response is based on the five-year comprehensive plan adopted by the government in 2003 (DOH, 2003). This included:

- Promoting measures to control HIV infection by practicing safe sex through abstinence, being faithful to one sexual partner and the consistent use of condoms;

- Safe blood transfusion;
- Early diagnosis and treatment of sexually transmitted infections;
- Voluntary counselling and testing (later changed to HIV Counselling and Testing (HCT));
- Prevention of mother to child transmission through the use of antiretroviral drugs and provision of replacement feeding;
- Provision of social grants to HIV positive people;
- The development of a safe, effective, relevant and affordable AIDS vaccine for Southern Africa through research;
- The use of antiretroviral drugs in the public service for prevention of mother to child transmission, post exposure prophylaxis and the clinical management of confirmed HIV patients; and
- Male medical circumcision.

The 2003 comprehensive response to the HIV pandemic expired in 2006 and was replaced in March 2007 by the *HIV and AIDS and STI Strategic Plan for South Africa 2007-2011*, which had two broad aims:

- To reduce the number of new infections (especially in the 15-24 age group because the future course of the epidemic depends largely on the behaviours young people adopt or maintain and the contextual factors which affect their choices); and
- To reduce the impact of HIV and AIDS on individuals, families, communities and society.

The five key priority areas were: prevention; treatment; care and support; human and legal rights; and monitoring, research and surveillance (DOH, 2007). After this plan expired it was followed by the current 2012-2016 strategic plan (DOH, 2012). The key strategic objectives of which are:

- Addressing social and structural barriers that increase vulnerability to HIV, STI and TB infection;
- Preventing new HIV, STI and TB infections;
- Sustaining health and wellness; and
- Increasing protection to human rights and improving access to justice.

The strategic plans from 2007 to date have highlighted the importance of psychosocial issues in the comprehensive approach to managing the HIV pandemic e.g. the focus on care, the consideration of human and legal rights and the involvement of the family, community and the society.

The use of antiretroviral (ARV) drugs in the public health service in South Africa was only approved in 2004, despite the fact that they had been in use since 1985 after the discovery of Azidothymidine (AZT), the first antiretroviral drug with significant effect on HIV (Mitsuya et al., 1985). Following the decision to use ARVs in the public service, mechanisms were put in place to implement the programme. These included identifying the health facilities where the programme could be implemented, providing the necessary resources and mass education of health workers on the management of patients with antiretroviral drugs, which was based on standard guidelines recommended by the WHO (WHO, 2003). The first Highly Active Antiretroviral Treatment (HAART) guideline, recommended for use in public service institutions, was divided into two regimes according to the 2004 National Department of Health Treatment guidelines:

- Regime 1(a) composed of Stavudine (D4T), Lamivudine(3TC) and Efavirenz (EFV);
- Regime 1(b) composed of Stavudine (D4T), Lamivudine (3TC) and Nevirapine (NVP); and
- Regime 2 composed of Zidovudine (AZT), Didanosine (DDI) and Lopinavir+Rotinavir (LPV/r).

There was provision for other drugs, which were not in the Standard List, to be motivated for if needed. The 2004 National Department of Health Antiretroviral Treatment Guidelines were further revised and replaced by the 2010 version with the following major changes (DOH, 2010):

- Due to the side effects of Stavudine and Didanosine their use in the public service was limited to patients who were responding very well to them with minimal side effects. No new patients were to be started on these drugs;
- Tenofovir or Zidovudine replaced Stavudine in Regime 1a;
- All infants diagnosed HIV positive were to be put on Highly Active Antiretroviral Treatment (HAART) irrespective of their CD4 percentage;

- All HIV positive pregnant women who were not on ARVs were started on dual antiretroviral therapy with Zidovudine and Nevirapine from 14 weeks of gestation up to delivery; and
- All HIV positive pregnant women and TB patients with CD4 counts of less than 350 cells/uL were to be started on Antiretroviral Treatment (ART).

In July 2013 a further decision was made to give HAART to all patients with a CD4 count of less than 350 cells/uL. The guidelines were further updated towards the end of 2014 when all patients infected with HIV with CD4 count of < 500 cells/uL, all children under the age of five years, pregnant women, TB patients and Hepatitis B infected patients irrespective of CD4 count, were recommended to be started on HAART. Discordant couples, whose partners are on HAART, were recommended to be on pre-exposure ARV prophylaxis. A further amendment followed the adoption of the “treat all” policy by WHO in 2015 where HIV is to be treated with ARVs on diagnosis irrespective of the CD4 count. This is to be implemented by South Africa in the public service from September 2016 (DOH, 2016).

The advent of HAART in the early 1990s, used in the context of a comprehensive approach to mitigate the HIV pandemic, resulted in marked reduction in the morbidity and mortality related to HIV infection in the countries which could afford it (Egger *et al.*, 1997; Hammer *et al.*, 1997; Montaner, DeMasi, & Hill, 1998; Palella *et al.*, 1998). New HIV infections globally were reduced to 2 million and mortality due to HIV related disease to 1.5 million in 2014. In 2000, 70,000 children were born with HIV through mother to child transmission in South Africa, while by the end of 2014 this had reduced to 7,000 per year.

In 2000 the price of ARVs for treating a patient for one year was USD 10,000. The countries most affected by the pandemic had the least access to ARVs as most of them were socio-economically challenged. Less than 1% of the low and middle income countries had access to ARVs. The inequity of access and injustice sparked a global movement through advocacy, civil activism, science (by developing cheaper formulations), political pressure and urging pharmaceutical companies to balance their profit with social accountability for relieving human suffering. The concerted collective

effort resulted in the reduction of the price of ARVs by 99% to USD 100 per person per year for first line formulation (Hoen, 2003; Lucchini Cisse, Comiti, Gaudry, & Moatti, 2003; Shadlen, 2007; Natrass, 2007).

The sixth Millennium Development Goal (MDG), which focused on halting and reversing the spread of HIV, was enacted by the UN in 2000. This set the goal of having 15 million people on ARVs by 2015 (UN, 2000). Wealthy countries were urged to support the socio-economically challenged countries to effect their response. The USA has played a leading role in this regard, mainly through the Presidents' Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria. The countries affected were also urged to prioritise the response to the HIV pandemic in their national budget. These efforts have yielded commendable results. Since 2000, USD 187 billion has been invested in the global HIV response of which USD 90 billion were from domestic sources, with 50% of the countries financing more than 75% of their responses from their own resources. The MDG-6 has been achieved ahead of schedule in that by the end of March 2015, 15 million people were accessing ART. By mid 2016 18 million PLWH had access to ARVs (WHO, 2016a, UNAIDS, 2016). In 2014, 40% of the people living with HIV had access to ARVs, an increase of 22 times baseline over 14 years. In sub-Saharan Africa 10.7 million people had access, 6.1 million of whom were women. This success has proved that ARVs can be scaled up in resource poor countries (UNAIDS, 2015).

Despite the delayed inception of ARVs in the public health service in South Africa compared to other countries, following activism by organisations like the Treatment Action Group and political change in the leadership of the Government and Department of Health in 2009, concerted effort has been made to make up for the delay by using a multipronged approach. This included adopting the strategy of task shifting, which involved the down referral of patients on ARVs from the care of doctors in referral hospitals to nurses in the primary health care facilities. Subsequently, nurses were also trained to initiate ARVs. This strategy together with an increased budgetary allocation for HIV/AIDS care has resulted in about 3.6 million people on ARVs in South Africa (DOH, 2015). This makes the ARV programme in South Africa the largest ARV programme in the world. There have been marked reductions in morbidity and mortality due to AIDS associated diseases. Life expectancy increased from 51 years in 2005 to 61 years by the

end of 2014. Mother to child transmission of HIV has reduced to less than 2%, from approximately 30-50% before the introduction of the Prevention from Mother-to-Child Transmission (PMTCT) programme (DOH, 2015). These are remarkable achievements in managing a disease which at one time was a death sentence, but is now a chronic manageable disease.

### **1.1 The Chronic Care Model (CCM)**

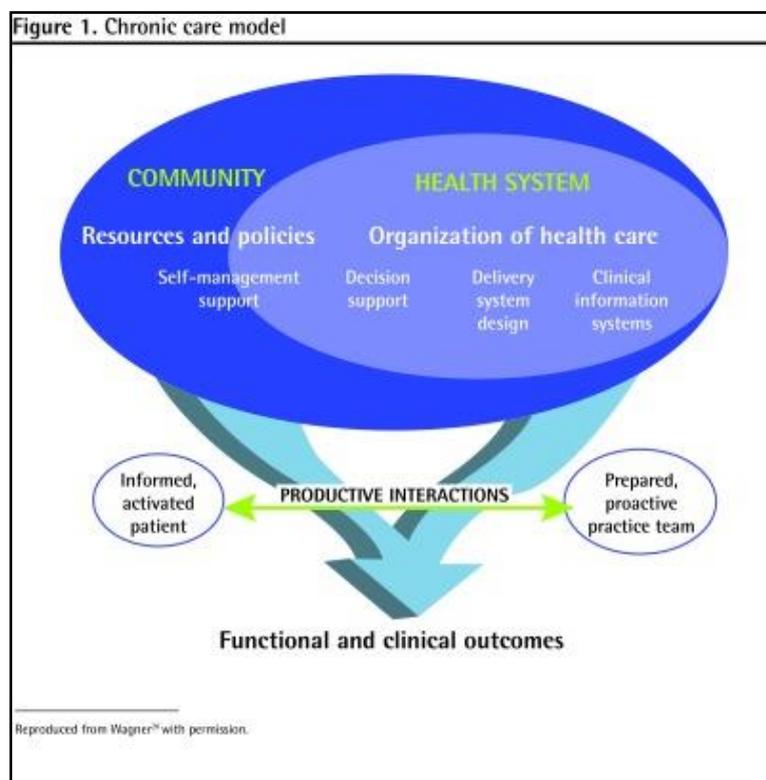
The WHO defines chronic conditions as “health problems that require ongoing management over a period of years or decades” (WHO, 2002). They include:

- Non-communicable conditions, e.g., heart disease, hypertension, diabetes, asthma, chronic obstructive pulmonary disease (COPD), epilepsy and cancer;
- Persistent communicable conditions, e.g., HIV/AIDS, TB;
- Long-term mental disorders, e.g., depression, schizophrenia; and
- Ongoing physical/structural impairments, e.g., blindness, amputation, persistent painful problems.

The care of patients in the health care system was originally based on the management of acute and infectious diseases. Episodic care of patients and a reactive health system was thus appropriate (Swartz, 2002; Wagner, 2002). However, with the increasing burden of chronic conditions and the need for ongoing provider-patient relationships, the acute care model became inappropriate (Rundall, 2002; Wagner, 2001). The Chronic Care Model (Wagner, 2002) was thus proposed (Figure 1.1). It consists of six distinct concepts identified as modifiable components of health care delivery:

- Organisational support: Management and staff buy in to the provision of quality care;
- Clinical information systems: Ability to monitor individual and population trends, provide data for effective and efficient patient care, including patient records and a reminder system;
- Delivery system design: Team approach with defined roles and system design, e.g., organisation of visits, follow-up of patients, referral system.
- Decision support: methods to improve patient access to evidence based care, e.g., alignment of specialist and generalist care including primary care;

- Self-management support: Empowerment of patients to care for themselves through patient education, problem solving, decision making, resource utilisation, the patient provider relationship and taking action; and
- Community resources: Patient advocates as community resources, e.g., Peer support groups, treatment supporters, community based interventions, e.g., cancer association, diabetes association.



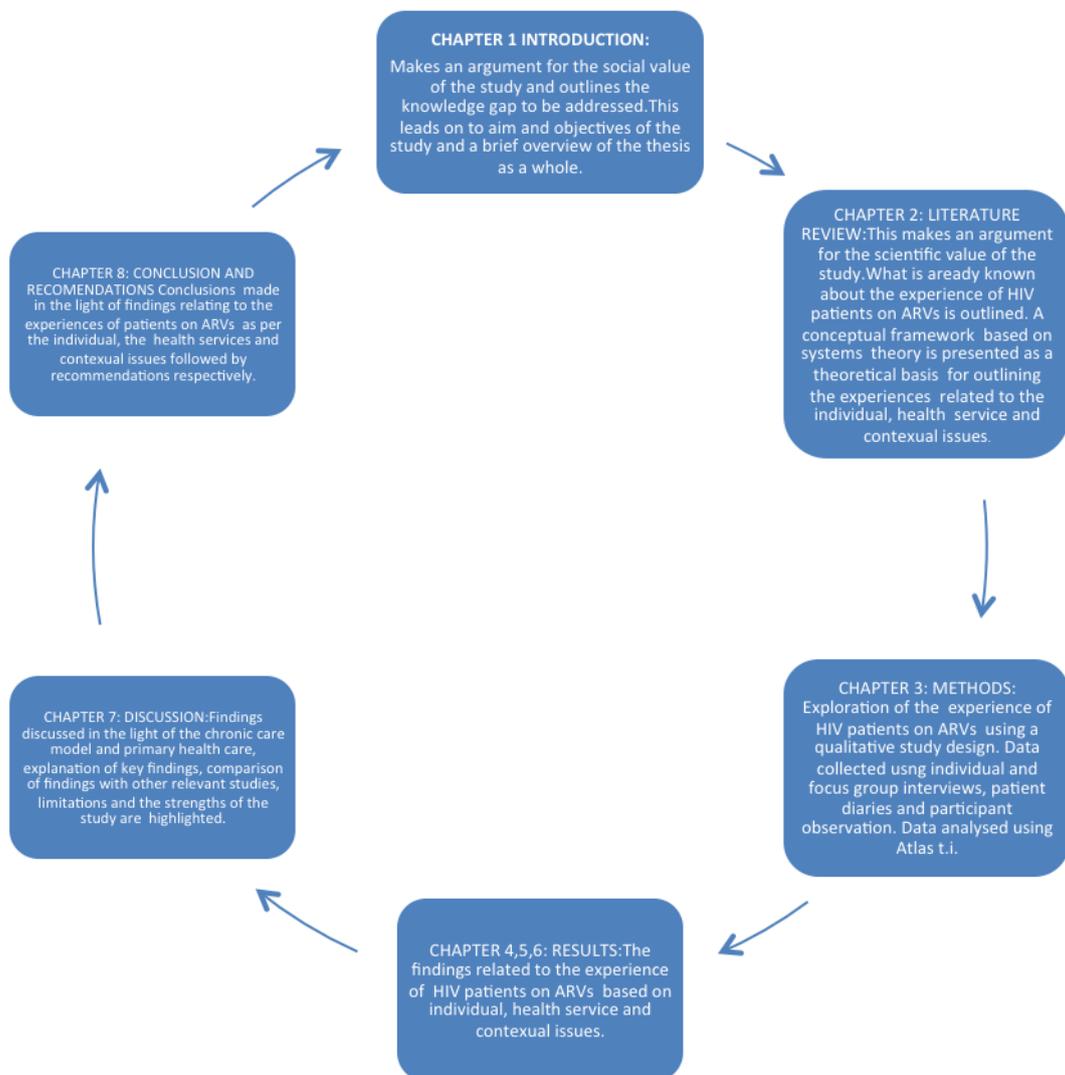
**Figure 1.1.: Chronic care model**

## 1.2 Thesis overview and chapter outline

This thesis is about the experience and perspectives of HIV positive patients. It particularly focuses on the care of HIV positive patients on ARVs attending the public health service facilities in the Eastern Cape Province. The psychosocial and contextual experiences these patients underwent individuals living with HIV infection were the issues for exploration in this study.

The Chapters in the thesis include: Introduction, Literature Review, Methods, Results, Discussion, Conclusion and Recommendations. The details of the logical sequence followed in the thesis is summarised in Figure 1.2.

**Figure 1.2. The logical sequence of thesis chapters**



### **1.2.1 Chapter One: Introduction**

The introduction makes an argument for the social value of the study and outlines the knowledge gap to be addressed. This leads on to the aim and objectives of the study and a brief overview of the thesis as a whole.

### **1.2.2 Chapter Two: Literature Review**

This chapter makes a scientific argument for the thesis. What is already known about the experiences of HIV patients on ARVs is presented in terms of individual, health service and contextual issues. A conceptual framework informed by systems thinking as a theoretical basis is presented.

### **1.2.3 Chapter Three: Methods**

The experiences of the patients on ARVs in the Eastern Cape are explored using a qualitative study design. Multiple methods of data collection are triangulated such as patient diaries, focus group interviews, individual interviews and participant observation. The findings were analysed electronically using Atlas-ti version 6.2 and the Framework Method.

### **1.2.4 Chapters Four, Five and Six: Results**

The presentation of results is based on the individual, health service and contextual related issues.

### **1.2.5 Chapter Seven: Discussion**

Key findings are discussed and compared with findings from related studies elsewhere. The findings are also related to the chronic care model and primary health care. The strengths and limitations of the study are discussed.

### **1.2.6 Chapter Eight: Conclusions and Recommendations**

Conclusions are made based on the findings in relation to each objective. Recommendations are made for health services, policymakers and researchers.

### **1.3 Ethical Considerations**

The study was approved by the Health Research Ethics Committee of the University of Stellenbosch (N06/10/197) and the Walter Sisulu University Research Ethics and Biosafety Committee (00039/08).

### **1.4 Conclusion**

This Chapter has made an argument for the social value of the study, outlined the knowledge gap and problem to be addressed, described the aim and objectives, and given an overview of the thesis. The next chapter argues for the scientific value of the study and presents a conceptual framework for the thesis followed by a statement of the problem and aim and objectives of the study.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.0 Introduction**

Chapter Two presents a review of the available literature regarding the experiences of HIV-positive patients on antiretroviral drugs (ARVs) in the public and private healthcare sectors. The review synthesises what is known and therefore also helps to define the knowledge gap addressed by this thesis, particularly in the Eastern Cape. A conceptual framework is presented to structure and guide the synthesis of the literature.

### **2.1 Search strategy**

The search strategy involved searching for published studies in Google Scholar, PubMed and Scopus using the search terms: (Experiences) AND (HIV positive OR AIDS) AND (Antiretrovirals OR ARV OR ART) AND (public and private health service OR facilities). Screening of the titles and abstracts then identified relevant studies. Government websites, national conference proceedings and research output reports from South African universities were also scrutinised for any relevant policy or unpublished work. The review was limited to studies in English from 1980 to 2015, and covers the periods from when HIV was first described, and from when the use of ARVs for HIV treatment started.

### **2.2 The theoretical basis of the study**

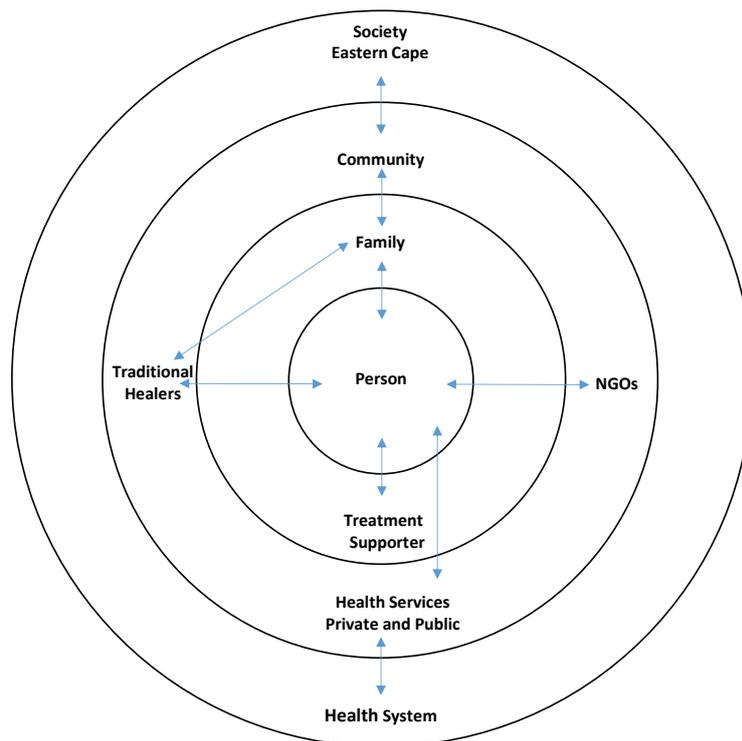
Systems theory was chosen as the theoretical basis of the study because it provided a model for understanding the complex relationships from which the patient's experiences of HIV and ARVs might arise. This same model might also provide a structure for identifying different interventions that might improve or change these experiences.

Systems theory holds the view that the universe is composed of numerous complex parts that are interrelated, interdependent and flexible; with each part nested within other parts to operate as a hierarchy of systems. In effect, smaller systems such as the individual person are nested within larger systems such as the family or the primary care service (Capra, 2014). Guided by systems thinking, a conceptual framework (Figure 2.1) was developed to depict the nested relationships and interactions of PLWH, which then leads to the experiences they had with their illness, which is the focus of the study. Based on

systems theory, the individual is placed at the centre of the circles, surrounded by and nested within the other circles, and representing progressively larger systems with which the individual interacts. There is interdependence and a dynamic flexible relationship between the systems at different levels.

On the one side of the model the individual is embedded in their family system; followed in the next level by the extended family and friends; then the community and the larger society. This forms one side of the model. The other side of the model relates to the health system. The immediate context in the health system refers to the community health workers and treatment supporters within the community. They are followed by the formal health system with its usual levels of primary, secondary and tertiary health care. The primary health care level includes the clinics, community health centres, private general practices, traditional healers and non-governmental organisations (NGO). Secondary care is provided by the district, and then regional hospitals. There is interaction between the different levels of the health system through the referral system.

Interactions also occur between the two sides of the model – the individual and the social system – within which he/she is embedded on the one side, and the health system on the other side. There are also interactions between the individual and the family, the community and society at large. The experiences of PLWH that have to do with diagnosis and treatment of HIV primarily relate to the health system, while their experience of taking ARVs and living with HIV relate to the family, extended family, friends, community and society at large. In line with systems theory, the two systems are not mutually exclusive; there are interactions between them. For example, while diagnosis and treatment of HIV are the primary responsibility of the health system, treatment supporters are often members of the family, while also related to the health system. The experiences of patients living with HIV infection are based on the totality of the whole model of the conceptual framework rather than the sum of the components.



**Figure 2.1 Conceptual framework using systems theory**

The following literature review is based on the conceptual framework and relates to how PLWH experienced the complexity of their “journey” through the two arms of the model. In other words, their experiences related to the health system on the one hand, and experiences related to the nuclear family, extended family, friends and community on the other hand and the interaction between the two arms of the model.

## **2.3 The individual experiences of PLWH on ARVs related to the health system**

### **2.3.1 The experiences related to the public and private health services**

The public health services in the Eastern Cape Province are structured according to the South African Department of Health (DOH) policy as provided for in Health Act 61 of 2003, and amended by the National Health Amendment Act of 12 of 2013 (Government of the Republic of South Africa, 2003, 2013). The health services fall within the public health system, starting with the community health workers (whose status in the public service is being formalised) as the entry point and a link between the community and the clinics. Above the clinics are community health centres

(CHC), district hospitals, regional hospitals, tertiary hospitals and one central hospital in the province, in ascending order respectively. Each level of care links with the other levels of care through a referral system that operates both upwards and downwards in an integrated manner. Most of the HIV care takes place at the regional hospitals, district hospitals and primary care level. Due to inconsistencies in the availability of medicines and other supplies in the public service, it is not uncommon to have a mixture of patients at the various levels of care, not necessarily based on the package of care expected from that level of health facility. This is a reflection of the flexibility of the system that allows for the interaction between the levels of the system in line with systems theory.

The private sector is in a mainly functional partnership with the government in rendering health services to the public at all levels of care, through private hospitals and general practices. NGOs such as Doctors Without Borders (Médecins Sans Frontières or MSF) are also important role players. The National Health Insurance (NHI) is intended to formalise the public-private partnership.

This chapter is structured according to the key experiences PLWH on ARVs go through as they access and utilise health services. It is important to state from the outset that in southern Africa, the general perception of the public health services is poor (Matsoso, Fryatt, & Andrews, 2015). This is despite successes in improving access to ARVs in Botswana (Steinberg, 2008) and South Africa (Matsoso, Fryatt, & Andrews, 2015). PLWH on ARVs are appreciative of the fact that ARVs have been made available. They are so dependent on them for their life that they fear they may become unavailable, therefore putting their health and lives at risk (Gilbert & Walker, 2009). The occasional media reporting on the challenges of funding, procuring and providing ARVs compounds this fear (Thorn, 2009; Heywood, 2009).

The journey through the public health services takes the patient through the process of testing for HIV, disclosing their status, starting ARVs, and normalisation of their lives as a PLWH.

### **2.3.2 HIV testing**

The “journey” of the PLWH through the health system starts with HIV testing. Despite the potential benefits, the decision to do the test is often not instantaneous, but

requires some consideration. This is due to the fears and shame related to the consequences of a positive result, the main one being stigma (Deacon et al., 2006; Steinberg, 2008; UNAIDS, 2015). The fear – which has persisted to date – relates to the perception created in the pre-ARV era that HIV is a fatal disease, Shame relates to the moral judgement held by society about sexually transmitted diseases (STIs), and the implication that PLWH have led an immoral life (UNAIDS, 2015). It is thus not uncommon for some of the patients to decline being tested, or to choose not to return for their results, particularly when the specimen is sent away to the laboratory for confirmation or other tests were taken that require the patient to come back for the results later (Dinah, 2005). The various reasons listed that cause people to hesitate to do the HIV test is a reflection of how this decision is taken in the context of a system within which the individual interacts, and relates to components of the system – which in this case is the society – and how this impacts on the decision making by the individual. This is all in line with systems thinking.

Some of the feared consequences may be due to misinformation. When MSF introduced one of the earliest ARV programmes in the public service, in and around Lusikisiki in the Eastern Cape in 2001, some of the inhabitants believed that the process of testing was actually responsible for infecting people with AIDS, and there was suspicion that this was the white man's strategy for exterminating black people (Steinberg, 2008). This view was given credibility by the politics of HIV/AIDS at the time and the dissident standpoint of the leadership of the government, which denied the link between HIV and AIDS. Therefore, testing for HIV was initially met with a lot of resistance in Lusikisiki and the surrounding areas in the Eastern Cape (Steinberg, 2008).

Most often the test is done as a response to the public campaign for people to know their status and to access care early. Individual motivations to test include the death of a partner, insistence by an employer, pregnancy, the desire to access a disability grant, insurance, a risky sexual encounter, development of an HIV-associated disease, or re-checking of a previously positive result (Campbell & Williams, 1999; Collinge, 2005). Re-checking a previously positive HIV result could be due to the person being in denial, as part of a general reaction to loss akin to one of the five stages of grief (Kübler-Ross, 1969; Schweitze, Mizwa, & Ross., 2010). Re-checking could also be

because of a lack of trust in the test result because of suspected inaccuracy. Media reports about test kits giving false positive results could also inform the decision to repeat the test.

To create a “spirit of openness” about HIV/AIDS and to confront stigma, regular testing is also encouraged after a negative result (Gilbert & Walker, 2009). Patients expect the HIV test to be done in privacy to ensure confidentiality. This is at times a challenge in the public service due to space constraints. Some health workers breach confidentiality by insensitively letting others know the HIV status of their patients (Bell, Mthembu, O’Sullivan, & Moody., 2007).

A trained health worker should do the test. The procedure starts with pre-test counselling, followed by informed consent per the WHO guidelines that are based on the Universal Declaration of Human Rights (UN, 1948). Post-test counselling then follows, focusing on, amongst other things, prevention, as well as how, where and when to access treatment and care. This process is at times not followed by health workers (Paxton *et al.*, 2004). The reactions to the test result take various forms, ranging from indifference to suicidal ideation. Indifference could be related to ignorance about HIV infection, while suicidal ideation may be due to the fear of death. Depression may be part of the process of the reaction to loss (Kübler-Ross, 1969). Depression and anxiety are known to have higher prevalence in PLWH compared with the general population, and in low- and middle-income countries compared with higher income countries (Lowther, Selman, Harding, & Higginson, 2014). Shisana *et al.* (2014) found the prevalence of depression was higher in PLWH compared with the general population. The HIV test should therefore ideally be done where there is immediate professional support to manage the reaction of the person tested (Bell, Mthembu, O’Sullivan, & Moody., 2007).

Despite the challenges associated with HIV testing, a high acceptance rate has been reported (Trotter, Bhayani, Florsheim, & Novak, 2010). In a national campaign based on the policy of HIV Counselling and Testing (HCT) as one of the strategies for mitigating the HIV pandemic, which was conducted by the DOH in South Africa from 2010 to 2011, 2 million people were tested compared with the 1.5 million that would

have been tested if this was done under the previous policy of Voluntary Counselling and Testing (VCT) (Matsoso, Fryatt, & Andrews, 2015).

### **2.3.3 Disclosure of HIV status**

Disclosure of HIV status is primarily done to obtain support from other close individuals such as one's partner, family members, close friends or health workers. It is also done so that sexual partner(s) can get tested or protected, to be open and to share the burden. In addition to disclosing to individuals, it can also be publically done as part of campaign to encourage people to get tested (Shisana et al., 2005).

Disclosure may not be done immediately due to fear of the possible adverse consequences, especially stigma related to moral judgement and blame, ostracism by family or community members, and discrimination. On the other hand, disclosure gives the individual an opportunity to come to terms with living openly with the infection for life (Gilbert & Walker, 2009). Other adverse consequences of disclosure experienced by PLWH included violence; loss of employment; termination of a relationship; abuse (physical and/or verbal); and loss of support from family, community, employers and employees.

Of all the negative consequences of disclosure, one of the worst reported was stigma and discrimination because they affect all aspects of the experience of living with HIV, including the management of the disease. Stigma may originate from the immediate family or from others who one interacts with at work, school, the community, or in the health services. Low self-esteem can compound stigma (Lowther K, Selman, Harding, & Higginson, 2014). More than half of the PLWH (53%) experience stigma, more so than those with other chronic conditions. PLWH in low-and middle-income countries are affected more than those from higher income countries (Lowther K, Selman, Harding, & Higginson, 2014). The decision to disclose thus occurs within a complex framework, and how the recipients of the disclosure react influences on how the patient is affected (Almelah, 2006). The complex framework is based on systems phenomenon.

Disclosure may occur inadvertently due to lack of privacy in a health facility, where others may overhear the results. Unprofessional health workers are also known to talk

to others about the HIV status of their patients (Paxton *et al.*, 2004; Gilson L *et al.*, 2005).

Muhamadi, Nsabagasani, Tumwesigye, Wabwire-Mangen, Ekstrom, Pariyo *et al.* (2010) reported similar experiences from patients in Uganda, which resulted in patients delaying seeking care at the HIV Clinic. Disclosure within the health facility may also be inadvertent as anybody seen in the vicinity of an HIV clinic is suspected of having HIV, as was experienced by some of the patients fetching milk for their babies at HIV Clinics (Bell, Mthembu, O'Sullivan, & Moody, 2007). If the medical files used by the patients look different from those of the other patients, this may also inadvertently disclose their status (Bell, Mthembu, O'Sullivan, & Moody, 2007).

The current recommendation is to treat HIV like any other chronic disease and integrate the care of PLWH into the general service rather than maintain it as a vertical programme. One of the reasons for this approach is to reduce inadvertent disclosure. The challenge then is to ensure that the unique requirements for the care of PLWH are accommodated within the regular chronic care services without compromising the standard of care.

Disclosure can also inadvertently occur as a result of the common symptoms associated with AIDS, such as weight loss, rash associated with shingles, loss of pigment in the lips, disfiguring body changes that occur as a complication of ARVs (lipoatrophy, lipodystrophy, or buffalo hump), and being seen in the possession of ARVs (Bell, Mthembu, O'Sullivan, & Moody, 2007).

#### **2.3.4 Treatment**

The inclusion of Highly Active Antiretroviral Treatment (HAART) as part of the comprehensive management of HIV infection has undoubtedly resulted in marked reduction in morbidity and mortality related to the infection. At the individual level, this translates to being healthier, and personal testimonies to this effect abound (Gilbert & Walker, 2009). The improvement in health may lead to resumption of normal life such as a return to work, social life, sexual relations, and resulting in reduced stigma and discrimination. The need for disclosure and social support may be reduced in order to avoid potential stigma and discrimination (Audu, 2014).

Maximum benefit from taking ARVs depends on good adherence, which has to be 95% or more to prevent the development of drug resistance (Bangsberg *et al.*, 2000, 2001; Roge *et al.*, 2004; Messou *et al.*, 2011; Nam *et al.*, 2008; Machtinger, Haberer, Wilson, & Weiss, 2012; Osterberg & Blaschke, 2005). Adherence to chronic treatment is generally a challenge, and the WHO estimate is generally about 50% (Brown & Russel, 2011). Measures used by PLWH or factors known to effect adherence include:

- One's beliefs about HIV and ARVs;
- Living for someone else (most often children, in order to ensure their growth to adulthood);
- Making use of one's support system, such as treatment supporters or family members;
- Having a trusting relationship with one's health care provider;
- The frequency of taking the medication (once-a-day dose, followed by twice-a-day dose is preferred);
- Being open about one's HIV status;
- A strong desire to stay healthy;
- Use of constant reminders from mobile phones, pillboxes, calendars or from healthcare providers and treatment supporters;
- Learning about the drugs and refilling one's prescription early or on time;
- Accepting the need to take medication; and
- Having support from one's partner as well as supportive spiritual or religious beliefs

(Malcolm, Ng, Rosen, & Stone, 2003; Schneider & McIntyre, 2003; Audu, 2014).

However barriers to adherence experienced by PLWH include:

- Forgetfulness;
- Excessive body weight;
- Side effects of the medication;
- Stigma;
- Negative attitudes from partners;
- Negative health beliefs about the drugs;
- Lack of confidentiality;

- Irregularly obtaining refills of one's prescription;
- Complex or frequent dose regimens;
- Being too busy;
- High burden of pills (for example taking ARVs and other medication);
- Sleeping through doses;
- Low income and poor education;
- No adherence aids or support;
- Language barriers between healthcare provider and patient;
- Lack of trust between healthcare provider and patient;
- Cost of drugs or other related costs;
- Need to take medication with food; and
- Reliance on alternative or traditional healing systems instead of allopathic biomedical treatment.

(Stone, Mauch, & Steger, 1998; Murphy, Roberts, Martin, Marelich, & Hoffman, 2000; Roberts, 2000; Golin, Isasi, Bontempi, & Eng, 2002; Kumarasamy *et al.*, 2005; Bezabhe *et al.*, 2014).

Misconceptions about ARVs, which also act as barriers to adherence, include the belief that ARVs cause AIDS, infertility and cancer (Muhamadi *et al.*, 2010). Barriers and enablers need to be identified and addressed in order for PLWH to get the maximum benefit of taking ARVs. Certain barriers or enablers may be more common in specific communities and it is therefore important to understand the specific context in some depth, as well as the complexity of each individual's situation. This study attempts to explore the context in the Eastern Cape and to characterise the issues experienced by the local predominantly Xhosa-speaking communities.

### **2.3.5 Access to the ARVs**

While PLWH laud the benefits of taking ARVs, they express fears related to the sustainability of their access to the drugs (Heywood, 2009; Health-e News, 2009b). This is because irregular access to the ARVs may compromise adherence and lead to treatment failure. The need for very high adherence requires an extra effort on the part of the provider to ensure a constant supply of the drugs, and the patients have to ensure that the drugs are taken as recommended. The fears of PLWH regarding

sustainability of access to ARVs in the public health services emanates from their generally poor experiences of accessing drugs in the public health system. The problem is commonly due to a break in the supply chain, resulting in so called “stock outs” (Matsoso, Fryatt, & Andrews, 2015).

The supply chain management system for the provision of medicines is a very complex system involving several role players at different levels. Solving the problem thus necessitates a holistic approach involving many role players. Stock out is a common problem in low- and middle-income countries, which unfortunately are the same countries disproportionately more affected by HIV infection.

In addition to the stock outs, PLWH may also experience difficulties in accessing health facilities because of lack of money for transport, and/or poor roads (Ssali et al., 2010). Some of the challenges relate to the social determinants of health and are beyond the mandate of the Department of Health because of their complexity. They are best addressed through inter-sectoral collaboration with other government departments. The inter-ministerial committee formed by the South African government as part of the strategy to mitigate the HIV pandemic is a response to this need. The provision of a social grant to indigent PLWH as part of the “social wage package” from the Department of Social Development is an example of inter-sectoral collaboration in the management of HIV infection (Matsoso, Fryatt, & Andrews, 2015). The grant is given to PLWH whose CD4 count is less than 100/ul (Stone, 1998; Murphy, Roberts, Martin, Marelich, & Hoffman, 2000; Roberts, 2000; Golin, Isasi, Bontempi, & Eng, 2002; Murphy, 2003; Kumarasamy et al., 2005; Bezabhe et al., 2014).

With rampant poverty amongst PLWH, compounded by ill health and fewer opportunities in the labour market for employment because of their HIV status, some PLWH feel that all those who have no source of income should be given the social grant without consideration for CD4 count. This demand will continue to escalate as the number of PLWH on ARVs will continue to increase as we approach the WHO “treat all” policy whereby HIV infection is recommended to be treated with ARVs on diagnosis, irrespective of CD4 count. This is one of the strategies for attaining the

global elimination of HIV by 2030, as set out by the UN Sustainable Development Goals (SDG) adopted by the UN in September 2015 (UN, 2015; WHO, 2015).

### **2.3.6 Experiences related to healthcare staff**

#### **Staff shortage**

Staff shortages are a common feature of the public health services in low- and middle-income countries. The reasons cited include inadequate numbers of trained staff, migration of professional staff to other countries, resignation due to poor working conditions, and lack of opportunities for promotion and development (Matsoso, Fryatt, & Andrews, 2015). PLWH have narrated experiences related to staff shortages which have led to long waiting times and disruption of their schedule for the day, with consequences such as skipping their scheduled time to take their ARVs and missing their transport home (Wilson *et al.*, 2010).

#### **Unprofessional staff behaviour**

Adversarial staff attitudes in public health facilities have been widely reported by the public. In a baseline national audit done in 2010 by the Office of Health Standards Compliance (OHSC) in the public sector in South Africa, it was established that only 34% of primary healthcare staff were found to be caring (Matsoso, Fryatt, & Andrews, 2015). Concerns have also been raised about unprofessional staff behaviour leading to the stigmatisation of PLWH. This undermines the goal of developing a trusting provider–patient relationship, which is known to facilitate adherence to treatment and promote the health of the patient (Gilson *et al.*, 2005). One of the reasons given for unprofessional staff behaviour is the intensity and pressure of the workload due to staff shortages, coupled with poor working conditions. Addressing unprofessional staff behaviours is attitudes is one of South Africa’s six ministerial priorities, and one of the National Core Standards (NCS) to improve the quality of care in the public service (DOH, 2011).

#### **Supportive experience**

A “clinic culture” is developed to regularly keep appointments. A relationship of trust should be developed with the healthcare providers and other regular attendants at the clinic, who may become an invaluable resource for the patient in times of need. The

clinic becomes a home where PLWH may feel less stigmatised and safe to share their experiences, and even their sense of humour. Well-informed patients are able to converse with confidence about their progress and technical terms such as CD4 counts and viral loads. Treatment in a caring environment contributes to physical, emotional and spiritual wellness, and reduces stigmatisation by making their HIV status less obvious to those who do not know. PLWH are appreciative of the role played by the health service in achieving this.

### **2.3.7 Experiences of treatment supporters and community health workers**

Treatment supporters form part of the team managing PLWH, especially in the public service where all PLWH on ARVs are encouraged to have treatment supporters. They were introduced in the public health service system with the national roll out of the ARV programme in 2004 (DOH, 2003). There were no experienced treatment supporters from elsewhere to provide South Africa guidance about their role other than successful experiences in Malawi (Walden, Mwangulube, & Makhumula-Nkhoma, 1999), Mozambique (Vaz, Gloyd, & Trindade, 1996) and Botswana (Norr K., Tlou, Moeti, Norr J.L., & McElmurry, 2004), where they had peer educators to facilitate ARV adherence and other interventions for the management of PLWH.

Treatment supporters support the patient in taking ARVs to ensure adherence for the maximum benefit of the patient, and monitor them for any problems related to their illness. In addition, community health workers may interact with the PLWH as they visit the households for which they are responsible in their municipal ward. Both treatment supporters and community health workers may help to link the patient with the local health services. PLWH are usually the ones who choose their treatment supporters, and their choice is usually based on a relationship of trust to ensure confidentiality and avoid stigma. Family members are often the first to be chosen by PLWH as their treatment supporters because they would have an established relationship of trust already. Peer treatment supporters who are also PLWH are chosen for the same reason (Nachega *et al.*, 2006). In addition, the patient may choose someone who has some moral authority so that they are more likely to listen to them and follow what the treatment supporter tells them (Ssali *et al.*, 2010).

Treatment supporters in the Eastern Cape need to be trained as they may not always have sufficient understanding of ARVs to offer effective support (Ruud, Srinivas, & Toverud, 2013). In the same study they also request that their work be formalised in the public service, particularly those who were also working as community health workers. Volunteerism is difficult in poor communities where energy needs to be focused on using one's time to generate an income for one's family (Friedman & Mottiar, 2005). The South African Government, through formalising the status of community health workers, is favourably considering this request. This is part of the Ward-Based Outreach Team (WBOT) in the re-engineering of primary health care as one of the strategies for the implementation of the National Health Insurance (NHI) (Matsoso, Fryatt, & Andrews, 2015).

### **2.3.8 The private sector**

The private sector's involvement with PLWH is through the health services offered by general practitioners, private specialists, nurses and other disciplines rendering private health care. Those PLWH who utilise the private sector are those who have insurance or can pay out of their pockets. The private sector in South Africa has had a longer experience with using ARVs compared with the public sector because of the delays in rolling out ARVs as a result of AIDS denialism in the early years. Subsequently, however, the majority of patients on ARVs are managed in the public sector. The challenging experiences of PLWH in relation to the private sector relate mainly to the costs involved. Funds running out before the end of the year, for those who are on Medical Aid, is not uncommon, which forces them to pay for services out of their own pocket or to resort to the public sector. Indeed, after ARVs were rolled out in the public sector in 2003, a number of patients who could not afford the private sector moved to the public sector. Compared with the public sector health service, the quality of care provided in the private sector is considered by the public (including PLWH) to be better (Matsoso, Fryatt, & Andrews, 2015). This possibly has to do with the services being more patient-centred and better resourced (Wilson *et al.*, 2010).

### **2.3.9 Traditional health practitioners**

In many of the countries worst affected by the HIV pandemic the traditional health practitioners are in the frontline of health service provision. Based on self reports, the global use of traditional medicine has been reported to range from 10% to 75%, and

from provider data, between 2% and 49% (Harris *et al.*, 2012). In the Eastern Cape and South Africa at large, traditional healers are often the first point of contact when someone is ill, especially in the rural areas (Wilson *et al.*, 2010). The amaXhosa ethnic group, who have very strong beliefs in traditional healing, predominantly populate the Eastern Cape. Most of the population make use of both allopathic and traditional medicine. One would expect the PLWH to do the same. It is reported in Uganda that some PLWH have regretted using traditional medicines when the delay in starting ARVs led to them becoming very sick (Muhamadi *et al.*, 2010). One of the reasons many western-trained healthcare providers give for discouraging the use of traditional medicine with ARVs is the fact that the interaction between the drugs are not known and may compromise the benefits of the ARVs.

### **2.3.10 Non-governmental organisations (NGOs)**

NGOs have played a key role in supporting governments in their comprehensive response to the HIV pandemic. Globally the key funders include PEPFAR (US DOS, 2010), the Bill & Melinda Gates Foundation and The Global Fund for AIDS, Tuberculosis and Malaria. Before the roll out of ARVs in the public health service, PLWH in a number of low- and middle-income countries were largely dependent on NGOs for their care. For example, MSF provided HIV care and ARVs to the rural community of Lusikisiki in the Eastern Cape Province (Steinberg, 2008). This programme was introduced at a time when ARVs were very expensive and out of reach of most of the people in low-and-middle income countries.

NGOs also played a key role, together with other role players, to lobby pharmaceutical companies to reduce the cost of ARVs by amending their patency rights and facilitating the production of generic ARVs at a much lower cost. International pharmaceutical company Cipla, from India, was given the global tender to produce generic ARVs for low- and middle-income countries. The generic ARVs produced by Cipla cost about USD 300 per patient per year, compared with USD 15,000 for the same drugs in their original form. The reduced cost of ARVs facilitated widespread roll out in the public sector (Lucchini, Cisse, Comiti, Gaudry, & Moatti, , 2003; Coriat *et al.*, 2003).

It was not smooth sailing for the NGOs in terms of their relationship with government where the HIV pandemic was concerned, and their relationship was at times

acrimonious. This conflict could filter down and result in the NGOs not feeling welcome by the community they were serving. This was the case with MSF when they introduced comprehensive care for PLWH at the primary health care level in Lusikisiki at a time when the South African government policy was against the use of ARVs. The community had received a lot of misinformation about ARVs and were not immediately receptive of the MSF programme. It was only after they saw the improved health of the PLWH who decided to accept the treatment that they changed their minds (Steinberg, 2008).

Other than provision of funds, Faith-Based Organisations (FBOs) that provide psychosocial support for PLWH need to be acknowledged. This is particularly important because PLWH experience a lot of psychosocial challenges such as stigmatisation because of the disease. FBOs often also provide practical support such as food parcels, help with school uniform and supplies, support groups, and orphan care. This calls for a holistic approach to their care by a team that includes people with expertise in the provision of psychosocial care (Lowther, Selman, Harding, & Higginson., 2014). While the FBOs also have the potential to mitigate HIV infection through prevention and spiritual guidance, it has been noted that their actual impact is limited by the church's difficulties in discussing sexuality, avoiding stigma, handling gender issues and accepting the use of condoms (Mash & Mash, 2013).

## **2.4 The experiences of PLWH in relation to the family, extended family, community and society**

### **2.4.1 The family**

The family forms the immediate natural support when ill health befalls any member of the family. In the case of PLWH who have partners, immediate support is expected from them (Gilbert & Walker, 2009). While families are often known for being supportive of PLWH, in the case of couples, the support depends on the level of trust and on gender-based power dynamics between them. In cultures where wives are expected to be submissive, communication regarding issues like disclosure of HIV status is challenging (Mash, Mash, & De Villiers, 2010). The infected partner may end up hiding their status for fear of the consequences, including violence for the female partner. The first person to get tested is often the female partner, who may

then be blamed for bringing the infection into the relationship. The local culture may condone male infidelity (multiple sexual partners), thus putting them at more risk of getting infected by sexually transmitted diseases, including HIV (Greig, 2003). The lack of support from family members may at times be based on misinformation about HIV infection, as was the case in Lusikisiki in the Eastern Cape where family members who went to be tested for HIV were ostracised and not supported because their action was in contradiction to the perceptions of the family and community about the MSF programme at the time (Steinberg, 2008). For the same reason the infected family member may experience discrimination within the family by being isolated. Family members may avoid physical contact and the sharing of domestic items such as food, utensils and bedding. The family may also not give support to the PLWH because of the general stigma attached to the infection by the community and wider society (Bell, Mthembu, O'Sullivan, & Moody, 2007).

#### **2.4.2 The extended family and friends**

Extended family and friends form an important part of the context immediately surrounding PLWH. The extended family is made up of people who have some blood relationship with the nuclear family. Normally they are nephews, nieces, uncles and aunts, and in the Xhosa community, often have a strong role to play in the life of PLWH. In terms of the experience that PLWH have with extended family, it would also vary in the same way as it does for the immediate family. Both positive and negative experiences would be expected.

Friends are people other than family and relatives with whom PLWH have a close relationship. Primarily the relationship is for emotional and practical support, but is subject to challenges like any other relationship. Extended family and friends often take the role of treatment supporter and have an important responsibility in the care for PLWH.

#### **2.4.3 The community and society**

The community play an important role in the experiences that PLWH go through. Community activist involvement in pressuring governments to provide ARVs was very successful in South Africa and Brazil. The Treatment Action Campaign in South Africa, led by Zackie Achmat, himself living with HIV, was one of the civil society

groups that won a constitutional court case against the government for failing to provide ARVs to PLWH (Nattrass, 2007; Nunn, Dickman, Nattrass, Cornwall, & Gruskin, 2012). This forced the government to roll out ARVs in the public health service in 2003 (DOH, 2003; Heywood, 2009). Brazil also had a similar activist group, which also resulted in the rolling out of ARVs in their public health service in 2001 (Levi & Vitória, 2002; Nunn, Dickman, Nattrass, Cornwall, & Gruskin, 2012).

Cultural practices in the community may also impact on HIV transmission – for example male circumcision among the Xhosas, and female virginity testing among the Zulus in South Africa – have the potential to reduce HIV transmission; the former from the proven benefit of Male Medical Circumcision (Auvert *et al.*, 2005; Bailey, *et al.*, 2007; Gray, *et al.*, 2007), and the latter from preventing HIV infection through abstinence. However the morbidity and mortality related to the complications of traditional circumcision and the violation of human rights related to the virginity testing are a cause for concern and result in tension between the traditional leadership – who consider themselves as the custodians of tradition – and civil society and government, who have a responsibility to protect the mainly young people involved (George, 2008). Traditional leaders influence the community's perceptions and beliefs, and ultimately shape the experiences of PLWH in the community (Campbell, 2010). Traditional leaders can influence the amount of stigma associated with HIV, and how community groups and families handle the issue. The community and traditional leaders therefore have a significant role to play in normalising the lives of PLWH.

#### **2.4.4 Normalisation of life with the virus**

Eventually PLWH may reach a way of living with the virus in that they accept and normalise the virus as one of the factors they must deal with while continuing to pursue their goals and to live meaningful lives. Disclosure of one's status would have been made to those who need to know. In the face of rampant stigma and discrimination, disclosure is selective, even within the family (Ogden & Nyblade, 2005; Ssali *et al.*, 2010; Obermeyer, C.M, 2011). A relationship is developed with the virus in an effort to have control over it (Gilbert & Walker, 2009).

Despite the challenges of living with HIV, some patients are motivated by a desire to live, while others are overwhelmed by the experiences related to the challenges and choose to terminate their lives through suicide. Living for others, often to ensure the growth of one's children to adulthood, are some of the common motivations to live. Resilience to continue with life is developed (Andrews, Williams, & Neil, 1993) as the patient goes through the complex experiences based on systems thinking.

Normalisation is the ultimate result of the interaction of the complexity of experiences related to the taking of ARVs, as explained by systems theory. This is what one would wish for PLWH on ARVs. This state of normalisation is akin to the acceptance stage of loss as originally depicted in the five stages of grief (Kübler-Ross, 1969), but adapted for the experiences by adults of HIV infection (Ross, Tebble and Viliunas, 1989). Given the vulnerability of PLWH, they may feel battered by the challenges of life and oscillate through the stages of loss that precede acceptance, namely: depression, bargaining, anger and denial before finally, acceptance. There is therefore a need for PLWH to continue to be supported in a holistic way by all the role players in their lives in order to sustain their state of normality.

## **2.5 Conclusion**

This Chapter is about the scientific value of the research. The results of a literature review on the experiences of patients with HIV and ARVs were presented. Systems theory was used to create a conceptual model for the structure of this chapter. It presented what is documented in literature about the patient's experiences of ARVs globally and nationally, revealing a knowledge gap in terms of the experiences of patients on ARVs in the Eastern Cape, as shown by the paucity of information in the literature in this regard. This thesis will thus specifically address the knowledge gap about the experiences of the patients on ARVs in the Eastern Cape. The problem statement and the aim and the objectives of the study follow.

### **The problem**

While a comprehensive approach based on a combination of methods can be credited for the achievements made in stemming the HIV pandemic, one cannot ignore the fact that it was the advent of HAART in the early 1990s that really tipped the scale. HIV is now regarded as a chronic disease (WHO, 2002), and the dream of an HIV-free world is

progressively gaining ground. The year 2030 has been targeted to achieve this through the Sustainable Development Goals (SDG) (UN, 2015). Preconditions have been set to achieve this goal, including: 90% of the global population living with HIV infection knowing their status; 90% of people diagnosed with HIV infection receiving ART; and 90% of all people receiving ART having viral suppression by the year 2020 (UNAIDS, 2014). The “treat all” WHO policy, that stipulates the treating of HIV infection with ARVs on diagnosis, irrespective of CD4 count, is one of the strategies for achieving the goal of an HIV-free world by the year 2030 (WHO, 2015). All UN member countries have been urged to draw up and implement programmes to achieve these targets. It can therefore be reasonably anticipated that in the absence of a cure or a vaccine against HIV infection, the current use of ARVs to mitigate the HIV pandemic will continue to escalate.

We are already in a situation where a large number of people in South Africa (3.6 million) are on ARVs. The chronic care model has been extensively applied globally in the management of chronic diseases like diabetes, coronary artery disease, chronic obstructive pulmonary disease, depression, and nicotine dependency (Wagner, 1998). One can anticipate challenges in the application of the model to the care of HIV patients because it does not sufficiently highlight the need to consider the psychosocial and contextual aspects of chronic diseases. While all patients with chronic diseases may have psychosocial and contextual issues, some of the issues related to HIV infection are unique. For example, the rampant stigma attached to the disease. This calls for HIV patients to be cared for appropriately using a bio psychosocial approach, which is not explicit in the chronic care model.

To improve the quality of care, there is a need to understand the psychosocial and contextual issues relating to the experience of HIV-positive patients on ARVs. Insight into these issues was lacking in the country at national and provincial levels, including the Eastern Cape Province, at the time of rolling out the ARV programme nationally in 2003/2004. In this regard, the literature review reveals a paucity of information concerning the Eastern Cape Province. This study, therefore, was planned in 2008 to explore the experiences and perspectives of HIV-positive patients on ARVs who attended the public service health facilities in the Eastern Cape Province. The findings will provide

information to improve the management of HIV as well as the organisation of the HIV programme.

**Key knowledge gaps about the experiences of HIV-positive patients on ARVs who attended public health facilities in the Eastern Cape Province included:**

- How patients incorporated the taking of ARVs into their lifestyle;
- The beliefs and feelings of patients regarding their ARVs;
- The positive and negative experiences of patients attending ARV clinics;
- How others such as family and friends reacted to their taking of ARVs; and
- The socio-cultural and contextual issues that impacted on the patients' ability to take ARVs.

**Aim and objectives**

This study aims to explore the experiences of HIV positive patients on ARVs who attended public health facilities in the Eastern Cape Province. Specific objectives based on knowledge gaps from the literature review were:

- Objective 1: How patients incorporated the taking of ARVs into their lifestyle;
- Objective 2: The beliefs and feelings of patients regarding their ARVs;
- Objective 3: The positive and negative experiences of patients attending ARV clinics;
- Objective 4: How others such as family and friends reacted to their taking of ARVs;
- Objective 5: The socio-cultural and contextual issues that impacted on the patients' ability to take ARVs; and
- Objective 6: To elicit any other unanticipated issues that arose in the patients' context or experiences that were significant to their ability to take ARVs.

It is hoped that any new insights and understanding that develop from the study findings will help to improve the ARV programme and the care of HIV patients in the Eastern Cape Province and beyond.

The next chapter looks at the methodology that was used to explore the experiences of HIV-positive patients on ARVs who attended public health facilities in the Eastern Cape Province.

## CHAPTER THREE: METHODS

### 3.0 Study design

The qualitative study design was used. The experiences of patients in this study context were unknown and therefore had to be discovered and explored qualitatively. It has been noted that where the aim of a study is to “explore” a phenomenon, the need is to understand the phenomenon rather than measure it. The understanding of the phenomenon of experience in this study is from the perspective of the participants. It is defined as what happens to that person through seeing; doing, feeling or living through an experience (Barnhart & Barnhart, 1990). It is influenced by what the person believes. The phenomenon of experience is in essence a rich and multifaceted qualitative phenomenon, which is difficult to represent and measure adequately in purely numerical terms.

Health practitioners, managers and policy makers are increasingly turning to qualitative methods to enhance our understanding of health and health related behaviour, and to improve the management and provision of health services (Brazil, Ozer, Cloutier, Levine, & Stryer, 2005; Green, 2011). Thus the choice of study design was also in keeping with current trends in research of this nature. In this study the experiences of participants included their taking of antiretroviral drugs in their individual, family and community contexts, as well as their experiences of attending the health services for HIV care and access to ARVs.

Four sources of qualitative data were collected and triangulated within the study design:

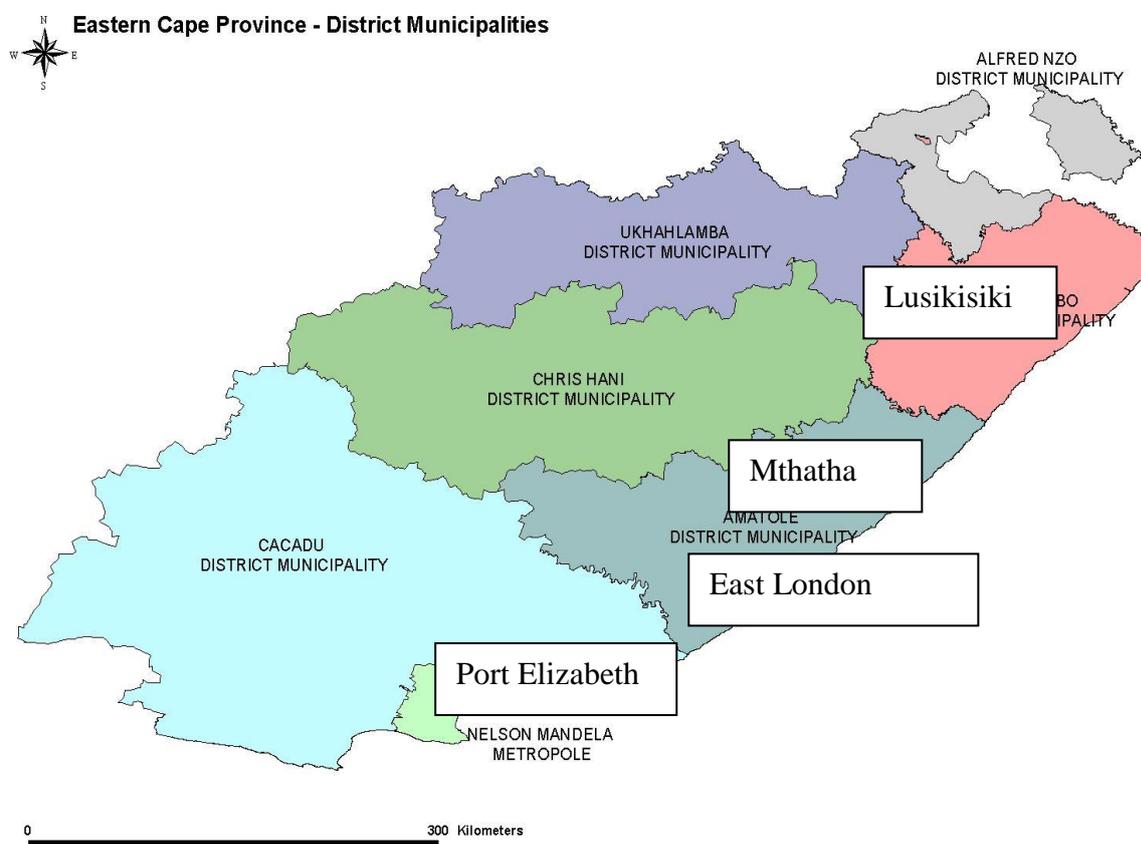
1. The experience of patients as explored through in-depth and focus group interviews.
2. The experience of patients as described in their personal diaries.
3. The experience of the patient’s treatment supporters/care givers through focus group interviews.
4. The experience of the patients through participant observation.

### 3.1 Setting

The study was conducted in the Eastern Cape Province of South Africa which is mainly inhabited by the isiXhosa speaking ethnic group which constitute about 78.9% of the

population, especially in the rural areas. The urban areas are also inhabited by a minority of other ethnic groups. The majority of the population is socioeconomically challenged. Unemployment is very high in the province and is estimated to be about 26%. Most of the population, especially the rural population, depend on social grants and remittances from relatives working in the province and elsewhere, especially in the Western Cape and Gauteng Province which have a high migration rate from the Eastern Cape Province (Statistics South Africa, 2013; Brand South Africa, 2016).

**Figure 3.1: Map of the Eastern Cape**



The HIV and TB Directorate in the Eastern Cape Province Department of Health is responsible for HIV and TB services in the province. Regional Hospitals have HIV clinics which serve as referral clinics for patients from district hospitals and community health centres. The primary care clinics refer patients to the community health centres. At the time the study was done, initiation of patients on ARVs was only done at the HIV clinics at the regional hospitals, but now nurses can initiate ARVs for uncomplicated patients at

the community health centres. The four regional hospitals selected for the study represent the three geographical regions of the Province: northern region – Mthatha Hospital at Mthatha and St Elizabeth Hospital in Lusikisiki; central region – Frere and Cecilia Makiwane Hospital in East London; southern region – Dora Nginza Hospital in Port Elizabeth. Each of the specialist HIV clinics are run by a team composed of general assistants, nursing staff, administrative staff, medical officers and a specialist. They all share the regional hospital pharmacy, except for Mthatha Hospital which has its own pharmacy. The regional hospital HIV clinics refer patients who need further care to the relevant specialist departments at the regional hospital, except St Elizabeth Hospital which does not have all the specialist departments. The patients who need specialist care for a discipline which St Elizabeth Hospital does not have are referred to Mthatha Regional Hospital or the tertiary Nelson Mandela Academic Hospital (Eastern Cape Department of Health HIV and TB Directorate)

My interest in HIV is linked to my general interest in infectious diseases. I developed this interest during my undergraduate training in Uganda where the prevalence of infectious diseases is very high. During the early 1980s I was privileged to be part of a team of scientists who were working on the emerging scourge of HIV infection in South Africa and actually participated in collecting data for the first national prevalence study in 1985. My passionate interest in HIV has continued to grow, mainly focusing on the clinical care of PLWH. My interest in ARVs and the patients taking them is motivated by the fact that ARVs are relatively new in the practice of medicine and there is a lot we still have to learn about them. With the highest population of PLWH on ARVs in the world, South Africa provides the ideal setting for learning about HIV and ARVs.

## **3.2 Selection of participants**

### **3.2.1 Patients**

A purposive sample was selected based on the ability of the participants to provide clearly communicated, information rich data for the study through in-depth interviewing (Suri, 2011; Patton, 1990). They were engaged in general conversation about HIV to assess this ability. Five male and female patients were taken from each of the four regional hospital HIV clinics to make a total of 40 adult patients. In addition, a purposive sample of five care givers of children was recruited from each of

the four sites to give a total of 20 care givers. The participants formed same gender focus groups. Other inclusion criteria for the selection of the participants were: being on ARVs for at least three months; and willingness to participate in the study by signing informed consent. Patients who looked too ill were excluded from the study.

The sample size was based on the experience that usually a sample of this size would be sufficient to qualitatively explore a phenomenon but was open to be increased if more issues were emerging and the interviews continued until a point of saturation was reached (Reid & Mash, 2014)

### **3.2.2 Treatment supporters**

A purposive sample of treatment supporters were invited to participate in focus group interviews. Two groups of six treatment supporters of the same gender, in each of the four sites, were interviewed.

### **3.2.3 Patient medication diaries**

At each of the accredited ARV sites in the Eastern Cape Province, together with the first issue of antiretroviral drugs, patients were given a medication diary, in the form of an exercise book, as part of their routine care. They were to record in the diary, in a narrative style, their day to day experience while they were on antiretroviral drugs. It was left to the patient to decide what to include in the diary. At the next visit to the pharmacy to collect repeat treatment, the medication diary was handed to the pharmacist/nurse. The pharmacist/nurse looked at the day to day narratives in the medication diary and made pertinent comments to the patient on any action that needed to be taken. Patient medication diary records for a period of one month of 25 patients from each of the four sites were randomly selected for inclusion for analysis. The process involved getting diaries from the first 50 patients coming for repeat ARVs. The diaries were numbered 1-50. These numbers were written on small pieces of paper and folded. One numbered folded pieces of paper was selected by the researcher or any of the two researchassistants while blind folded. The diary correlating to the number selected was the first selected diary for inclusion for analysis. The other 24 were selected using a table of random numbers. Monday was the busiest day of the week at all the HIV clinics. One Monday in the month was

selected at each of the clinics to select the 25 diaries. Of the 100 diaries selected from the four sites only 24 had information worth analysing.

### **3.2.4 Participant observation**

The two research assistants recruited for the study spent two consecutive days at each of the four sites as participant observer's details follow under data collection below:

## **3.3 Data collection**

### **3.3.1 Patients**

The patients, care givers (for children) and treatment supporters were invited to participate in in-depth interviews in which their experiences with taking or supporting other people in taking antiretroviral drugs were explored in a quiet, private room using an interview guide (Appendix I & H). The questions in the interview guide started with general introductory questions followed by more specific questions based on the study objectives, which were then followed by probes and further questions to give depth to the responses. The interviews were conducted by the two trained research assistants who were honours students in psychology and the researcher. The participants had a choice to be interviewed in either English or isiXhosa. Acutely ill patients and those who did not consent to participate were excluded from the study. The interviews were recorded with a digital tape recorder and transcribed verbatim. Permission was obtained from the participants for tape recording.

Data were also collected from patients using focus group interviews. The focus group interviews took place in the quiet and private room where the interviews took place. One of the research assistants conducted the focus group discussion for each gender group using an interview guide, while the other research assistant recorded the interview using a digital audio recorder after obtaining consent from the patients, and also took notes on the focus group interviews. The interviews were later transcribed verbatim.

### **3.3.2 Treatment supporters**

The focus group interviews were conducted by the researcher and the research assistants in the language preferred by the majority of the group, using an interview guide (Appendix I), and followed by probes and further questions where appropriate

to achieve in-depth understanding. Interpreters were used where necessary. The focus group interview was recorded by one of the research assistants using a digital recorder; so that the facilitator could concentrate on the discussions. The research assistant also took field notes. The recorded data supplemented by the field notes was subsequently transcribed verbatim.

### **3.3.3 Patient medication diaries**

The narrative data about the daily experiences of the patients was recorded in an exercise book given to the participants when they came for care and collected from them during their next monthly visit. The regimen the participants were on was also recorded in the book. This was part of the care for patients on antiretroviral drugs, using forms designed for the purpose and collected from the patients by the pharmacist as they collected their monthly supply of treatment. This practice was not standard across the province, hence the decision to use exercise books. The day to day experiences diarised by the patients were typed and analysed together with the data collected using the other methods, as below. The details of the selection of the diaries are as above.

### **3.3.4 Participant observation**

The “mystery shopping” technique (Cunningham, Green, Miles, & Rigby, 2005) or alternatively the “pseudo-patient” (Bulmer, 1982) was used for data collection. The two research assistants who were recruited for the study, both with a psychology background, did the data collection after undergoing training in participant observation by the researcher. The process involved the research assistants sitting with patients as they waited for services at different points of service delivery within the HIV clinic and at the pharmacy. The research assistants pretended to be patients. Where the pharmacy had a mixture of patients the research assistant sat next to or near a patient on antiretroviral drugs who would have been identified from the HIV clinic. As the research assistant sat with these patients, she had a prolonged engagement with them listening to them as they spontaneously talked to others about their experiences with antiretroviral drugs and interacted with them where necessary to gain an understanding of the issues that they raised. Direct observation of how the system was operating from the researcher’s perspective as a pseudo-patient was also noted. The participant observation was based on a guide (Appendix J), with which the

participant observers were thoroughly familiarised before the study as part of their training. The observation took place for two consecutive days at each site on any of the days except Fridays which were generally not busy and half day for patient care. Field notes on their observations were unobtrusively recorded from time to time during the course of the observation. The notes were a thick description of what had been seen or heard rather than interpretive. The observation, as outlined in the guide, covered the physical and social environment of the clinic; interactions between patients, staff and others; the activities going on; verbal and nonverbal communications; and any other observations of note. The observers were also required to record how they were feeling as they did the observation, and how that could have influenced their observation. The participant observers were required to be disciplined and conscientious in taking detailed field notes and verbatim quotations that captured the participant's views in their own words. Neither the patients nor the staff at the clinic or pharmacy knew the identity of the participant observers to avoid influencing their actions or what they talked about.

### **3.3.5 Training of the research assistants**

The research assistants were Honours Post Graduate Psychology students who were also doing their own research projects for the course. They had already covered research methodology and other basics of research in their programme. The training they had with me included introduction to research including research methodology with emphasis on qualitative research and protocol training related to this project. Emphasis in the training was put on making sure they understood what was expected of them as research assistants. Role plays were done by them to facilitate their training.

### **3.3.6 Reflexivity**

The researcher, having vested interest in HIV Medicine, could have unintentionally influenced the interviewees in their responses to the questions, as could the other interviewers. This had the potential to bias the collection of data, thus affecting the quality of the data and the validity of the study findings. However, the use of four different methods of data collection for triangulation was to ensure consistency in the data collected and minimise bias. One had also to make a conscious effort to avoid influencing the responses of the participants. The research assistants were Honours

Psychology students who were non-medical and were having their first encounter with a large number of HIV positive patients. The experience helped to raise their awareness about the magnitude of the HIV pandemic and the experiences of PLWH. It reminded them of their own vulnerability to the infection and the need to avoid getting infected. They were emotionally pained by some of injustices the patients experienced while in the care of health care providers. In the anticipation of such feelings affecting the quality of data collected, they were continuously reminded to maintain neutrality in the course of data collection. A debriefing session was held with them at the end of each day where they were able to share their feelings and were counselled when needed.

All methods of data collection were piloted at Mthatha Hospital HIV Clinic to resolve problems arising before the implementation of the study. The pilot also served as part of the training of the research assistants by the researcher. At the end of each day of data collection, I had a meeting with the research assistants where peer briefing and member checks took place to ensure data credibility and I kept an audit trail of what was happening on a day today basis.

### **3.4 Data analysis**

The qualitative data from the in-depth interviews, focus groups, diary narratives and participant observation were transcribed verbatim from the audiotapes and analysed by content thematic analysis, using ATLAS-ti Version 6.2 computer programme. This was preceded by reviewing of the transcripts for completeness and accuracy by reviewing the audiotapes where applicable. The steps involved in the analytical process were:

- a) Immersion in and familiarisation with the data by reading the text from the data collected.
- b) Construction of a thematic index with a list of codes organised into categories (Appendix M).
- c) Application of codes to all the qualitative data sources in Atlas-ti.
- d) Collation of data with the same codes in a specific family within Atlas-ti and creation of an output as a single document (chart) that could be saved and printed.
- e) Interpretation of the chart to identify the range of opinions or experiences within specific themes and to look at the relationships or associations between themes.

The researcher was trained in the use of ATLAS t.i by a service provider.

### **3.5 Ethical considerations**

Signed Informed Consent was obtained from all participants before the interviews and the focus group discussions (Appendices F and G). The participants were given a copy of the signed consent form. Confidentiality with respect to the identity of the participants and the information shared was ensured. During the focus group discussion participants were not referred to by their real names, but designated A, B, C, D, E, and F and called according to the designation given to each of them. The research assistants acting as pseudo patients had ethical clearance. The hard copies of the data collected was kept under lock and key at all times and only accessible to the researcher and the research assistants. The soft copies were password protected. The data collected and audio files will be archived by the researcher for at least five years after dissemination of the findings. Permission was obtained from the Provincial Department of Health for carrying out the study on state patients and having access to patient records through the Director of Clinical Governance of the respective hospitals. Ethics approval was obtained from the Research Ethics Committees of the University of Stellenbosch, (N06/10/197) under which the study was done, and Walter Sisulu University (00039/08) as the study setting was within its jurisdiction for ethical clearance.

### **3.6 Conclusion**

This chapter described the study design, methods, data analysis and ethical considerations used in this thesis. The next chapter presents the results of the study.

## CHAPTER FOUR: EXPERIENCES PATIENTS ON ARVs RELATED TO PERSONAL ISSUES

### 4.0 Introduction

Chapter Four presents the findings, at individual level, of how people experienced the process of being tested, diagnosed, and treated for HIV, and how they coped with their HIV status. Their experiences are covered under three main themes:

- The experiences in relation to the diagnosis of HIV infection;
- How patients incorporated the taking of ARVs into their lifestyle; and
- Beliefs, feelings and practices of patients, treatment supporters and caregivers regarding ARVs.

### 4.1 The experiences related to the diagnosis of HIV infection

#### 4.1.1 Testing for HIV

The diagnosis of HIV infection was based on a positive test result. As there was no cure for the disease, being HIV positive was associated with dire consequences related to suffering and ultimate death. The knowledge of the benefit of ARVs in controlling HIV was probably not so widespread at the time. The fear for HIV infection was reflected in the way people reacted when they tested positive. It varied from acute stress to suicidal ideation, and even actual suicide. The concerns about their families as well as the consequences of the loss to the family were also articulated.

*“After I heard about my status I cried, thinking that I am going to die. I was unable to sleep. I was thinking about my children more than anything else. My worry was that I was not sure about their status and I had a picture about Nkosi Johnson. [A South African HIV/AIDS child activist who was born with the virus and died at the age of 12 in 2001.]” (Patient, Mthatha)*

*“I experience loneliness and thoughts that does not stop.” (Patient, Mthatha)*

*“Do you know in our village there is a girl who once killed herself and her four children ... She took the liquid that is used to clean the tank and went to a distant place from her home with the children and drank that liquid there. When people discovered they noticed that here she was dead with the four children lying in different places ... Fortunately she had written a letter and in that letter she had written that she didn't want her children to suffer after she had gone.” (Caregiver, Lusikisiki)*

Rather than face the consequences of the knowledge of a positive test result, many people opted to not get tested despite the various campaigns for them to do so. Patients also got involved in the campaigns for people to learn their HIV status through testing so that they could access cares early enough to avoid complications. Those who got tested tended to do so because of their partner being positive, or as part of routine antenatal testing during pregnancy. Help was at hand to support some of those who went for the test.

*“I feel for people who are still unaware of their status, more especially this festive season, they are going to be carried by the wheelbarrow just like a dog if they do not take care of themselves ... Is there a person who is still afraid of this virus, I feel for her or him. If my cousins were wise enough and tested themselves early, they would have been alive and dancing with me now. The only thing that was needed to them is to take the ARVs. I miss them. May their souls rest in peace ... I motivate you people, talk to your relatives, educate them on ARVs, motivate them to come and test themselves so that they can be helped before it is too late.” (Patient, Mthatha)*

*“So when I saw those pills [on him] I decided that even myself I am going. I won't stay at all, but I said to myself that I [would] tell him that I have seen these ARVs [on him], and I discovered that he has been on ARVs for three months. Also I had heard that when you sleep with a person [who is on ARVs] ARVs, by so doing they [ARVs] get into your system even if you are not using them. I said [to him] I don't want to die, let's go to the clinic so that I can get tested.” (Patient, Mthatha)*

*“My wife was pregnant and she went for [her] monthly check-up, and was tested positive. I was at work then, she phoned me and I couldn’t believe it. I told my colleague, only to find out she [my colleague] was having HIV and AIDS, and it had been five years now. She was very supportive, she accompanied me to go and see my wife. I tested myself and it was negative. I am still waiting for six months so that I can go and test again.” (Patient, Mthatha)*

#### **4.1.2 Acceptance of the positive test result**

Acceptance of the positive HIV status was considered to be important for the ARVs to work. This made sense because one is unlikely to adhere to treatment for a problem one has not accepted. This was also important for the normalisation of their lives as PLWH. It was easier to accept a positive result if one anticipated it. In this case one would have had a chance to prepare for acceptance of the results. Having another family member on ARVs facilitated the acceptance of the positive test results because of the anticipation that support could be at hand when needed. Having accepted their own results they could support and inspire their peers who had not accepted their results to do so. Peer education to encourage those who had not accepted their HIV status happened in the clinic.

*“I notice one thing, if you have accepted your sickness the drugs assist you a lot in improving the situation.” (Patient, Mthatha)*

*“I suspected I was positive so when the result came I accepted it” (Patient, Mthatha)*

*“My child is not the only one at home taking ARVs, my sister is using them [too], so that is why we accepted it so easily and we take things slow now.” (Lusikisiki Caregiver)*

*“We are all HIV positive here [at the clinic], there is no person who is queuing for someone else; and we asked for it. Is there a person who still fears the HIV and AIDS?” (Patient, Mthatha)*

### 4.1.3 Disclosure of HIV status

Disclosure of one's HIV status was a process that was often preceded by apprehension. The need to disclose, if found positive, was at times a barrier to getting tested. After testing positive there was the possibility of taking ARVs, which could also inadvertently disclose one's status. Delay in accessing care could have dire consequences.

*“What worries me a lot is that the people who are working do not want to test or to take ARVs because they are afraid to be known of their status, so now they end up dying.” (Treatment Supporter, Lusikisiki)*

Disclosure was largely selective – even within the immediate family – and definitely within the extended family, friends and wider community. Public disclosure was not popular. Even if one accepted one's status, this did not necessarily mean that one was ready to disclose to everyone. There was anxiety that one's status would be shared with others who one was not keen for them to know one's status. Selective disclosure was also related to lack of or inconsistent support from specific people, as well as widespread stigma and discrimination against people living with HIV. However the drawback of selective disclosure was the potential to interfere with adherence because the ARVs would then be hidden or taken secretly; or the prescribed recommendations, such as taking ARVs after food, may not be followed.

*In one clinic a relative of one of the patients was shocked to see her, as she had not disclosed her status; and she asked, ‘What are you doing here, are you sick all along?’” (Patient, Mthatha)*

*“From where we stay it's only me and my partner who are aware about the kid's status, not anyone else. When we come to fetch his treatment people only know that he is coming for chest check-up.” (Caregiver, East London)*

*“One priest at Slovo village once said in the church, ‘All those who are HIV positive stand up I want to pray for them.’ I told myself that I am not going to do that. All those who knew my status looked at me, and I never stood up.” (Patient, Mthatha)*

*“When I did tell my friend, who is my neighbour, about not telling my in-laws about my status because they will talk too much, she advised me to take them [ARVs] and keep them at her home so that when they are around I should just go there and drink them [ARVs]. That is not good for me at all. At times I take them even if I have not eaten.” (Patient, Port Elizabeth)*

Conversely, there were those who saw value in disclosing their HIV status for the benefit of getting support, and this particularly facilitated adherence to their ARVs. The more one disclosed, the more support one received. It also made them feel free to share their experiences with others. This facilitated peer education. The HIV clinic provided fertile ground for such education, where patients were not self-consciousness about their HIV status.

*“When I heard about my status, I locked myself in my room for two weeks. The person I [then] told was my mother. She cried, and by that time I was strong enough to handle everything.” (Patient, Mthatha)*

*“I for one have no problem with that; I am a kind of person who is outspoken. I told everybody, even the visitor, that at such-and-such a time I will take my pills, so remind me. I am reminded even by the kid; I just teach him not to take them, but to bring them to me. If I am going out I take some with me which is enough for the trip. I am not hiding it at all.” (Patient, Port Elizabeth)*

*“I told everybody at home about her [the child’s] status, so we are reminding each other [to take the ARVs].” (Caregiver, Port Elizabeth)*

*“The day I came here I was motivated by my sister over there, she was disclosing and telling us about where she came from with HIV; and I told myself that what is so difficult for me, not to be like her.” (Patient, Mthatha)*

#### **4.2 How patients incorporated the taking of ARVs into their lifestyles.**

To ensure adherence to ARVs, patients were advised to use a method (or methods) they could incorporate into their lifestyle. Patients used both technological and non-technological means.

#### 4.2.1 The use of technology

The use of mobile phone alarms to remind patients to take their ARVs was commonly practiced, as mobile phones were widely available even in the rural and poor communities. They were commonly-used by both patients and treatment supporters.

The fact that mobile phones can be used to set time, have an alarm, can be used for verbal and written communication, and are portable and affordable, made them a popular method for reminding patients about the time for taking their ARVs. The treatment supporter may also set his or her own mobile phone alarm to remind the patient when it was time to take treatment. When the patient's mobile phone was not functioning (such as due to a low battery), the patient then still had the treatment supporter as a backup to reminded him. This method worked particularly well for couples, where the partner was also the supporter.

*“I bought this phone so that I can set the alarm as the reminder.” (Patient, Lusikisiki).*

*“I am setting the phone alarm and once it rings, I give her.” (Caregiver, Port Elizabeth)*

*“What I do since she doesn't stay with me is that, we told one another that when you see a call back [‘Please Call Me’ text] you should know that it's time to take treatment, the same story when it's in the evening.” (Patient, Mthatha)*

*“We are setting our phone alarm.” (Patient and treatment supporter for spouse, Port Elizabeth)*

One of the disadvantages cited was that the alarm could ring at inconvenient times, and could even inadvertently disclose their status.

*“He uses a phone to remember, but he told me that we should not both use the phone because the alarm will ring even if we are in some places; and he said he will call me even if he is at work so that I can take them, he would buzz me when it is time.” (Patient, Mthatha)*

A clock or watch alarm was used by some of the patients, but not as frequently as the use of mobile phone alarms. The possession of watches and clocks has generally declined since the advent of mobile phones, as they have the function of keeping time.

*“I use the watch. I take them at eight in the morning and at eight in the evening so I always make sure that around those slots I am close to home; and when I am going out of town I take them with me.” (Patient, Lusikisiki)*

*“I am setting the alarm at 05:45, I am putting them [ARVs] in the water so that at 06:45 he can drink them before he eats. Again at 08:00 he should take his Bactrim. He is taking them at 06:45 in the morning, and again at 06:45 in the evening he is taking the other one. So I should not miss a minute.” (Caregiver, East London)*

A few patients also used the radio to remind them. The use of a radio to remind patients when it was time to take ARVs was often linked to the time that regular programmes were broadcast. However, radios were not used as frequently as the mobile phones. The use of radio compared to mobile phones could have something to do with the fact that they were generally kept at home and could not easily be moved and used elsewhere. Although many mobile phones did have radios, it was not always possible to keep the radios on in public places.

*“At home it is even known by a child who is two years old. When it is seven they tune in to the seven [o’clock] news and say ‘seven treatments’; and when it is eight they say, ‘eight treatments’. At eight in the morning, they already know it, even myself I know it by heart.” (Patient, Mthatha)*

A pill calendar displayed in a frequently occupied part of the house was also used as a reminder. Compared with radios, the advantage of pill calendars was that they could be folded and taken wherever the patient went.

*“The reason for me not to forget is that I am putting her calendar on the fridge and on the room divider. The other one I have photocopied it so that I can always have it wherever I go. Every time I open the fridge I see the pill calendar.” (Caregiver, Port Elizabeth).*

Pillboxes are widely advocated for use by patients to facilitate adherence, although only two people who participated in this study used them. This could be related to their scarcity.

*“I used to forget them, but now I am using my pillbox. I have two of them, the one in the bag and the one that I put next to the light switch. When I switch off the light I see it.” (Patient, Port Elizabeth).*

*“No, she is not forgetting them; when I am not at home and when I come back and check I find that she has taken them. She is having a pillbox so I keep on checking it.” (Treatment Supporter, East London)*

#### **4.2.2 Non-technological means**

Some of the patients believed that they had internalised the time of taking their ARVs such that it just became integrated into a habitual routine as part of the day. The “feeling” when their ARVs were due was also related to specific times. Those who used this method strongly believed that it worked, and even encouraged others to use it. This method may have been perceived to work based on estimated time for taking the ARVs. But for the ARVs to work optimally, the exact times for taking them have to be followed. Only using a watch, clock, mobile phone or any other device that can measure time can ensure this. This therefore casts some doubt on relying on this method on its own. The “feeling” approach could possibly be used in conjunction with the use of a time-measuring device.

*“It is in the head, I know that at six [in the morning] it is time for the pills, and again in the evening at six I eat and drink my pills.” (Patient, Lusikisiki)*

*“I trained him, now it’s in his head, he is not forgetting. He is schooling so at seven o’clock he reminds me to give him the pills.” (Caregiver, Lusikisiki)*

*“It has entered my system because he is no longer reminding me.” (Patient, East London)*

*“We use nothing to remind ourselves. It’s just in our heads and he knows his time for taking treatment. He is clever, that one. We remind each other.”* (Caregiver, East London).

*“It is in my mind, I don’t want to depend on the cellphone because when the battery goes off what are we going to do?”* (Patient, Port Elizabeth)

Comorbidity with other conditions, which requires additional treatment, made it more difficult to solely rely on memory, instinct or habit. This could have been due to memory overload and also the brain not functioning optimally when the patient was not well, particularly when the brain was affected. Indeed the memory improved as the patient became better.

*“I was unable to remember when I was still new in the programme; it was at that time I was diagnosed with TB Meningitis and I would forget. When I stopped using TB treatment I began remembering taking ARVs. I know my time of taking treatment that it’s seven.”* (Patient, Mthatha)

Some participants felt symptoms “reminding” them of when their treatment was due. Could it be that some of the patients developed a feeling akin to “addiction” to the ARVs, and were having withdrawal symptoms due to subtherapeutic blood levels, as the symptom(s) seemed to improve by taking the ARVs? The use of symptoms by patients to remind of when their ARV treatment is due needs to be explored further.

*“But what happens now to me, if I am outside doing whatever I am doing I normally feel [a] headache when it is time and I would stop everything and take my treatment.”* (Patient, Mthatha)

*“My body reminds me – I feel dizzy, cramps and [a] headache, and I would know that I have to take my pills.”* (Patient, Mthatha)

*“Even if it’s eight o’clock and there is no power, I will feel [a] headache and I will know that it’s time. I just say, ‘my pills’, and they normally bring me and they would*

*ask me whether I haven't forgotten. Even when if I am rushing to town, I would put my pills in my bag, I remember that I have got pills in it.*" (Patient, Mthatha)

*"When it's that time you normally take treatment you just become dizzy and immediately after taking them you feel better. At times even if you delay a bit thinking you will take them later, the bad feeling persists until you take them."* (Patient, Mthatha)

Family members or treatment supporters were often involved in reminding the patients about their treatment. Under normal circumstance the family provides the immediate support when one of them is not well, so one would expect them to do the same for the family member who is on ARVs. Others outside the family were also involved in giving treatment support. This method was often combined with the use of technology to remind them. The support was preceded by disclosure of status as previously mentioned.

*"My husband doesn't forget, he warms food and dishes it out and after that he takes treatment. Even myself I am reminded by him, [I] have no problem."* (Patient and treatment supporter, Mthatha)

*"I am reminded by my kids I am staying with."* (Patient Lusikisiki)

*"Her cousins and siblings always remind her when it is seven o'clock."* (Caregiver, Lusikisiki)

*"Yes, I used to forget it but my treatment supporter used to remind me, she is my sister."* (Patient, East London)

*"I am reminded by my sister, she is giving her child too."* (Caregiver, Port Elizabeth)

*"I told everybody at home about my status so we are reminding each other."* (Caregiver, Port Elizabeth)

Time-linked activities that occurred regularly were used as reminders for taking treatment.

*“What I used to do is that when I am going to the prayer gatherings I took them at 7:30.” (Patient, Lusikisiki)*

### **4.3 Beliefs, feelings and practices of patients/ treatment supporters/caregivers regarding ARVs**

Beliefs, feelings and practices of patients, treatment supporters and caregivers regarding ARVs were broadly divided into positive and negative. The former referred to beliefs, feelings and practices that were considered to be beneficial regarding the management of HIV infection, while the latter were considered not to be beneficial.

#### **4.3.1 Positive beliefs, feelings and practices about ARVs**

The benefits of taking ARVs were widely acknowledged. There was a huge difference in their health before and after the inception of ARVs. The patients felt better, stronger, and some felt more beautiful. The CD4 count also increased, thus improving their immunity and making them healthier. Being healthy enabled them to plan for the future as they had regained hope to live longer compared with what they had anticipated before taking ARVs. They felt that for the ARVs to work, one had to believe in them. This could be related to the placebo effect of ARVs. The patients' healthy appearance reduced the misgiving of others about them being HIV positive. All these benefits of the ARVs motivated the patients to adhere to their ARVs.

*“My belief is that they make a person to recover. I used to hear people saying different things about them, but I know them from experience. They work, I was a person who would always feel weak, I would have this and that but the ARVs work a lot.” (Patient, Mthatha)*

*“I expect them [ARVs] to boost my CD4 count and stay healthy.” (Patient, Lusikisiki)*

*“There are two newlyweds in my community, they are both taking ARVs, but you can't say that, they are beautiful, fat and healthy.” (Patient, Mthatha)*

*“I believe that I am where I am – fine and healthy – because of the ARVs, so I can’t stop taking them.”* (Patient, East London)

*“I expected him to die but he survived, now I want him to get well and grow. I want him to go to school.”* (Caregiver, East London)

*“I strongly believe that they work for people who believe in them, to those who want them to work for them.”* (Caregiver, East London)

While the link between the increase in CD4 count and the improvement in health was welcome, the fact that it was used for deciding whether or not one should have a social grant was challenging for some, as they could lose their grant or not be able to apply for one when the CD4 count improved. On the contrary, some felt that the rules regarding social grants were not fairly applied because in their view, it was correct for the grant to be stopped for those whose CD4 count had increased to acceptable levels.

*“The positive thing about these pills is that they are very strong. My viral load was very up and the CD4 count low, but now the CD4 count is very high and that is very good, so much that I am unable to get grant because of the high CD4.”* (Patient, Lusikisiki)

*“I think that even the CD4 count of those who were diagnosed positive before us has increased, but they still get the grant.”* (Patient, Mthatha)

In the desperation that comes with poverty, the social grant being dependent on CD4 count could have lead some of the patients to not adhere to their treatment so that their CD4 count remained low, thus entitling them to continue getting the social grant.

After starting ARVs, the appetite of the patients improved. A good appetite was also associated with being in good health, especially when it was accompanied by weight gain.

*“They (ARVs) are helping a lot because you could notice the increase in weight and appetite.” (Treatment supporter, Port Elizabeth)*

*“It is true ARVs lead to weight gain. I was weighing 30 kg, but now I am weighing 60 kg.” (Patient, Lusikisiki)*

*“I do not have a problem after I have taken my medication except that I had a lot of appetite. And another thing is that my body is very active.” (Patient, Mthatha)*

*“Now I wake up in the middle of the night and eat, and I am the first one to wake up in the morning and eat.” (Patient, Mthatha)*

The increased appetite associated with taking ARVs created its own challenges because of food insecurity due to high levels of poverty. The need for food was also increased due to the fact that some ARVs had to be taken after food. There was therefore an outcry from the patients for the challenge to be addressed. The government was expected to attend to the challenge. The relationship between taking ARVs and the need for food security involve a number of factors that collectively constitute a complexity as depicted by systems thinking. This should thus be kept in mind in addressing the challenge.

*“What I want the government to know is that we are hungry and ARVs are making us even hungrier.” (Patient, Port Elizabeth)*

*“When you wake up you become very hungry especially when you have taken Stocrin the previous evening.” (Patient, Mthatha)*

*“I am so hungry in such a way that I have a headache that feels as if I am having a plastic full of water inside my head. And another thing which contributes to this head is that my treatment has ended two days ago and I am afraid to take Dispirin [an aspirin] before asking my doctor. It gets worse when I am hungry.” (Patient, Mthatha)*

One of the patients associated sexual arousal with taking ARVs. It was difficult to tell whether this was a direct effect of the ARVs, or if it was actually as a result of the

general improvement in the health of the patient that lead to normal functions of the body, including the restored sexual function.

*“At night erection becomes so strong, but sometimes it stops. And after that urine is so hot when you pee.”* (Patient, Mthatha)

The painful micturition could be pathological.

ARVs were associated with increased longevity, enabling patients to fulfil their aspirations of parenting their children. This was a very strong motivation for adhering to the ARVs. It was very significant at the time when HIV infection was associated with poor prognosis and hopelessness.

*“But what I like about these pills is that when you take them you die at a time you were going to die, your death is not influenced by your HIV status.”* (Caregiver, Lusikisiki)

*“I expect to live a longer life and I know that I will still fulfil my dreams that I had before I got sick.”* (Patient, East London)

*“I now have hope to live long enough to take care of my children until they are adults.”* (Patient, Lusikisiki)

Another very strong motivation for taking ARVs was the fact that patients looked so healthy that their HIV status could not be presumed from their appearance.

*“They do not believe me when I say I am an HIV positive person. They say I am lying because I have nothing that suggests [it].”* (Patient, Mthatha)

*“I believe that they are helping. Originally I am from Cape Town and what is happening there is that there are day care facilities that take care of sick people. I used to visit them a lot and people there are healthy, and strong; you can’t say they are [HIV] positive.”* (Patient, Port Elizabeth)

For those who believed in God, prayer was considered important for augmenting the effects of ARVs. Prayers were conducted every day in all public health facilities in the Eastern Cape Province. Their belief in God could have boosted the placebo effect of the ARVs.

*“One such praying session was taking place at the Mthatha Hospital HIV clinic where on this particular occasion everyone in the clinic was asked to pray individually after [the patients] singing, ‘Fulfil your promise Lord’. [Someone then prayed] ‘We pray for those who lose hope, every day we are burying, every day we are crying and our hearts are always in pain, we are also dying on the roads due to accidents.’” (Patient, Mthatha)*

#### **4.3.2 Negative beliefs, feelings and practices about ARVs**

While the benefits of ARVs were appreciated, there was worry about the sustainability of the stock due to the historical inconsistencies in government policies, and the fact that they were expensive.

*“I guarantee the ARVs, but I am worried should they ever be finished because there is a rumour that now that Manto Tshabalala Msimang [South Africa’s former Minister of Health] is dead, ARVs will be no more also.” (Patient, Mthatha)*

*“It is also said that they will also be finished because [South African President Jacob] Zuma is in power.” (Patient, Mthatha)*

*“It is said that it will be finished since it costs a lot of South African money.” (Patient, Mthatha)*

There was a growing illicit market for ARVs, especially Efavirenz, to enhance the effect of some recreational drugs. This posed a risk for patients on ARVs as they were in danger of being robbed, and also risked injury in the process.

*“Be careful of the thugs, they are taking these ARVs because they mix them with dagga. They robbed a man at Ngangelizwe location and took the ARVs.” (Patient, Mthatha).*

Some PLWH got involved in this illicit trade of dealing in ARVs by becoming suppliers. They too obtained their supplies by any means possible, including crime.

*“People are so desperate for these ARVs, so much that one of the patients who was not yet on ARVs forged the signature of a nurse so that he could be given the pills. Unfortunately he was caught and as we talk he is in jail.”* (Patient, Mthatha)

#### **4.4 Side effects of ARVs**

A number of patients experienced various forms of discomfort while on ARVs, which they interpreted as side effects. Associating ARVs with side effects was already well known to most people; as the initial delay in introducing ARVs in the public sector in South Africa was because ARVs were considered too toxic for the management of HIV, and the belief was that it would cause more harm than good. By the time this decision was reversed that perception was already established, and it continued to be held as one of the prominent drawbacks of being on ARVs. Patients were therefore sensitive to any deviation from normal that they experienced while on ARVs. The central nervous system, gastrointestinal, musculoskeletal, skin as well as ear, nose and throat side effects were the most common.

##### **4.4.1 Multisystem side effects**

Multisystem side effects resulted from ARVs affecting different systems of the body. It was not uncommon to have a number of side effects in the same patient, probably because of the combination of several drugs. The patients were on Highly Active Antiretroviral Treatment (HAART), which necessitated them to be on a combination of three or four ARVs to achieve the efficacy expected of them. The patients, felt drunk, had rash, painful feet, swollen feet, numbness of the feet, stomach full of air, reduced appetite, itchy eyes, headaches, strange dreams, difficulty in swallowing the ARVs, anger and stress. Because of the benefits, most patients continued with their ARVs despite the side effects.

*“These pills cause rash, ring worms, lumps and even anger. Even if the weather has changed you become drunk, especially with 3TC.”* (Patient, Mthatha)

*“They didn’t make me so sick that I would even sleep on the floor; but with me they make me have stress, I would also feel that they haven’t gone down my neck [throat] and they take time to go down my neck [throat]. Another thing, my stress develops when I have heard some bad news. Also I have problems of swelling of the feet and [a] painful right leg.”* (Patient, Mthatha)

*“My feet are painful, I can’t walk with them without pain, and at times they would feel numb. At times I would feel like a person who is choked. Ever since I started ARVs I have that problem, but I haven’t stopped using treatment. I told them here at the clinic, they said I would be fine, but there are no changes.”* (Patient, Mthatha)

*“I am extremely sleepy, got bad dreams. The following morning my eyes were itching, my stomach has a lot of air, my body is very tired and weak, I sneeze, and the nose is itchy.”* (Patient, Mthatha)

*“My body is painful, I don’t have appetite, and I have [a] headache.”* (Patient, Mthatha)

Anger and stress were mentioned as side effects of the ARVs. Both are emotional reactions. This could also be related to the psychosocial reaction to loss (or grief) caused by the positive HIV status, or both. Unfortunately, at one of the clinics this was ignored by the healthcare provider attending to the patient, reflecting a biomedical mechanistic approach to the patient rather than a biopsychosocial approach, which is more in line with systems approach to patient care.

*“Yes, another thing is she quickly becomes angry.”* (Treatment supporter, Mthatha)

*“They cause problems for me, if there is something that hurt me, I would feel very itchy, [and] I would be angry such that I would break anything in the house. The radio volume should be low. Another thing is the feet problem. I reported them here at the clinic until I gave up. They do give me treatment, but it doesn’t help me.”* (Patient, Mthatha)

*“I become so aggressive in a way that no one can talk to me in any manner, I don’t want any noise; feel like being alone in a quiet place.”* (Patient, Mthatha)

#### **4.4.2 Skin and body shape effects**

The side effects related to the skin commonly presented as rashes, boils, itching, and changes in skin colour and hair. While the other side effects mainly caused discomfort, the skin and hair changes were a concern because of the disfiguring effect. More seriously and worrisome was the inadvertent disclosure of their status and the resulting consequences of stigma and discrimination that was caused by disfigurement.

*“After starting the pills, I developed pimples on the skin. They were itchy and painful.”* (Patient, Mthatha)

*“I developed itchy rash on the face. They gave me Allergex and it became better.”* (Patient, Lusikisiki)

*“I have noticed two dark spots that developed, but they are not too much.”* (Patient, Port Elizabeth)

*“I have boils sometimes, they are painful and they just burst on their own at times. Other times I have to be operated at the hospital for them to become better.”* (Participant observation, Mthatha)

*“My complexion is light, but since I started ARVs I became dark, but slowly I am becoming lighter each day. The dark complexion that I developed after starting ARVs was making me feel so bad and I was always frustrated because of that.”* (Patient, Port Elizabeth)

*“The issue of my body change in complexion made my CD4 count to be up and down since 2009 because I was always frustrated.”* (Patient, Port Elizabeth)

One patient’s skin complexion had changed so much that she had to carry her identity document with her at all times so that she would not be mistaken for a foreign

national. Africans from other sub-Saharan Africa regions of north of South Africa are generally perceived by South Africans to have a darker skin. With xenophobia raising its ugly head every so often in South African, local nationals do not like to be mistaken for foreigners.

*“There are ups and downs of taking the ARVs because they have changed me a lot. This is not my complexion that I was born with. In 2005 when I went to town I used to take my identity document with me because people were unable to differentiate me from people from other parts of Africa. My skin was dark and my hair was changed.”*  
(Patient, Port Elizabeth)

The participants had various changes in body shape that were attributed to ARVs. These changes included bulging of the abdomen, big breasts, thin arms, flattened buttocks, thin lower limbs, a hump on the upper back and facial changes that made them look older than they were. The change in body shape was often attributed to a capsule that was one of the drugs in the combination with the other ARVs. This capsule was most likely d4t as it was the only ARV in capsule form in use in public service at the time, and it is indeed known to have the mentioned side effects on body shape.

*“There is a pill, it’s a capsule, and what it does is to take the fat from one place to another where it likes and it’s where I get frustrated because my shape has changed.”*  
(Patient, Port Elizabeth)

*“These side effects are giving people a wrong impression about us, I don’t like it when the person is going to call me grandmother because I am not that old and the person is calling me that because of the changes in my face.”* (Patient, Mthatha)

*“I am developing a [big] stomach and the bottom of my feet is becoming small. People used to ask whether I’m pregnant or not? I would tell them that I was pregnant, but would never give birth”* (Patient, Mthatha)

*“The only change that I had after I have started taking ARVs was the side effects. I developed huge breasts, the bottom of my legs got slim and my bums got slim too. I*

*was taking d4t, 3TC and Nevirapine then, but they noticed the changes and they changed me to another regimen, but my condition is still the same, I never got back to my normal shape.” (Patient, Mthatha)*

*“I don’t like these pills they are changing my shape so badly – my bums are decreasing and my stomach is big so much that the stomach hangs over my lap.” (Patient, Mthatha)*

*“I have some complaints because since last year my body has changed, it is not the same. My breasts are too big, bums are small, arms are thin and the bottoms of my legs are thin too.” (Patient, Port Elizabeth)*

*“A person who is taking the pills at times develops a buffalo hump at the back and what is happening is that the capsule takes the fat and stores it wherever it likes.” (Patient, Port Elizabeth).*

*“The pills have changed my body shape. I have developed the upper body and developed veins. I love short trousers, but I am no longer wearing them. I have spoken to the doctors; they told me that the pill that was going to help me was not available. It was last year then. This year they promised and drew some bloods to check some few things. The results came and they told me that my body fats were moving from the lower body to the upper body, so that was why I was developing the veins and gaining more weight on the upper body.” (Patient, Port Elizabeth)*

Eating well was proposed by one of the caregivers as one of the solutions for countering the change of body shape, especially in children, to avoid the inadvertent disclosure of one’s HIV status. The challenge was the availability of food, which she suggested the government should address.

*“Kids who are [HIV] positive need to eat healthy food because they have bones in the face that suggests their status, so if the diet is not good they become worse. So we would love to be supported by the government.” (Caregiver, Port Elizabeth)*

Some of the patients opted to stop the ARVs instead of tolerating the side effects related to change in body shape. As some of them were not sick at the time, they were more worried about their looks and what others would think about their HIV status than the HIV infection.

*“ARVs make you fat on the upper areas; I decided that I am stopping them. I said I won’t stand that thing especially because I was feeling no pain at that time, I wasn’t sick. The problem I had was the rotten wound-like thing, but it wasn’t painful. So I decided that I would rather stop using ARVs than to develop something that will be seen by everyone.”* (Patient, Mthatha)

*“Even myself I once believed in what people say. I took Bactrim and completed it, and when the time came for me to take ARVs I said sorry [declined]. I was told that I am going to have small leg and a, huge abdomen as if I am pregnant. I said hey, what am I going to do with this; and they said, ‘You will see, you will be like this and that’. And when a person is passing they would say, ‘Look at her’ and ‘You will be like that,’ and I would exclaim, saying, ‘Yhoo!’”* (Patient, Mthatha)

*“I decided that I am stopping those pills. I met my father and told him that I’m HIV positive. He had lost his wife who was HIV positive, but who feared to get tested. I decided that I won’t go to the clinic at all because I didn’t want to have small legs. I asked myself how I would feel if I see myself developing long teeth such that they appear even when I tried to close my mouth, when everything was right before I used ARVs. I didn’t want to see myself losing my hair and I said ‘No, no, no!’”* (Patient, Lusikisiki)

However most of the patients felt that the health benefits of ARVs outweighed the side effects related to change in body shape.

*“I expect to see her healthy. I get worried when I think about whether my children would be able to endure when I’m dead, because other people complain about how ARVs change the body shape. But I always tell them that shape is not important, health is.”* (Caregiver, Lusikisiki)

#### 4.4.3 Central nervous system (CNS) side effects

This was the most affected system, with symptoms such as confusion, dizziness, drowsiness, and feeling drunk. This could be because the entire first line combinations of ARVs included Efavirenz, which has many CNS side effects.

*“When you use these drugs for the first time, you notice many changes, unusual things happening. Even when you talk you don’t make sense.”* (Patient, Mthatha)

*“They make me dizzy. I took them at night and went to bed. I fell but I didn’t feel that I was falling.”* (Participant, Mthatha)

*“When I ate fatty foods they made me dizzy.”* (Patient, Mthatha)

*“These pills make me dizzy; I can’t even drink, when I took them.”* (Patient, Mthatha)

*“Even when the weather has changed, you feel drunk.”* (Patient, Mthatha)

Some of the patients experienced unusual dreams during the first few weeks after starting ARVs. Efavirenz was implicated as the cause.

*“The only thing that he reported to me is that he is having the nightmares, he is dreaming about snakes. He is only five years [old], so it is difficult for me to explain to him why he is having nightmares. I am suspecting Efavirenz.”* (Caregiver, Lusikisiki)

*“They made me dream about my old life, things that happened long time ago.”* (Patient, Mthatha)

*“I always get bad dreams.”* (Patient, Mthatha)

*“He used to dream about snakes biting her sister.”* (Caregiver, Lusikisiki)

*“After I started them I started having nightmares.”* (Patient, East London)

*“I had several dreams in one night. I fought with three men, but by the power of God I defeated them and escaped getting stabbed. I lost my child and looked for him with a painful heart. I saw a child but she was a girl, mine was a boy, I was drowning in a river and I saw a bunch of grass, I held it and I was safe. I had a beautiful mansion house which I was cleaning; I had a lot of money and made a budget for how I was going to use it. I lost my Bible and my Church robes.”* (Patient on Day 2 of treatment, Mthatha)

*“I dreamt about having an infant I didn’t love as a mother should; vomiting, stomach cramps, diarrhoea and was being carried because I was unable to walk. [I dreamt about] dying people even if they were not my relatives; and cattle were entering a room I was crying in at the same time. When I woke up my heart was painful.”* (Patient on Day 3 of treatment, Mthatha)

Hallucinations were experienced by some of the participants.

*“I have visions when it’s dark in the room and see ducks, horses, geese and birds.”* (Patient, Mthatha)

*“My sister was seeing the soldiers, things that we do not see, but as time went all that stopped, she is fine.”* (Treatment supporter, Port Elizabeth)

One of the most common CNS symptoms experienced by PLWH were headaches. Other than side effects of the ARVs, some of the headaches could have been caused by the stress related to living with HIV infection, resulting in tension headache.

*“I am experiencing strange, severe headaches. It starts from the back of my neck and spreads all over the head.”* (Patient, Mthatha)

*“I experience [a] headache at the back of my head, my body is very down. I don’t want to talk to anyone.”* (Patient, Mthatha)

*“Today my body was painful a lot and I feel headache.”* (Patient, Mthatha)

*“I started my day very well with the treatment, but later it made me have [a] headache that made me to sleep for two days. When I woke up on the third day I was about to go to the hospital [when] the headache stopped.”* (Patient, Mthatha)

#### **4.4.4 Gastrointestinal system side effects**

The gastrointestinal system was another of the most common systems affected. Most of the symptoms were self-limiting and managed by the patients without seeing a health worker. They were able to continue with the ARVs despite the side effects. The gastrointestinal side effects often started with nausea and vomiting.

*“This morning I took my pills and felt like vomiting, but after an hour I felt better, and at night I did not have any problem.”* (Patient, Mthatha)

*“I feel nauseous after taking my pills.”* (Patient, East London)

*“I felt nauseous and could not eat well.”* (Patient, Port Elizabeth)

The nausea and vomiting in some cases progressed to diarrhoea, abdominal pains and weakness from loss of fluids, resulting in dehydration and electrolyte imbalance.

*“I feel weak, had [a] painful stomach, vomited and had diarrhoea.”* (Patient, East London)

*“I am vomiting and having diarrhoea for three days. I have strong pains right in the middle of the stomach.”* (Patient, Mthatha)

Some participants experienced heartburn and pain they attributed to stomach ulcers. The heartburn suggested excessive acid in the stomach; although the presence of ulcers could only have been confirmed by doing endoscopy.

*“They [ARVs] make me have stomach ulcer and heartburn.”* (Patient, Mthatha)

*“Recently I am having heart burns during the night, but not every day.”* (Patient Port Elizabeth)

Taking the ARVs on an empty stomach provoked stomach pains, but they continued nevertheless to take the ARVs. The fact that the patient felt stomach pains after taking ARVs would suggest that they were probably supposed to be taken after food. It is possible that the patient was taking ARVs on an empty stomach because of lack of food. This is one of the challenges of managing HIV infection in a socioeconomically challenged population. This also illustrates the connections between the components of the system that contribute to the experiences that the PLWH go through. Despite the challenges, most patients tried to adhere to the ARVs.

*“When I take these tablets on [an] empty stomach I get stomach pains. Most of the time I take them on [an] empty stomach because I do not want to miss them.”* (Patient, Mthatha)

Some patients tried self-medication to relieve some of the symptoms, with or without success.

*“I also vomit a lot; I eat these orange pills in order to feel better. I do not like food.”* (Patient, Mthatha)

*“I have heartburn and used to take Gaviscon and feel better, but now it doesn’t work.”* (Patient, Mthatha)

One of the patients felt bloated and lost his appetite for food. This could have been because of indigestion related or unrelated to ARVs.

*“I woke up and had no appetite. I am full even though I have not eaten.”* (Patient, Mthatha)

The ARVs didn’t seem to go well with fatty foods. Some of the ARVs were possibly not fat-soluble, in that fatty food interfered with their absorption.

*“When I eat the pills with fatty food I feel like vomiting.”* (Patient, Mthatha)

*“My treatment made me not to be interested in any fatty food. After I had eaten my evening pills I had burning sensation throughout the night. The following morning I vomited a substance, but I didn’t go to the doctor.”* (Patient, Mthatha)

#### **4.4.5 Ear, nose, and throat (ENT) side effects**

Some patients experienced ENT problems – including dental problems – while on ARVs. Patients attributed these to side effects even though they could be due to HIV complications related to poor immunity, thus making them susceptible to various infections.

*“After taking my treatment my nose is full of mucus with big veins on my head which are hurting.”* (Patient, Mthatha)

*“Ears are deaf now and they discharge liquid.”* (Patient, Mthatha)

*“I have got painful gums and they are disgusting and rotting away.”* (Patient, Mthatha)

*“I have running nose, but I am not feeling cold.”* (Patient, Mthatha)

*“All my teeth are painful. I just swallow the food without chewing.”* (Patient, Mthatha)

Others had symptoms involving multiple systems. This was not a surprise, as HIV infection results in multi-system complications because of the compromised immunity.

*“I experienced bleeding from the nose when I woke up in the morning, and [a] severe headache. I have got rash starting from the back to the stomach.”* (Patient, Mthatha)

*“My feet and throat are painful. I have headache also.”* (Patient, Mthatha)

*“Today my feet and throat are painful; my body is extremely painful also. I always cough a lot ever since I became positive.”* (Patient, Mthatha)

*“I have painful teeth and the lump that is painful under the armpit.”* (Patient, Mthatha)

#### **4.4.6 Endocrine system side effects**

Although not common, some patients complained of gynaecomastia, one of the effects that ARVs had on sex hormones. Enlargement of the male breast tissue was a grave and obvious concern, which lead to feelings of emasculation.

*“These pills make me develop breasts but I am a man. I reported to the doctor and he changed my treatment.”* (Patient, Mthatha)

#### **4.4.7 Side effects with eyes and vision**

The side effects related to the eyes were not common, but included pain, blurred vision, itching, tearing, poor vision and blindness. Some of the symptoms are suggestive of an allergic reaction to the ARVs, while other symptoms could be related to the complications of HIV infection.

*“I feel as if there is smoke and mist in my eyes.”* (Patient, Mthatha)

*“My eyes are itchy even though not painful.”* (Patient, Mthatha)

*“I have eyes that are unable to see properly since I started ARVs.”* (Patient, Mthatha)

*“In the morning my eyes feel like I am wearing spectacles. I feel misty in the eyes and at times I used to have tears.”* (Patient, Mthatha)

*“Blindness is very common these days, my eyes used to have tears.”* (Patient, Mthatha)

*“My eyes are painful and they are even reddish in colour. It is painful to keep the eyes open.”* (Patient, Mthatha)

#### 4.4.8 Respiratory system side effects

The respiratory systems side effects were rare, and only a cough, a congested chest and difficulty in breathing were reported. The symptoms seemed to be more related to the complications of HIV infection than the side effect of ARVs.

*“Today when I woke up I coughed a lot as if I will have a congested chest.”* (Patient, Mthatha)

*“When I am coughing I spit thick sputum.”* (Patient, Mthatha)

*“I have difficulty in breathing.”* (Patient, Mthatha)

#### 4.4.9 Genitourinary system side effects

Genitourinary system side effects were not common. Only women reported them, and they included vaginal itching, pimples in the vagina, earlier and shortened menstrual periods, and vaginal discharge. It was difficult to definitively attribute the symptoms to the side effects of ARVs. Some could have been due to other pathology related to the complications of HIV infection.

*“My vagina is itching. I feel like using my nails for scratching it.”* (Patient, Mthatha)

*“I have a painful pimple inside my vagina.”* (Patient, Mthatha)

*“I began my day very well but the problem I had is to be on [my] period before my expected date; but it took only one day, so I don’t know whether it stopped because I took the treatment or not.”* (Patient, Mthatha)

*“By the time I was pregnant I developed big hard pimples around the waist, and the other one was next to the vagina and on top of it. I did report them.”* (Patient, Mthatha)

*“I had discharge and I came to the doctor for that.”* (Patient, Lusikisiki)

## 4.5 Conclusion

Participants highlighted the importance of HIV testing as the basis for the diagnosis of HIV, and therefore a gateway to accessing care. Acceptance of the test result facilitated adherence to ARVs. Disclosure of one's HIV status was a challenging experience because of the stigma attached to it, and the discrimination against people known to be living with HIV. Disclosure was thus largely selective. Both technological and non-technological methods were used to incorporate ARVs into one's lifestyle and therefore support adherence. Patients, treatment supporters and caregivers were motivated by the health benefits of ARVs to adherence to them. Many of the symptoms attributed to ARV side effects were in fact symptoms related to the complications associated with HIV infection. Although the side effects were challenging, they did not usually outweigh the benefits, and therefore the majority of patients did not stop taking ARVs because of them.

The next chapter will discuss the experiences of HIV positive patients on ARVs in relation to the health services.

## **CHAPTER FIVE: THE EXPERIENCES OF PATIENTS ON ARVS WITH HEALTH SERVICES**

### **5.0 Introduction**

Chapter Five is about the experiences of patients on ARVs in relation to the health services. The health facilities where data was collected were HIV clinics, which were all located within regional hospitals. During the period of data collection, the patients were referred to these clinics by the various departments of the hospitals, district hospitals, community health centres and primary healthcare facilities attached to them, as well as other health service providers such as doctors in private practice and non-governmental organisations.

They were initiated on ARVs if they met the criteria set out by the National Department of Health Guidelines for managing HIV positive patients on ARVs. The patients were managed at these hospital-based clinics for three months before being referred back to the nearest local primary healthcare clinic to continue with the ARVs; unless they had problems that necessitated them to continue receiving care at hospital level.

The themes that emerged from the interviews have been categorised into a framework suggested by Kringos, Boerma, Hutchinson, Van der Zee, & Groenewegen (2010, pp. 6-11) that defined the core dimensions of a primary healthcare system. This framework provided a relevant and systematic way of organising the themes. The framework grouped key dimensions into three broad groups:

- Structure referred to issues related to governance, policy, finances and training of the workforce;
- Process referred to issues related to access, continuity, comprehensiveness and coordination of care; and
- Outcomes referred to issues related to quality, efficiency and equity.

### **5.1 Structural issues**

The major structural issue was the provision of social grants and food parcels at the clinics. These issues were understandably raised because of the expenses the patients had

to incur because of their condition and because the majority of them were economically challenged. The ARVs had to be taken with food, and food was required to meet their general nutritional needs. Sustenance was also needed in the clinic because it took so long for patients to be fully attended to, plus care was less positively received when people were hungry. Food was also requested to take home to feed the other members of the family, which was a reflection of food insecurity and poverty. Food insecurity impacted on adherence to ARVs because some patients were at times unable to take their ARVs because of a lack of food. The appeal was made to particularly give consideration for children to be given food. Children in particular need food more than adults because it is necessary for their growth. Furthermore, they are also entirely depended on their caregivers for food.

These experiences highlighted the importance of food security when caring for PLWH. The fact that the challenge of food insecurity was imbedded within a complexity of interrelated factors is in line with systems theory. The message was clear that provision of food at the HIV clinic was expected to be part of the standard care for PLWH. The challenge of poverty also needed to be addressed.

*“I wish that people could be given some food parcels, because sometimes people arrive here very early in the morning and spend the whole day here. Time for taking their pills finds them here, and there is no money for buying food.”* (Patient, East London)

*“I wish I could be given food to eat here and carry some home, but now when you are hungry you would wish that no one speaks to you even if the topic is important.”* (Patient, Mthatha)

*“What I can ask is that children be given food, children stay here and become hungry the whole day especially when you don’t have money.”* (Caregiver, Lusikisiki)

*“The only thing I can suggest is for the government to support us with a R200 social grant as well as food parcels so that people with kids can take food parcels every month. Secondly we are struggling, some of us are not working and we have nothing to eat because we need to take food before we take the drugs. As for myself, when I take them on*

*an empty stomach I become very weak and blind. I am not working, I have no grant nor do I receive food parcels.*” (Patient, Port Elizabeth)

The challenge therefore was the provision of food for the needs stipulated above. As most of the HIV patients attending the public health facilities were economically challenged and depended on social grants, food parcels and / or food provided to the patients during their visit to the health facility, the link between poor food security and adherence to ARVs was a key issue. The revoking of the disability grant when the CD4 count increased to a level the patient was considered well enough to work was a challenge for those who did not have an alternative source of income.

*“I do not have a grant, I am struggling and the food is expensive.”* (Patient, Mthatha)

*“The same government who is not giving us a grant is the one who is telling us not to take them on an empty stomach.”* (Patient, Mthatha)

*“I started ARVs by the time I was pregnant, I was six months then, they did nothing to me. The problem is that we are taking them on an empty stomach because we don’t have money to buy food, we don’t have a grant.”* (Patient, Mthatha)

The food given at the health facility was appreciated and missed when this service was discontinued.

*“The soup you used to give us was so good but you stopped now. If I happen to get some healthy food it feels better.”* (Patient, Mthatha)

The outcry to government for financial support or food parcels was huge and at times conflicting. On the one hand some argued for everyone who was HIV positive and had been given a social grant to continue receiving it indefinitely, while on the other hand some were unhappy with those whose CD4 count had increased and were healthy but were still receiving a social grant.

*“Can I ask how the Government stops giving us a grant knowing that we haven’t stopped being HIV positive, because even this treatment needs food before you take it?” (Patient, Mthatha)*

*“I think even the CD4 count of those who were diagnosed as HIV positive earlier than us has increased but they still get the grant. We so wish to get it and not necessarily for ourselves but for those who are so sick who are always lying down. The example is that lady who would say she would take the ARVs and end up vomiting them because she had taken them without having eaten food and I would even plead with her that she shouldn’t vomit them but to take them at another time instead. I can’t afford also but at least I am given food by my mother if my husband is not working so that I can make porridge for the child.” (Patient, Mthatha)*

Examples of local clinics that provided food were given. This was evidence that it was already being implemented in other clinics and needed to be rolled out in other clinics as well. This was a cry for equity in the public service delivery.

*“I saw something unusual in Qumbu, they get food there and it’s plenty. Grocery is so plenty and it surprised me. The girl I said died because of TB, she went there to take her pills, she was also given food even though she regularly attends clinic here and not at Qumbu. I was so surprised.” (Patient, Lusikisiki)*

*“Where my father is taking the treatment they are very fast, they are cooking and patients are given food to eat and then they take their treatment.” (Treatment supporter, Mthatha)*

Getting the social grant was a challenge even for those who qualified for it. Despite having a low CD4 count, one of the patients who had applied for a social grant did not succeed. He attributed this to a doctor who did not recommend him. Some of the providers shifted the blame of rejecting the application to the computer to avoid being held responsible. This was a case of ‘collusion of anonymity’ where nobody in the healthcare team wanted to take responsibility for the outcome.

*“Doctors say we are well even if we have a low CD4 count, doctors are cruel especially here at the Gateway clinic. Last year you would notice that he (the doctor) was not happy*

*and he would respond and say, 'Hey! It is as if you are HIV', and he would sign whatever he has to sign and when you go to SASSA [South African Social Security Agency] you would be told that the computer rejects you.*" (Patient, Mthatha)

The need for financial support was a common theme that was strongly expressed by all respondents. In the spirit of *ubuntu* (a Nguni term loosely translating to "human kindness"), the dependence of patients on neighbours for financial support helped in emergency situations and was therefore considered a temporary measure, but it was not seen as sustainable and could not replace the responsibility of the state in this regard.

A shortage of ARVs was mentioned, but only at one of the local clinics. This could have been due to supply chain problems, which were not uncommon in the public health service.

*"I am going to talk about N, the clinic that I am using. There are either no ARVs there or not enough. At times they used to advise us to share the pills because they are scarce."* (Patient, Lusikisiki)

The sharing of ARVs at the clinic by patients when there was a shortage was a concern because of the potential for disruption of adherence and the development of resistance to ARVs.

## **5.2 Process issues**

The process covers access, continuity, coordination and comprehensiveness of care.

### **5.2.1 The availability and accommodation of access to health services**

The availability of services refers to issues relating to capacity and types of services available, while the accommodation of access to health services is about how services are organised to facilitate access.

#### **5.2.1.1 Capacity and type of services**

The HIV clinics at the regional hospitals provided vertical HIV specialist care for patients referred from various institutions, as mentioned above. In addition, they also catered for walk-in patients who had not been referred. The clinics covered wide

geographic areas but had limited capacity in terms of available space, resulting in overcrowding and heavy patient loads.

*“The patients are starting to be impatient, they are shouting for their numbers or names to be called. I never stay here until 13h00, they used to be fast or are we increasing.”* (Participant Observation, Mthatha)

*“It is full here; people are in numbers as if they are looking for vacancies, all these people are [HIV] positive. Other people are lying on the grass and others are sitting on the chairs while others are standing.”* (Participant Observation, Mthatha)

Toilet facilities were inadequate for the number of people being serviced, and the problem was compounded by water shortages. The space and the number of chairs were limited, making it uncomfortable for patients who might have to stand for a long time. Maintaining cleanliness and good hygiene was therefore often a challenge. Due to limited space, the toilets were often not far from where patients were queuing. Patients were complaining because of the smell, and some people were moving away from it, leaving the chairs next to the toilet empty.

*“These people are taking too long inside this toilet.”* (Patient, Mthatha)

One of the female patients who wanted to use the only toilet in the clinic complained about the length of time the occupant spent in the toilet, Another female patient laughed and remarked: *“Maybe she is cooking samp and mealies [which take long to cook] in there.”* (Participant Observation, Mthatha)

After a patient used the toilet facilities, none of the other patients wanted to enter, even though they needed to relieve themselves, until a hospital cleaner sprayed air freshener.

*“The person who just left the toilet needs to clean her stomach because the smell is making me dizzy.”* (Participant Observation, Mthatha)

*“Firstly there is no water here [to drink]. There are those containers that are leaking; there are no disposable cups. We are using one cup that is not washed between uses. This is not hygienic at all.”* (Patient, East London)

*“When you are used to a place it’s difficult to leave it. It is not nice here, it is not like in Cape Town; it is nice there.”* (Patient and Participant Observation, Mthatha)

In stark contrast to the experiences cited above, one of the participants specifically commended the clean, spacious environment and adequate furniture at one of the clinics; as well as the privacy provided and the orderly way in which the patients were managed by the staff.

*“I want to acknowledge the kids department, they are so caring there. It is clean, spacious with adequate furniture. We are always on a queue and we have privacy with the nurse and the doctor.”* (Treatment supporter, Port Elizabeth)

### **5.2.1.2 Accommodation of access**

Long waiting times were a common feature of the HIV clinics because of the patient load and the staff shortages. The unavailability of staff when they were needed, poor time management and some slow clinic processes such as waiting for a stamp at the registration counter were cited as some of the other reasons for long waiting times. The services were not organised to cater for working people whose time at the clinic was limited. The reception area and the pharmacy were specially mentioned for their poor service and long waiting times. Both were at very strategic positions in the patients’ pathway through the clinic as reception was the first point of access to care, and the pharmacy the last. Whatever happened at the reception and the pharmacy would impact on the patient’s perception of the quality of care. While staff shortages were beyond their control, the actions of the available healthcare providers reflected a lack of patient-centred care.

*“The nurses are few today, so much that the service is slow and one of the patients is complaining about the pace.”* (Patient, Mthatha)

*“There are long benches where patients are waiting to be seen by the doctor, they are all sitting down and nurses are going up and down in front of the patients and none of them has been attended to yet.” (Participant Observation, Mthatha.)*

*“Only they [the HIV clinic] issue ARVs, but I didn’t have problems moving up and down in order to get treatment; but my problem is when I come to the clinic, only to be told that the doctor is not available. This month they told me that they are not aware as to when will the doctor be available, and even the ones who were here yesterday didn’t see the doctor. So tell me, I have a treatment I have to take called Fluconazole, even they themselves say I shouldn’t miss that treatment.” (Patient, Mthatha)*

Another patient had an initial positive experience of being attended to professionally and to his satisfaction. But as time went on the situation changed, the availability of doctors started becoming unpredictable. Whether this was due to shortage of doctors or negligence was difficult to tell. The fact that the patient was able to initially get a service to his satisfaction meant that it was possible to get such a service at this health facility. The challenge was being able to sustain of the quality of service that patients had become accustomed to.

*“I was blinded by the fact that I was coming for the first time, they treated me well. When the time goes and I came for the follow up visits, things had changed. I can’t tell you when the last time I was seen by the doctor was. I am here because I am sick and I am not sure whether I will be seen or not.” (Patient Port Elizabeth)*

Time management seemed to have been a huge challenge. The health workers managed time in their own way and in the process compromised on the time they actually had left over to render services to the patients. This reflected a governance weakness in the affected health institutions.

*“The pharmacists arrive very early but they start working very late, they arrive at 07h30 but open the dispensary at 10h00. Most patients are rushing to work, they are hoping that it would be opened by at least 08h00, but that didn’t happen.” (Patient, Mthatha)*

*“The nurses have just gone for tea for 45 minutes. To the patients it is as if the tea break took five hours, they are groaning and complaining.”* (Participant Observation, Mthatha)

*“There was a time I spent five hours, I arrived at 06h00 and went back to work at 12h00. I even asked the nurses what they wanted us to do.”* (Patient, Port Elizabeth)

*“One of my children passed away, she was HIV positive and she was admitted here. In the wards it was not nice at all. We arrived there at 09h00 but we were attended to by the doctor at 21h00.”* (Caregiver, Lusikisiki)

*“There are delays here; there is nothing much I notice except that they converse a lot.”* (Patient, Mthatha)

*“We used to wait here at the passage, but now we wait outside. We experience rain, cold and hot sun there. But when you come inside you find that the staff is having a conversation.”* (Patient, Mthatha)

The service at the reception was particularly cited for being substandard, partly because of the need for patients to get a date stamp as evidence that they had been registered and to be able to access the services related to their care. There was considerable delay in getting registered because of the stamp. The delay at the reception impacted on the time the patients were able to access the other services, and the time the patient ultimately had to spend at the health facility. The staff at one of the health facilities knew what to do to avoid delays but would only do so when management forced them. Measures needed to be put in place to ensure that the staff did their work.

*“The problem I’m seeing is the issue of administration at reception; I wish that the ARV clinic could have its own stamp and its files in the building. You will find that we wait there for a long time, waiting for the clinic card, the queues are very long, taking us the whole day to collect the pills, whilst you will find that there is not much work at the ARV clinic. At times we used to have disagreement at the reception desk and we*

*report it to the matron at the ARV clinic, she would go straight to the reception and solve the problem.” (Patient, Lusikisiki)*

*“The side that is giving us problems is the OPD. We used to arrive there at seven in the morning and leave that place at one in the middle of the day waiting for a stamp.” (Patient, Lusikisiki)*

*“The person at the reception, the one who is registering our names, when she is bored she takes her bag and leaves. She used to say, ‘I am not employed any way, I am volunteering.’ That is another problem we are facing.” (Patient, Mthatha)*

*“The problem here is that the process is very slow. If you arrive here at seven [am] you would leave this place very late. In most instances you would have left your place without having eaten, and you would be very hungry when you leave this place; and as such you would feel as if you shouldn’t talk to anyone. But we bear with each other as patients.” (Patient, Mthatha)*

The patients were able to recall better instances of service they had received in the past at one of the health facilities, in contrast to what followed later. This implied that the healthcare providers were capable of rendering a good service, but were inconsistent. They were unhappy when the issue was raised by patients, and punished them for doing so.

*“There at MGH [Mthatha General Hospital] at the container [prefabricated structure] we were treated very well, I don’t know maybe since the container was small they worked very fast so that people would be released for the container to cool, but here maybe the process is slow. At times the doctor would close the door for some time since he is on a phone call, or wouldn’t allow anyone to enter since he is still having a conversation with a nurse. At times you would notice that there is a person who is far sicker than you, who needs help urgently. We were made to wait outside because we raise these things; we are fighting for their rights.” (Patient, Mthatha)*

Other activities that slowed down service delivery included meetings that took place at the clinics from time to time. Some of the meetings involved patients as well.

Patients found these to be a disruptive waste of time, possibly because of a lack of communication by the staff about such meetings.

*“A guy comes out complaining that they have been recruited to the support group and they have been told that they won’t stay long in the recruitment meeting and now they are taking longer.”* (Participant Observation, Mthatha)

The patients were given appointment dates for review and for them to get their ARV treatments. Some complained that the pharmacists punished them for not keeping their appointment by serving them last, not serving them at all, or insulting them. The patients had to endure the consequences of missing appointments and had to effectively beg to be given their treatments. Effort was not made to find out why the patients missed their appointments. Viewed from the perspective of systems theory, this was a reflection of a lack of understanding by the dispensary staff about the fact that the failure of the patients to keep their appointments to collect their ARVs was the end result of a complexity of interrelated factors. These need to be explored to appreciate the reasons the patients sometimes don’t honour their appointments to collect their ARVs.

*“When I went back to Z clinic for my follow up visit I was shouted at by the nurse there because I forgot some pills that I was supposed to be showing there at the pharmacy. The nurse who was there said, ‘This is your virus, it’s not going to change, if you are careless, you are careless for yourself and I know that you depend on Thabo Mbeki who is fighting for your rights, but he is not here now, stop being careless’. I know that nurse and I can point her out if you want.”* (Patient, Port Elizabeth)

*“ I experienced some problems on my follow up visits. At times I used to skip the dates to fetch the pills and that causes the problems for me because they said, ‘This is your virus not ours so we don’t have the problem with that, go back you will come on another date next month.’ All I used to do was to be patient and keep coming until I had a person who was willing to help me. My sister used to come here and she was not getting any help until I came with her and talked on her behalf, and that’s when they helped her and told her to come again for a follow up visit.”* (Patient, Mthatha)

Patients sensed that staff gave priority to some patients based on their social standing rather than on medical grounds. Employed people were also given priority and this was perceived as unfair by some patients. The healthcare providers were perceived to be practicing inequity and had a bad attitude towards patients.

*“You know what, even here at IDC [Infectious Disease Clinic] they say that, when they are taking their relatives and serve them first and then we complain, they say, ‘Hey you are so proud of this virus as if you are selling it.’ The worst thing is that we have no idea how we got it, they are not treating us well at all.”* (Patient, Mthatha)

*“I was treated well except some instances when you have come very early you see some people attended before you on the basis that they are workers, workers, workers! Workers should have their own time, for example, from eight to ten; so that we won’t come very early knowing that it is still time for the workers. It becomes worse when we have come very early, and leave at five, to be told that first preference is given to the workers. Some people come and have little conversation and you see them leaving. It would be better if the treatment is the same.”* (Patient, Mthatha)

*“The pharmacists are very slow and arrogant, and people are complaining that they are biased because they help their relatives first.”* (Patient, Mthatha)

*“We are going to stay the whole day here, these nurses are taking their relative’s cards first and they are putting us at the back. He was the first one to come but he has been served at the fourth place.”* (Patient, Mthatha)

The HIV clinics at the regional hospitals were providing a vertical service and were separated from the other service areas of the hospital. Over time people got to know where the clinics were located in the hospital. While this may have served the purpose of finding the clinic easily, the drawback was the correlation of the clinic with HIV, and therefore the inadvertent disclosure of the status of anyone seen at or in the vicinity of the clinic. The person might then be subjected to stigma and discrimination as a result. At the hospital pharmacy, the use of colour-coded cards or boxes labelled to identify patients according to their clinical

conditions also inadvertently disclosed their HIV status, and at times resulted in those patients being treated differently. The participants were very unhappy with the separation of the HIV clinic from the other service areas of the hospital, and the record-keeping system that did not protect the confidentiality of their status.

*“It was very scary and embarrassing because you will find people who know us so we always think about what they are saying. We are labelled as people who belong to the building that is made of wood. We are separated from other people, our situation is known by everyone.”* (Patient, Lusikisiki)

*“Another thing they do is to separate the boxes where we put our clinic cards, our box has a big ‘S’ written on it. They give us big papers that show that we did not pay and that is embarrassing because we are labelled now that we are going to the wellness clinic.”* (Patient, Port Elizabeth)

*“I hate the idea of passing Gateway clinic on your way here [the HIV clinic at Mthatha Hospital Complex] because once you pass the clinic and come this way, people know that you are on ARVs.”* (Patient, Mthatha)

*“It is true we do not want to be known, we are coding everything, when we go to the clinic we say we are going to the ‘university’ just to blind [mislead] the crowd, and we call the clinic cards the ‘certificates’. We are even given the nicknames by the health workers and we know and understand that.”* (Patient, Mthatha)

*“I met a girl whom I knew outside the clinic. She said she came to fetch the pills for someone else, but I knew she was lying. I told her I had come to fetch my treatment. People are afraid of this thing [HIV]. It is difficult for them to accept it even if they see other people having it.”* (Participant Observation, Mthatha)

There were also situations where the patients were prescribed treatment, which was not available at the HIV clinic, so they had to go to the main hospital pharmacy where they were treated differently from other patients. The appeal was for comprehensive care under one roof.

*“They do not want to see us at the hospital pharmacy. When they see the green card for HIV patients on ARVs, they don’t want to see us, and it’s as if we are going to infect them. I wish they could bring us everything here in the IDC dispensary, all the medication including those for other AIDS-related illnesses.”*  
(Patient, Mthatha)

### **5.2.1.3 Acceptability of services – positive experiences**

Many patients described their relationship with the health workers in positive, albeit fairly superficial terms such as “fine”, “good”, “nice”, “sweet”, or “no complaint”.

*“It’s fine.”* (Patient, Lusikisiki)

*“It’s good and perfect, there was no problem.”* (Patient, Port Elizabeth)

*“I have no complaint, there is nothing funny [untoward].”* (Patient, East London)

Other patients, treatment supporters and caregivers revealed a deeper rapport with healthcare workers by using words such as “caring”, “tolerant”, “courteous”, “supportive”, “patient”, “respectful”, “friendly”, or “loving”. This difference could have been because of their role as treatment supporters or caregivers, which helped them to develop a better relationship with the health workers. A good relationship facilitated acceptance of their HIV status, gave them hope and enabled them to learn how to take care of themselves, including the use of ARVs.

*“Since I started coming here [HIV Clinic] I never experience any negative thing. We share jokes amongst us and with the health workers. We are like brothers and sisters. The relationships help us to realise that there is no big deal to this thing of HIV; we are just taking the pills to keep us in a good state. The relationships that we have with the health workers and the ones that we have as patients help to give hope to the person who comes to the clinic for the first time, he or she will realise that there is no big deal in having HIV. All that doesn’t mean the person should stop taking his or her pills everywhere he or she goes.”* (Patient, Lusikisiki)

*“When I first came here I was on the wheelchair and was served with respect; the others as well.”* (Patient, East London)

*“People here are so friendly, people of this place [HIV Clinic] do not make you feel as if you are not of this place; you just feel at home.”* (Caregiver, Lusikisiki)

*“They were very sweet, they were very good, and they explained to me and made me feel very right. They made me understand that as the baby is using this he will be fine, it will do something to him.”* (Caregiver, Lusikisiki)

*“It’s fine, they love him and his doctor is happy for him so much that he used to give him money when he visited.”* (Caregiver, East London)

*“The health workers are accessible and listen to us, more especially those who are at the reception. They used to ask how we are feeling, how are we treated by the pills? They are so caring so our relationship is perfect.”* (Patient, East London)

The relationship with other patients was considered to be beneficial in terms of sharing experiences of living with HIV and supporting each other while in the clinic. There was also a form of peer education.

*“I like this place, it makes us to have hope that we still have a longer life to live; you see that you are not alone in this thing.”* (Patient, Mthatha)

*“I know that people here are having the same problem as I do, I listen and gain some information from others.”* (Patient, East London)

*“The patients were fine and understanding. There are cases where you will find that there is a person who is in the wheelchair and the health workers used to start with those people and I do not have a problem with that because I can’t expect a person who is critically ill to wait the whole day while I am fresh and not weak like him or her.”* (Patient, Port Elizabeth)

As part of their care the patients were taught about HIV and how to manage it. This was appreciated by a number of participants as ARVs – being a lifelong treatment with unique expectations of the patients taking them – warrants a clear understanding about the drugs in relation to the management of HIV for the maximum benefit of the patients.

*“Everything was fine; I attended the classes where they taught me how to take the pills, name of the pills etcetera.”* (Patient, Lusikisiki)

*“Something that is positive about this clinic is that even before I started taking these pills I was taught all the expected things of a person who is on ARVs. They told me how to take these pills, they took me to the doctor and they took me to the X-ray. I never had any problem. Even after I tested positive I never had any problem before, I know that HIV is for us.”* (Patient, Lusikisiki)

*“I was with her on that day and there was nothing bad, she was advised by the health workers on how to use the pills and so on.”* (Treatment supporter, East London)

*“In all that I thank our health workers who take good care of us and they taught us many issues concerning the ARVs. I thank them.”* (Patient, Mthatha)

A few patients also mentioned other positive experiences related to the health services, such as:

- Counselling by the staff;
- Efficiency of the staff;
- Motivation provided by the healthcare workers;
- Home visits by a nurse;
- Availability of a doctor in the clinic to attend to patients;
- Getting review and repeat-treatment dates from the health workers for the continuity of care; and
- Genuine concern of the health workers about adherence.

Though one respondent mentioned each of these, they represented a more positive experience amongst a minority.

*“The first person I disclosed to was Dr C, he counselled me. That counselling helped me to deal with my status, get stronger and stronger every day, and I started the pill count for two weeks, then after that I started to take the ARVs. I was pregnant by the time I tested, I was not sick so I never got sick, and I have never been a bed-ridden case.”* (Patient, Mthatha)

*“There is a nurse who just passed away recently and she was the only nurse that was treating me very well. She is the one who motivated me that you get bad treatment when you meet someone who is ignorant in her character. This nurse used to ask me where my husband was, and I would tell her that he was outside. She would say call him to come in and I would do that, she would chat with us until we are finished.”* (Treatment supporter, Mthatha)

*“I am helped by one nurse who offered herself to clean me at home and she would also apply some therapeutic cream in my private parts.”* (Patient, Mthatha)

*“What I like about this clinic is that when you have a problem you are seen by a doctor.”* (Patient, Lusikisiki)

*“The positive aspects is that the staff is treating us well, we get all the pills we want on time, they are giving us dates that are suitable for us to come even before the pills are finished. They are fast when they are working so we do not stay here for a long time.”* (Patient, East London)

*“Some of them are caring; because you will find that they are concerned about what are you using to remind yourself about taking the pills.”* (Patient, Port Elizabeth)

In response to the positive experiences they had in the healthcare services, some participants expressed gratitude towards the health workers.

*“I just want to thank the health workers who care a lot about us.”* (Patient, Mthatha)

*“She was always sick, but I want to acknowledge the hospital, they have helped my child a lot.”* (Caregiver, Port Elizabeth)

*“I acknowledge the service of this clinic.”* (Patient, Port Elizabeth)

*“I thank the nurses who are taking care of us, bear with us. We apologise even for those who make trouble at the hospital, I heard [about it but] I was not there that day.”* (Patient, Mthatha)

#### **5.2.1.4 Acceptability of services – negative experiences**

In contrast to the positive experiences of patients on ARVs with the health services, they shared their negative experiences in much more detail and with a lot of fervour.

##### **5.2.1.4.1 Poor communication**

The quality of care rendered by the staff was found to be wanting in many instances, particularly in relation to communication. Patients complained about a lack of explanation regarding how ARVs were dispensed in the clinics. The normal practice was to give one month’s supply of ARVs.

*“Why are some patients given a two month supply and others a one month supply?”* (Patient, Mthatha)

Patients also complained that staff did not listen to their problems or viewpoints, and came across as authoritarian.

*“The doctor that used to attend to me is not Xhosa speaking, he is very careless, he talks while you are talking, he would argue with you when you present your problem, at times he would ask who is talking here.”* (Patient, Mthatha)

*“I gave birth and the child was found to be without the virus. I again went to Dr X, and he said I told you long ago to go and seek for contraceptive pills. He is not helpful, he wrote all those things that make us unhappy. He wrote things like, ‘you have a tendency of asking me questions when I am late, I am a person I have my*

*own problems too, I am also sick.’ There are a lot of things he wrote there, he is telling us about his problems, but it doesn’t end there.” (Patient, Mthatha)*

#### **5.2.1.4.2 Lack of patient-centeredness**

Healthcare providers were found to be lacking in their consideration of the patients as people with feelings, thoughts, expectations, rights and other needs. The patients had all come primarily to seek help in various ways related or unrelated to HIV, and needed support in coping. They expected empathy and respect. Instead they were judged, insulted, disrespected, stigmatised, discriminated against and exposed to bad attitudes. They generally did not receive the care they expected.

*“Another thing is that they should mind what they are saying to people because when you talk something that is going to hurt a sick person it’s bad, they get hurt easily.” (Treatment supporter, East London)*

*“Another thing is the way people are treated, they [staff] do not care, most [patients] are coming here very sick and they [staff] say whatever they want to say to people, so that is not nice to sick people. Some of us are not getting healed because of the way we are treated.” (Patient, Port Elizabeth)*

*“What an attitude! They should try to understand because I am not saying they are not human, they have feelings, and they should be patient with all different kinds of people. Most people are not even aware of the processes and procedures that should be followed when coming to take the pills, I wish that they should understand that most people are frustrated and confused with all this new visitor in their body, so all I am saying is patience – they should bear with us.” (Patient and treatment supporter, East London)*

*“They are rough in a way, they insult us at times and sometimes we share some jokes with them. The doctor used to say, ‘You and your virus.’ And I said, to him, ‘Yes it’s mine, I never bought it,’ and he laughed.” (Patient, Mthatha)*

Some of the participants described staff as a mixed bag of people with different or inconsistent behaviour and ways of doing their work. The provision of care varied. This was understood in the light of staff being human and subject to stresses of life like anybody else, but the appeal was for them to be conscious of that and not to take out their frustrations on their patients.

*“They are not the same, most of them they just work for a living, some of them are showing their personal stress to us and we do not have energy for that. They are delaying us until 15h00, while the dispensary is closing at 15h00.”*  
(Patient, Port Elizabeth)

*“They are not the same really. If you go to the professional nurse they do help you, but others have an attitude.”* (Patient, Port Elizabeth)

Some health workers were judgemental, dismissive and blamed patients, which in some instances led to them being denied the service.

*“One black doctor who was working here was just looking at the patient’s face and saying, ‘Go home and work, you are healthy, you are not going to get a grant, it’s only for disabled people.’ Some say they would ask the regimen they were taking and if you don’t know it, the doctor would say that is not possible”.*

An old man remarked. *“I don’t know them as we talk’.”* (Patient, Mthatha)

*“One lady went outside to answer her phone, when she came back it was her turn to forward her card and the pharmacist refused to take it, saying the lady was not in the queue. She cried out loudly and she was served.”* (Patient, Mthatha)

*“One nurse passes the patients and they look at her and whisper, ‘She is having it and she is silly as if she is clean. One time she said to me, ‘Do you have a man?’ and I said yes, she asked again, ‘Do you sleep with him?’ and I said, ‘Yes’. She continued, saying, ‘You are not ashamed of yourself, how can you sleep with a man while you are sick and weak?’ I was angry and insulted*

*her back, she was shocked and attended to me quickly and then I went.”*  
(Participant Observation, Mthatha)

*“I was pregnant and still mourning the death of my father’s child, she was going to be buried on Saturday and I was about to give birth on Friday. I got to the hospital and told them that I was going to give birth; they denied [refuted it] and told me to go around. I wanted to go to the toilet, but I didn’t because I knew it was not a toilet [I needed] but the baby that was coming. I felt the pains and leaned on the bed shouting, telling them that the baby was coming, but they ignored me. The baby came and they shouted at me accusing me of using something that was going to speed up my labour pains.”* (Patient, East London patient)

This lack of trust in the patient was alleged to have resulted in some patients being deprived of consideration for financial assistance from the state.

*“I also want to second my colleague, our doctors are very arrogant, they do not care that you have a child and struggling, they just tell you that you are fine, go and find a job.”* (Patient, Port Elizabeth)

*“The place that is ignorant is this clinic [IDC], they are very ignorant. There was a sister here, the one who was involved in a car accident such that her legs and head were separated from the body; that nurse was troubling me a lot. I was sick then and she was about to draw some blood but my arm was not in good position for her, she said, ‘Look sister, don’t do this to me, I am not sick, you are the one who is sick, and I will never have your virus. ‘She broke my heart so badly, so much so that I even talked about her at home.”* (Patient, Mthatha)

*“They are not addressing us with respect.”* (Patient, Mthatha)

*“The relationship is fine except unique days where you would see that a person is stressed by her own issues and she would just howl at you.”* (Patient, Mthatha)

A doctor at the hospital refused to prescribe repeat Fluconazole for a patient who was taking it for cryptococcal meningitis. He insisted that the patient should go and see the doctor at the HIV clinic despite the patient telling him that there was no doctor in the clinic during that period, and patients who had to see a doctor were referred to the hospital. This unethical and careless behaviour by the doctor could have resulted in the patient not getting the Fluconazole.

*“I arrived to that doctor who told me that he won’t do another person’s work. That doctor told me that there is a doctor at the IDC and he is new, I know him. I said that is confusing because I was told at IDC that there is no doctor. He said it was not his business and I didn’t know what that meant.”* (Patient, Mthatha)

Over time patients got to know and develop good relationships with the staff so that they were able to seek help directly from them. Staff they knew would assist them willingly, so patients would try to avoid those whom they knew from experience were not amenable to helping them.

*“Most of the time we depend on the person who you see is going to listen to you. Some of them we pick up their attitude while she is talking to other patients and we end up avoiding being helped by her.”* (Patient, Port Elizabeth)

### **5.2.2 Issues with the co-ordination of care**

Co-ordination between levels of care was an issue as the policy was moving towards more down referral of patients to the primary care platform for on-going treatment. This policy was adopted with the good intention of improving access to healthcare to PLWH by providing services near where they lived, and reducing costs of travel to the regional hospital. In reality, patients had their own individual reasons for deciding where to continue with their healthcare after the initial three months of care in the hospital clinic was completed.

While some patients were in support of the idea of continuing with their care at the nearest local clinic, others chose not to for various reasons, such as stock outs of ARVs at the clinic, inadvertent disclosure of their HIV status to their community, and to opt for the more comprehensive hospital services with more regular availability of ARVs. Stigma and discrimination against PLWH was the main reason for some patients being against down referral. Some expressed the fear that the down referral would result in them stopping taking the ARVs; while other patients felt that the practice of down referral violated their rights. The fact some staff spoke about their HIV status to others also discouraged them from being down referred.

*“The problem I used to have is the money for transport when I come to fetch the pills. So I would ask to be transferred to the local clinic.”* (Patient, Mthatha)

*“They do transfer us to our nearest clinic, but you have not met with the person who can do that for you. They did transfer me to my clinic but that clinic had no ARVs so I was forced to go to another clinic and that cost me money because I had to take two different taxis to reach the clinic that had ARVs. So I decided to use IDC instead, and it is convenient for me. Other people like this arrangement of not using their nearest clinics because they do not want to be known by their communities, other nurses talk a lot about people.”* (Patient, Mthatha)

*“I would like to see clinics improved, but not the hospitals because people come here and crowd the place instead. People have the problem that they don't get treatment from their local clinics hence they come here.”* (Caregiver, Lusikisiki)

*“Where we stay we do have our own clinic but I have my own reasons for choosing the one I am using and not the one in my community. Maybe I am not ready to be known by the people in my community, so I choose to take it [ARVs] somewhere else. Now my concern is this issue of being transferred. I am afraid of how I am going to take the treatment where I do not want to go? I might end up stopping taking it. I said to her [his partner treatment supporter] today I am afraid of going to another clinic because we might end up stopping taking it.”* (Patient, Mthatha)

*“I suggest that there should be posters all over the walls that stipulate the rights of the patients. One of them is the one that says patients have the right to take treatment where they like to take it, but then the health workers are talking and saying it’s the government who ordered them to transfer us because they [the staff] are not enough, so I would like the government to hire more staff. We want to take the treatment where we like to take it.” (Patient, Port Elizabeth)*

Overcrowding at one of the hospitals was attributed to patients choosing to use the hospital for their care despite being referred to their nearest clinic. This resulted in staff being overloaded with work, and the call was made for the employment of more staff. The fact that the patients had to pay for the service at the hospital compared to the clinic, where the service was free, was cited as a disadvantage.

*“It was not always crowded here as it is now, people are running away from their clinics and they come here because DN Hospital is very quiet, so all those who do not want to be known by their community members come here. This causes overcrowding, more work and shortage of staff. At times the doctors are helping to take the patient’s blood pressure. When they come to the hospital to get help they are requested to pay at the reception, compared to the clinics where the service is free.” (Patient, Port Elizabeth)*

*“As I said I was also under the treatment of TB and I ended being admitted in NM Hospital. And when I was there they didn’t give me the treatment that they were supposed to give me [ARVs]. They only treated TB and when I came back here they told me that I had defaulted and as such I had to start afresh. It was then difficult. I was unable to walk or do anything, and at the same time I had sores in my private parts to the point that I still feel them. Yes I use this Betadine and they say I should stay in water, but they don’t get healed.” (Patient, Mthatha)*

### **5.2.3 Issues with comprehensiveness of care**

The need was expressed for HIV clinics to provide comprehensive care, and for the pharmacy to provide other medications as well. The discrimination experienced by HIV patients at the regional hospital pharmacy was more reason to consider the request. The option of getting treatment from the nearest health centre or clinic also

had its shortcomings, mainly medication stock outs. The staff at the health centre or clinic was not helpful in facilitating the process of getting the medications on behalf of the patients from elsewhere – for example from the hospital – if they didn't have stock. Provision of a comprehensive service at the HIV clinic, including stocking medicines other than ARVs at the dispensary, would save the patients the time of having to resort to buying the medicines from private pharmacies or private doctors.

*“The negative thing about this clinic is that they only provide us with ARVs. When you have a headache you are sent to MGH [Mthatha General Hospital], so now you have to walk a long distance in hot or cold weather. When you get there you will have to join another queue. If we were taking our ARV treatment there [MGH] it would be easy because everything was there – when you have a skin problem there is a skin clinic, there you don't have to walk a long distance. I wish that they could make a skin clinic here at IDC because we do need it, and of course other issues need to be addressed. We are discriminated against there a lot.”* (Patient, Mthatha)

*“Another thing that I will ask since even myself I once had feet problems to the point that I had to go to the GP because I didn't get help here. I request that all pills should be made available here in this clinic, that having to take some in this clinic and others up there, this up and down is not nice.”* (Patient, Mthatha)

*“I have these pills that I will take from the local clinic while I take others here. My wish is that I would get them all here because I don't like to be in that clinic and I would be told I should come to this clinic. At times I would even request them to phone this clinic so that I won't struggle [when I get here], but they would refuse. That didn't treat me well.”* (Patient, Mthatha)

*“I support her, because they would prescribe this treatment and you will only leave at three or you end up not going. Last time I ended up not going since it is very far at Mqanduli. I only bought Brufen since I saw that it was prescribed. Another treatment that was prescribed, which I didn't know, I decided not to buy.”* (Patient, Mthatha)

### 5.3 Outcomes of care

### 5.3.1 Issues with the quality of clinical care

Some health workers failed to adequately explain to patients the follow up and monitoring requirements, as well as the management plan, thus causing an unnecessary delay in starting their ARV treatment, without giving valid reasons. Effective communication between the healthcare provider and the patient is fundamental for good patient care. Where effort was made to communicate well with the patients, this was acknowledged. Some doctors did not examine patients. Patients felt records were poorly organised and laboratory services were also poor. Some of the patients only got served after losing their temper with the healthcare providers. Due to these issues, one of the patients even suggested that PLWH should rather be employed to take care of them because they would understand them better from personal experience.

*“The sisters here are not the same. There are those who would answer you well and you feel satisfied, and there are those ... [statement was not completed]. Just like the issue of testing every six months, I was never told about that. Also every month your CD4 count is checked, but I was never told. I asked the doctor, saying that ever since I started using ARVs I never tested for anything. He told me that every six months I will test. So it is good that you be told of such information when you start using ARVs because if I wasn't told I wouldn't know. When I tested, my results were not complete; they didn't include the CD4 count. I then asked them whether I should test again and they said no I should wait.”* (Patient, Mthatha)

*“I started taking my treatment in Port St Johns. They gave me a very hard time there; they didn't want to start the ARVs. They used to give excuses, they said our manager is not here so we won't give you the pills.”* (Patient, Mthatha)

*“Yesterday we were insulted here, by the time we were entering the room they said, ‘Take this person away, even if she stopped taking ARVs that is not our problem.’ We left this place at 3pm while we arrived at 7am. We went home empty handed; we didn't get those pills so we have to come back again. She is unable to walk, she is using crutches and I am assisting the other side that is better. All I am saying is that they are very arrogant here.”* (Treatment supporter, Mthatha)

The poor communication resulted in patients being dissatisfied with the quality of care. Complaints raised by patients, which constituted the reason(s) for consultation, were ignored and not addressed. Patients felt that their expectations were not met.

*“They are not addressing our problems well. You see I do want to go and work for myself, I do, but the problem is that I am having the problem with my feet, they are painful. When I’m reporting it to the doctors they said I should continue with my treatment, it is going to make me fine. I never get better ever since I started these ARVs .I am trying my best, it’s not like I don’t want to work.”* (Patient, Mthatha)

*“When we report these things to the doctors they take time to take action, they want to see us falling down before they do something. I have this paper where I wrote the cream that is believed to boost the fat in the face and I wanted them to help me find it if they knew anything about it. The sister in charge came with it from the workshop she attended, they had been shown the previous condition of the person before she started using it and after she has used it [before and after pictures], but no one could help me and that is bothering me a lot.”* (Patient, Port Elizabeth)

*“I just want to add to what the lady has said, what I didn’t like is that I was told I have TB and took TB treatment, and it would happen that I forget everything. I was then taken to another doctor and I was told I have TB meningitis, so I was told there was a motivation form that I had to take from MGH, and that gave some difficulties since I had to go to General Hospital. There I was told that I won’t get the form and at the same time they said I should bring the form here at the IDC, and again they would tell me that they have already filled the form for me. I ended up getting that form there at the General Hospital on my third try after I was forceful,. It was said that I should go to any doctor to complete the form even though I struggled to get him, when I got him he told me that it is the last time for him to do this, he never again would do the work of the IDC workers. But I had told the sister that it was said that I should take the treatment without stopping, things like that need to be looked at.”* (Patient, Mthatha)

Physical examinations, which most patients expected when a doctor attended them to, were not done. Patients usually shared their experiences of the service they received

with others; probably partly to inform them about the kind of service they were likely to receive in the particular health facility or from a specific healthcare provider.

*“He is taking care of you in a way, but he is not right at all, he is not caring. I did go for contraceptives and went back home. My husband asked, did he examine you or put you in the bed, I said no he just wrote the prescription, he was so surprised.”* (Patient, Mthatha)

Gaps in communication left patients feeling a sense helpless. This was experienced when one of the patient’s records could not be traced and no one was willing to thoroughly search for the records. The healthcare providers didn’t seem to be bothered by the implications of the missing records as much as the patient’s caregiver.

*“What I am going to say as the negative aspects is that when we get here the first thing we do is to take the clinic folder and we are helped very well in getting them. Secondly you will find that it is lost and when you ask you are not addressed in a decent way. What they do is to tell you to go and fetch it where you left it. I am talking about today’s treatment, that’s what they told me. You ask yourself how I am going to know it because you left it last month, when you come back to say you can’t find it they say go and take the copy of your folder, which is not good because that means the history of the child is lost.”* (Caregiver, East London)

Poor follow up of patients was a reflection of a lack of care. Not ensuring that results of investigations were available to shed more light on the patient’s condition, or not accessing the progress of the patient while on treatment, was indicative of disinterested staff. Experiences like these led one of the patients to lose his temper, and only then did he get served. Another patient expressed a wish to be attended to by peers who were living with HIV because of the belief that they would manage patients better based on their own experiences.

*“One other problem is that after five months I have to test for CD4 count. I was tested by one sister, but when I came back after a month to collect the results they were still not available. I went there many times but there was no clear report until the doctor tested me again himself, but even with him I couldn’t get my*

*results. I had to be harsh in order for me to eventually get them.” (Patient, Mthatha)*

*“They do not monitor the patients. If the patient’s pressure is dropping or increasing, they are doing nothing about that, even if you complain they are doing nothing. I wish they can employ people who are HIV positive; but the trick is that we are illiterate, because those people will understand our world and we would talk the same language.” (Patient, Port Elizabeth)*

#### **5.4 Conclusion**

The experiences patients had with health services were generally very poor. There were a few patients who reported good interactions with some of the healthcare providers and who were complimentary about the education on HIV and ARVs, as well as peer support at HIV clinics. There were structural problems related to the provision of social grants and food, overcrowding, and poor hygiene and cleanliness. Patients reported long waiting times; uncaring healthcare providers; inadvertent disclosure of their HIV status (leading to stigma and discrimination); lack of patient-centred care; and inequity in access to care. There was some resistance to down referral from the hospital to the local clinics by patients, who gave reasons such as wanting to avoid unintended disclosure to their community; the unprofessional practice of some staff who reveal the patient’s HIV status to others; and the perception that clinics were less comprehensive and offered a lower quality of care. Specific experiences related to poor communication between patients and healthcare providers, and lack of follow up of patients with detrimental consequences were cited.

The next chapter focuses on the experiences of the patients on ARVs with their contextual issues.

## **CHAPTER SIX: THE EXPERIENCES OF PATIENTS ON ARVS RELATED TO CONTEXTUAL ISSUES**

### **6.0 Introduction**

Chapter Six is about the contextual issues related to the experiences of patients on ARVs. The patients' context in this respect included the family, community, workplace, school, treatment supporters and traditional healers. The chapter is divided into four sections:

- The positive reactions of the family and others;
- The negative reactions of the family and others;
- The experiences of treatment supporters; and
- The socioeconomic, cultural and other contextual issues.

### **6.1 Positive reactions of the family and others**

The positive reaction of the family and others was seen in the form of helpful support given to the person when they tested positive for HIV and needed to go on ARVs.

#### **6.1.1 Support structures and how they came about**

Not surprisingly, immediate family members mainly supported the patients; who included brothers, sisters, mothers and partners. The support was preceded by the acceptance of one's HIV status, and disclosure to one's family. The acceptance of the patient's status by the family was also important for the quality of support they received. Whereas fathers were not mentioned as front-line supporters – except in one instance where the man was widowed – it did not necessarily mean that they were not supportive.

*“I am supported by my sister and brother. We are concerned about our lives, so that's what is motivating me.”* (Patient, Lusikisiki)

*“Because she is my mother she is not treating me bad.”* (Patient, Lusikisiki)

*“At home they are aware of her status and since she told all of them, they accepted her and support her a lot.”* (Treatment supporter, East London)

*“The family is treating me well, they were surprised because I was not that sick when I tested, and they accepted it because I accepted it.”* (Patient, Lusikisiki)

After losing his wife, the father of one of the patients had to join his children in the front line to support his child.

*“At home they accepted me and support me a lot although I no longer have a mother, I only have my father and my siblings, so they are the ones who are supporting me, they are not [HIV] positive, but they are so much loving and taking care of me. They show me love and support in a way I never saw before.”* (Patient, East London)

The other supporters were made up of friends, teachers, workmates, health workers and other members of the community.

Disclosure or knowledge of the patient’s HIV status preceded the appropriate support. This was at times selective due to the potential for negative reactions from some family members or others, which could have had adverse consequences for the patient. Patients came to the conclusion that disclosure should be selective and tailored to their unique circumstances, due to the different forms of stigmatisation and discrimination. The health workers in the clinics, however, generally promoted total disclosure and disregarded people’s specific concerns and situations. This may have been because the HIV programme is driven by public health principles and evidence that adherence is better in those who disclose. This approach was therefore contradictory to the more patient-centred approach desired by patients. For example, some of the mothers were selective about who should know their children’s status.

*“The only person I trusted was my brother who is not drinking liquor because he is not going to go around talking about my child’s status.”* (Caregiver, East London)

*“I only told his teacher [about the child’s HIV status].”* (Caregiver, Lusikisiki)

Acceptance of the patient following disclosure of his or her status was important for the quality of support, though at times this depended on individual circumstances. In some cases acceptance appeared to depend on who tested HIV positive first. For example, in situations where the husband tested positive before the wife, he would accept the wife's status more readily if she subsequently also tested positive. However, if the wife was diagnosed first, she was more likely to face the consequences of being perceived to be the one who infected the husband. This could be due to the power disparity between husband and wife in the Xhosa culture, as well as the assumption that whoever tests positive first must have been the first to be infected.

*"I am sure there was going to be a problem if it was me who got sick first. He accepted it because he is the one who came with it."* (Patient, Lusikisiki)

Knowledge of one's HIV status by the family and the community was seen as beneficial, particularly when their status was accepted. This made them feel free to take their ARVs openly, trying neither to hide nor avoid discussing their status. The family would also help by reminding the patient when it was time to take the ARVs, thus assist with adherence.

*"It helps when you are known by people as well as the home support, because what is going on is that I knew my status after my child, so now I keep these pills in the fridge. When we are visited by our cousins they see them but because they know our status there is no problem."* (Patient, Port Elizabeth)

*"He is my brother, what happens my sister is that this thing begins from the family. Immediately when you know that you are positive, if the family accepts you it becomes easy to take the treatment in a proper way, an example when you have to take it at 08h00, you get reminded. Hence those who are not supported would hide their treatment and as a result struggle to take it on time."* (Patient, Mthatha)

*“The community members are treating her fine just like any other person; her friends visit her as before she started taking them [ARVs] and she is not discriminated against at all.”* (Treatment supporter, East London)

Support by the community in one instance started negatively as one patient was initially stigmatised and discrimination against, but this changed with time. This could have been as a result of HIV education in the community and the members awakening to the reality of HIV infection not being just an individual or family issue, but a community-wide one to which everybody was susceptible. It was therefore important for them to learn about and understand the disease. The easiest and least challenging way to learn about HIV was from the community members who were living with the disease. However, going to the clinic for such information proved to be more challenging for some people, who chose instead to turn to PLWH within their communities for information.

*“The community members do not need to be told, they just know our status without being told. At first they were saying bad things, calling me names, but now they are getting closer because they want to know things, they need help but the problem is they don’t want to go to the clinic.”* (Port Elizabeth, Patient)

In return for the support he received from his community following his openness about his HIV status, one of the patients was paying it forward by encouraging them to get tested.

*“In my community I am known by everybody, not that I am preaching it, but I am not hiding it. I help many people in the community because I used to advise some of them to come and test.”* (Patient, Port Elizabeth)

One of the patients attributed acceptance and support from the family to their Christian background.

*“At home they are Christians. They know that sickness can attack anyone any time, so because of that they are supportive.”* (Patient, Lusikisiki)

### 6.1.2 The kind of support that was rendered

Support could be seen as non-specific emotional backing and acceptance, as well as specific practical actions. Practical support came mostly from family members, It included facilitating adherence by reminding the patients to take their ARVs; accompanying them to the clinic or hospital; providing money for transport and other needs; and providing food for them to take with their ARVs. The emotional support and practical help from family members was usually seen as part of their familial obligation, while non-family members did the same in the spirit of *ubuntu* (an African idea that we are only human beings through the humanity of others).

*“My brother is supporting me a lot, when you come for the first time to fetch the pills you come with your treatment supporter, so he is the one who is supporting me. He is the one who always makes sure that I have something to eat. (Patient, Lusikisiki)*

*“When I come to fetch the pills I tell them straight that I am going to take my ARVs, they give me the bus fare without saying a word.” (Patient, Lusikisiki)*

*“I get motivated because at home they are so supportive; they help me to take the ARVs on time.” (Patient, Lusikisiki)*

*“They never discriminate against me at home; they just support me and remind me to take pills.” (Patient, East London)*

*“Support from home is important, but another key thing is to accept yourself. I do not want to lie; at home they support me fully. By the time I started the pills they cost R1000 a month, and my sister was paying that money for me every month until they were available in the public sector and I was transferred there. I believe that HIV is not killing us, we are killed by not being accepted at our homes.” (Patient, Port Elizabeth)*

*“In my community people there are aware of my status and there are a lot of people who are HIV positive and we understand each other.” (Patient, East London).*

*“There is a lady who is my neighbour who uses ARVs; she is a poor person. Some sisters would come and give her food.” (Patient, Mthatha)*

## **6.2 Negative reactions of the family and others**

Negative reactions from family members and others were those attitudes and actions that patients perceived to be uncaring and/or unkind. The family members involved included parents, siblings, aunts, uncles, cousins, nieces and nephews. Others referred to people the patients interacted with outside the family, such as in the community, at work or at school. The anticipated reaction of the person informed the decision of whether or not to disclose their HIV status. Selective disclosure was even practiced within the family unit. Selective disclosure was sometimes a challenge to adherence.

It was stated by one of the participants that this negativity was not always permanent, and that people’s attitudes sometimes changed over time, becoming more accommodating of PLWH.

Negative reactions included stigmatisation, isolation, fear, discrimination, insults, and judging the person. Stigma and discrimination were the dominant negative reactions from both family and others.

### **6.2.1 The negative reactions of the family**

Despite the fact that support for each other forms part of the primary core function of a family, this is subject to what kind of people the family members are, the types of relationships the different family members have with each other, as well as the external influences the different family members are exposed to. Therefore a variation of reactions was to be expected from the family members.

*“People are not the same, even the siblings. Let’s say you have seven sisters and you have told three of them, you will find that one of them is discriminating or trying to isolate you. I am talking from experience. Last year we had a funeral at home and I borrowed a nail cutter from one of them [my sisters], she gave it to me and after I finished using it she said, ‘You can have it’. I got affected with that because I was not sure whether she was giving it me as a sister or what. I tried to borrow something*

*else, a hair drier, she said to me, 'Let me dry first and then you can have it.'*"  
(Patient, Port Elizabeth)

*"The person who insulted me was my younger sister; she was standing outside the yard shouting. I told my boyfriend and he said I should ignore her because one day she would have it [HIV]."* (Patient, Port Elizabeth.)

*"I noticed that she likes playing alone, she is isolating herself from the others. It's just once in a while where you would see her playing with other kids."* (Caregiver, Port Elizabeth)

*"At times it is difficult, they at times fight on their own as siblings, and when they fight they used to insult the one who is [HIV] positive because of her status. She is not hiding it, but she gets hurt when you always remind her."* (Caregiver, Port Elizabeth)

*"Her father is the other one who insults her when he gets drunk."*(Caregiver, Port Elizabeth)

The attitude of the patient and the emotional exhaustion from caring for the patient may at times cause the family to behave in a non-supportive way towards the patient. This is akin to the "burn out" that healthcare providers experience when caring for patients who need high emotional support. The reaction of the family to a loved one's HIV diagnosis may be part of a more complex family dynamic.

*"At times we used to be angry with her [PLWH] because we are human beings, we get tired. We tolerate her and support her despite many challenges because we are a group of siblings. If she is cross with me the other one understands and tries to talk sense to both of us."* (Treatment supporter, East London)

Sometimes, however, the situation becomes so gruelling for the family that tempers flare.

*"One time she fought with my elder sister and the fight was very serious. My sister was frustrated by her [PLWH] reluctance to learn how to use crutches to reduce the*

*burden of having to carry her around. She got tired and had to leave home to stay somewhere else for a while. She left me with her, we also fought, we were not seeing eye-to-eye, and she didn't want to eat. Our grandmother had taught us that sick people must eat healthy food. In the end she understood my point.”* (Treatment supporter, East London)

### **6.2.2 The negative reactions of the community**

The community treated PLWH differently. They were discriminated against, insulted, isolated, stigmatised and were regarded as immoral. Discrimination included not sharing certain items – such as kitchen utensils – with them for fear of getting infected. It was also difficult for them to forge intimate relationships with potential partners.

*“There is a sister in the community who is related to my husband, she came to my house and insulted me saying that I am the one who brought HIV to my husband. I was so hurt that I went straight to her and told her to stop saying things about me.”* (Patient, Port Elizabeth)

*“Community members are sometimes giving us problems, they are kind of discriminating against him [PLWH], and at times you could see that most people do not share anything with him, things like water glasses.”* (Treatment supporter, East London)

*“When you try to ask someone out to date her, her friends would say leave that one he is having HIV. But we do not care about that.”* (Patient, Lusikisiki)

Due to adverse experiences from community members, PLWH unanimously advocated for selective disclosure. They revealed a tendency of people to whom they had disclosed to circulating the information to others.

*“The community members are not aware of my status. The reason is that some people make fun about other people's sickness.”* (Patient, East London)

*“It’s good to disclose but not all the time, everyday and everywhere, because if you do that you end up being the talk of that community you disclosed to; people tend to call you names and talk behind your back if you disclose too much.” (Participant Observation, Mthatha)*

*“People let’s not take this thing easy, most people and nurses are taking the issue of disclosing as easy as you are doing now. Once you disclose even to people around you, they judge you as if you are a prostitute or something similar.” (Participant Observation, Mthatha)*

*“It is not easy. People are talking and I remember after I have disclosed [HIV status] at one of the awareness campaigns that took place, they said we are paid so that people can disclose. That was very funny because they could see that I am sick but they were just trying to make fun of me.” (Patient, Mthatha)*

The participants felt that the negative reactions reflected ignorance on the part of the community. They thus called for the education of the community about HIV infection.

*“There are still people who need to be educated. In my community I called the social workers for my neighbours. My sister was having TB and we didn’t know what the problem was, the community members were always asking and talking behind her back. I reported them to the social workers to attend to the matter.” (Caregiver, Port Elizabeth)*

*“There are still people who need to be educated about HIV, they change their faces when you tell them about your status, and they have attitude when you tell them.” (Patient, Port Elizabeth)*

*“We are staying at the township where most people have not tested themselves so they talk behind our backs. If they do, most people we are having problems with are those who test negative. They give those who test positive names; they used to say positive people are dying.” (Patient, East London)*

### 6.2.3 Negative reactions at school

Schools form part of the community. The attitude of schools towards PLWH was a reflection of the community's attitude. Given the above-mentioned perceptions of the community about PLWH, it was therefore no surprise that the situation at schools was no different. This was despite the fact that schools are supposed to have programmes to educate both learners and educators about HIV. The unfavourable situation at schools made it difficult for children living with HIV to attend school normally, and it was heartbreaking for the parents of these children.

*"I have been called by the principal of his school, he told me that he should stop attending school because he is going to infect other kids. He asked me to put in writing the health condition of my child."* [Crying] (Caregiver, East London)

A parent had to take her HIV positive child to another school because of abuse.

*"The thing is we don't care about what people say or do; we changed him from the school he was attending to the disabled one. It is a mixed school. I want him to be exposed to this situation and I don't want him to be abused. Another reason is that it is the nearest school to our home."* (Caregiver, Lusikisiki)

### 6.2.4 Negative reactions at work

Discrimination by employers was cited as one of the trials faced by PLWH. The perceived burden the employer could have to carry as a result of employing someone whose health was potentially compromised may also have informed the employers' actions. Employment opportunities for PLWH were thus reduced, further increasing their challenges of adhering to ARVs. Non-supportive working environments also contributed to non-adherence.

*"In order to get my job, when I was applying I hid my status otherwise I would not have got the job; I later disclosed."* (Patient, Port Elizabeth)

*"At work on the day I was late, the maintenance guys came to fix the shelves there, they broke the shelves and when I came in they told me that all my stuff have been taken and kept somewhere else in the store. I was so worried because I kept some of*

*my pills there. One of them noticed that I was not fine with all this. They now knew that I was on ARVs. I was stressed and always isolated myself from people. Since then I always kept an eye on them and always suspicious of people.”* (Patient, Port Elizabeth)

Loss of work could be as a result of the employer’s unwillingness to employ someone living with HIV, or due to the deterioration in the health of the employee. An unfavourable working environment for the patient – such as negative reactions to their HIV status – could lead to someone leaving their job. A PLWH could also decide to move closer to family where support would be better.

*“I can go to work [is able to work] but the problem is that I wrote my status in my CV, so when they see it they reject my application. I wish the government could take care of that.”* (Patient, Port Elizabeth).

*“I changed my job from Cape Town and came here because I noticed that the workers were abused there. I have worked as a fisherman there for more than forty years. I experienced a lot of abuse. While the person is sick the bosses do not make an effort to help. They start to make an effort when the person is dead.”* (Patient, Port Elizabeth)

### **6.2.5 Consequences of negative reactions**

Negative reactions of the family and others affected the patients in various ways. PLWH lost friends, spouses and romantic relationships, but hope in ever getting married in the future.

*“There are times they like to use terms that are insulting and you would see that they are distancing themselves from you. I lost all my friends, but some of them came close, they are attending the clinic.”* (Patient, Port Elizabeth)

*“People do talk and point fingers at us and at times they go around talking behind our backs about our status. They continue to talk until we are abandoned by our wives.”* (Patient, Lusikisiki)

One of the patients wondered if her HIV positive status ruled out marriage for her, but other patients encouraged her and advised her to disclose her illness to her future spouse.

*“Get married my sister, but be honest and tell your husband that you are positive so that you cannot be fighting with him when he finds out about it.”* (Participant Observation, Mthatha)

Patients hid their ARVs in order to avoid inadvertent disclosure to people they were not comfortable telling. A common occurrence was for people to remove their ARVs from the original packaging and put them in something else to mask what was inside.

*“Four patients, who had just got their ARVs threw the original containers into the rubbish bin and put all the pills in the plastic they had come with.”* (Participant Observation, Mthatha)

Taking ARVs covertly had the potential to compromise adherence.

*“He was already taking ARVs, even though he kept that a secret, but I noticed that, and he still tried to hide it when I was interrogating him.”* (Patient, Mthatha)

*“At work it happens that you didn’t disclose to your friends and you have to take the pills all the time. I am working under pressure, it happens that when I arrive in the morning at 08h00, I have to go to the toilet and take the pills. It is always busy at work and sometimes I used to remember them at 10h00 and the problem is that I am always hiding that I am taking the ARVs.”* (Patient, Port Elizabeth)

*“The issue of taking pills affects me both at work and where I am staying in the flats, where there is always a crowd. I did not disclose to all of them and that is impossible. They are always concerned as to why I am always alone. Ever since I started them [ARVs] I never became fine although I have all the support I can get, but emotionally I am not coping at all.”*(Patient, Port Elizabeth)

As previously noted, an anticipated negative reaction would often lead to PLWH not disclosing their status, or to selective disclosure. A mother who accidentally discovered her daughter's HIV clinic card when she was doing the laundry was conscious of the fact that disclosure was daunting. The father was angry that their daughter had not disclosed her status to them.

*"The Lord is still with me. She hid it [HIV status] at first and I found out accidentally when I was washing her clothes and came across her clinic card. I understood, but her father wanted to shout at her, but I stopped him. I took it that she was not ready to tell us, or was afraid."* (Treatment supporter, Mthatha)

*"No I am not the only child, there are other young girls [siblings] who I do not like to know my status because they are still dating and they just started that, so they are not aware of their status. My understanding is that I do not want to confuse them. For the community members they are not aware, I don't want them to know, they have a tendency of talking behind our backs."* (Patient, Lusikisiki).

*"What usually destructs me is the presence of my sisters-in-law; they are not aware of my status. I get uncomfortable when they are around because they are distracting me, sometimes you would find that they are in my bedroom and my pills are there and that was a problem as I would not be able to take my treatment."* (Patient, Port Elizabeth)

PLWH were also displeased with fellow patients disclosing each other's HIV status to the community without their consent.

*"Let's stop discussing other people's status. Some of us do not want to be known and what we do is to go and tell people that we saw so-and-so at IDC taking ARVs. That is not good at all."*(Patient, Mthatha)

*"In my community I have a problem with a girl who is my neighbour who teaches about HIV using me as a reference. But she is not even aware of her status. She used to come to our house and see us taking ARVs because we don't hide them. This girl would ask me whether that is a treatment and I said yes, and she asks whether it is for high blood pressure and I would tell her no, it's HIV treatment."*(Patient, Mthatha)

### 6.2.6 Measures suggested by PLWH to reduce negative reactions of family and others

Patients had different coping mechanisms to deal with the emotional pain caused by family and others who reacted negatively to their status. Some PLWH tried to ignore, shut out and/or not focus on the negative reactions of others. These were tactics to prevent negativity from affecting them.

*“Another problem, people at our townships are talking, they are saying things that hurt, but I told myself that I for one I do not care. First of all is to accept your condition, you didn’t ask for it. Secondly it is not like you are not taking a good care of yourself. Maybe your husband brought it for you and now you are in that situation.” (Patient, Port Elizabeth)*

*“We decided to ignore and forget about them because they look at us as different people from them. What keeps us going is the fact that the person who is pointing fingers at us is not even aware of his/her status so you are better than him.” (Patient, Lusikisiki)*

*“People at work are the kind of people who just talk carelessly. I told myself that if I listen to them I will get hurt every day of my life. The people who understand my situation are my supervisors; otherwise my colleagues are careless.” (Patient, East London)*

Patients and caregivers were encouraging people who did not know their HIV status to get tested. This could have been partly to curtail those who tested positive from continuing with their insensitivity towards PLWH.

*“I encourage the youth to test and I tell them if they fear to be known here at their village, they should rather come and test here at the hospital so that they could be helped.” (Caregiver, Lusikisiki)*

The anguish of being the victim of stigmatisation and discrimination pushed one PLWH to pray that the people who were persecuting her would get infected so that they would have first-hand experience of being victimised. This was an

example of using religion as not only for coping, but also a fighting back mechanism.

*“In my community people are talking. What is happening at my home we were not allowed to go and play or visit at other homes. They took it as if I did not want to greet them; they were calling me names, and one of names was that I was a ‘tsunami’. I prayed to God that He should give this virus to the person who was calling me ‘tsunami’ because he was making me feel pain.”* (Patient, Port Elizabeth)

One of the benefits of taking ARVs and eating well was the fact that the health and overall appearance of PLWH improved, quietening down the negative sentiments because their appearance didn’t inadvertently reveal their status. The improvement of one of the participants taking ARVs had a dual advantage – not only did she stop “looking” like someone with HIV, but her natural fairer complexion returned, thus sparing her from xenophobic incidents. PLWH called on the government to assist with the provision of healthy food.

*“Kids who are positive need to eat healthy food because if they have bones in the face, that would suggest their status. We would love to be supported by the government.”* (Caregiver, Port Elizabeth)

*“I was looking exactly like people from Central Africa; people were even calling me names. I continued to take the pills until they made me better. I never changed the treatment, it is now that I am going to change it.”* (Patient, Port Elizabeth)

### **6.3 Experiences of treatment supporters**

Treatment supporters were part of the team that assisted patients on ARVs. Their role involved supporting the patients at home and when they visited health facilities. They counselled the patients about adherence to ARVs, storage, side effects, taking treatment with food, as well as educated them about the basics of HIV and they discussed their social problems with them.

Treatment supporters walked alongside the patients during the course of their journey, from post diagnosis and acceptance of their condition, all through to their willingness to take ARVs, and beyond. The majority of treatment supporters were family members such as spouses, siblings, children, nephews and nieces. Couples who were both PLWH supported each other very well. Others included neighbours and friends. The majority of treatment supporters were women on ARVs. The few male treatment supporters were spouses or partners who were also HIV positive.

Parental responsibility was a strong motivator for treatment supporters to take care of their own children who were HIV positive.

*“We are forced to be motivated, more especially if you are supporting your child because to him or her you are the last hope. My child whom I am supporting is responsible and takes good care of herself and the pills.”* (Treatment supporter, Port Elizabeth)

*“I support my brother’s son, and my husband and I am also a patient. My husband and I have just started our treatment. He was diagnosed in April, but he had not accepted his status at that time. He was even dodging taking the Bactrim he was given. He would leave the Bactrim at Idutywa, but I wasn’t sure whether he had not left it intentionally. As time went he was coughing and became very sick but became better when he used treatment. We came here for the purpose of getting the treatment, but he was told that he must go to Butterworth where his file is. We persisted and we were eventually given treatment.”* (Patient and treatment supporter, Mthatha)

*“Since my wife and I started taking the ARVs, we are supporting and helping each other to reach that point of peace with ourselves.”* (Patient, Port Elizabeth)

Since it was impossible for treatment supporters to be with the patient all the time, it was important for them to capacitate them to be independent to ensure that they continued to adhere to the ARVs in their absence.

*“I am leaving in January, hence I decided to monitor him closely so that even before I go I can see that he takes the treatment at the right time. But I realise that he takes*

*them seriously when checking yesterday. I came with them yesterday and it was hot, hence I decided to put them in a cool place. I knew that he takes them at around seven and around six he sent a child to collect them from me.”* (Patient and treatment supporter, Mthatha)

Treatment supporters warned patients against alternative healers who tended to not only confuse them, but also encouraged them to stop taking ARVs. Some even claimed that they could cure HIV.

*“There would be people who would come and tell you that they have a cure for HIV. If you do not listen to them you will be fine.”* (Treatment supporter, Lusikisiki)

Those treatment supporters who were also HIV positive were more effective in their role as they understood the issues more and drew on their own experiences of living with HIV. Support groups also had a vital role to play – that of supporting the supporters. Likewise, couples supporting each other seemed to work exceptionally well.

*“I am also a patient myself and involved in the support group at Mabheni. I met her in the door-to-door we were doing as home visitors, she had just arrived from Johannesburg and she wasn't well. She told me her story and I accepted her and also told her that we are sisters in health issues. I also told her that she should accept the situation, this not the end of life. We continued in the support group and I realised that whenever we are in the support group she cries. And when I made a follow up I became aware that her husband passed away, she did have the grant, but it didn't meet the needs of the children.”* (Patient and treatment supporter, Mthatha)

*“I saw the difference from me, I got sick and was given the ARVs. I became fine and that motivates me a lot.”* (Patient and treatment supporter, East London)

*“I am working in the programme that deals with HIV/AIDS issues. I have HIV and I am on treatment. So that motivates me to help others.”* (Patient, caregiver and treatment supporter, East London.)

*“I am supporting my older sister. At first she was supported by my mother, but because she was drinking liquor heavily I decided to take over. I am taking the ARVs too but I am stronger than her. I usually accompany her to take her treatment at the clinic. I said to her I was not sick and not aware of my status until I was told by my boyfriend to test because the girl he was dating together with me was pregnant and tested positive.”* (Patient and treatment supporter, Port Elizabeth)

One of the treatment supporters linked up her patient with an NGO to empower her to establish her own vegetable garden in order to cut down on food expenditure.

*“An NGO assisted the patient and myself to set up a vegetable garden, which helped to improve her diet and reduce the cost of food.”* (Treatment supporter, Mthatha)

### **6.3.1 Challenges experienced by treatment supporters**

Some of the patients that treatment supporters cared for were emotionally fragile and/or unstable because of what they were going through with the disease. This manifested in various ways, including aggression and violence. This was likely the anger stage of Kübler-Ross’s five stages of grief (Kübler-Ross, 1969). The aggression and anger was sometimes targeted at the treatment supporters.

*“The difficulty I have is that he beats me, it became difficult to make him take his ARVs. I would say to him, ‘Wake up and take your treatment.’ And he would say, ‘Leave me alone.’”* (Treatment supporter, Mthatha)

*“I am supporting my niece. She was very sick and her eye was removed. She is also angry and aggressive. When I wash her she used to fight with me because of pain she thought I would cause her to have. I thought her reactions were due to poor counselling so she could not understand what was going on in her life. As we talk she is admitted at the Provincial Hospital.”* (Treatment supporter, Port Elizabeth)

Facilitating adherence is one of the core functions of treatment supporters. While they may have tried their best to ensure the patient was adhering to treatment, they were

not always successful. The patient's state of mind – such as denial, which leads to not accepting that one is HIV positive – could result in the non-adherence to ARVs.

*“At home there is this child I took to the clinic for contraception. In the clinic they offered to test her. She tested positive and was given Bactrim. She took it only for two days and then stopped taking it. She refused to go for more treatment. We have been trying to talk some sense to her, but she is very careless, she likes partying and going out. I am afraid of her condition; she is giving me some problems. When I ask her to move in with me she refuses, if she accepts she stays for two days only and goes back home.”* (Treatment supporter, Mthatha)

Acceptance of one's HIV status was a progression; it could take some effort to achieve.

*“The first thing it was difficult to accept. I tried to make her understand that whenever she has problems with the treatment, she should meet the doctor. I also encouraged her, saying that even in the support group you can ask about the pills and even the side effects. This will help. For instance if a certain pill has a problem, it can be changed.”* (Treatment supporter, Lusikisiki.)

How well the patient adapted to this new life of living with HIV depended a lot on the treatment supporters imparting their knowledge to the patient, and on the patients internalising and practicing what they have learnt.

*“I first advised her regarding food and then the treatment. I also told her not to be fearful, that she should not hide her treatment. I also don't want her to be afraid of me. If she has done any mistake, she should inform me. I also remind her about the time [to take her treatment].”* (Treatment supporter, Lusikisiki)

A patients being unable to afford food was a huge challenge for treatment supporters. This was a prevalent problem as most patients did not have a regular income, and social grants were not always enough able to meet the needs.

*“Another thing I want to say is the issue of food; we are struggling, we don’t have money to feed our kids.”* (Caregiver and treatment supporter, Port Elizabeth)

*“Coming to the issue of money, my mother is receiving the foster care grant for the child, but it is not enough to take care of the child who is on ARVs.”* (Caregiver and treatment supporter, Port Elizabeth)

*“I am struggling, I have no money to support her although she is getting the support grant, but it is not enough for her. She does have a father, but her father is useless because he is not supporting the child at all. There are a lot of things they make me feel so bad when I talk about them.”* (Treatment supporter, Port Elizabeth)

Treatment supporters, who do not choose their patients, were expected to deal with a range of different personalities and come up with ways of coping. An example was the patient who battled to work through not having food.

*“When she is hungry she does not listen, I must be next to her always to console her until she is alright. I tell her that this is not the way to behave when you are on treatment. I would tell her not to always worry even for minor things.”* (Treatment supporter, Mthatha)

Treatment supporters also battled to help patients who experienced side effects from the ARVs.

*“They are very stubborn and when they start to develop some side effects they just want to stop taking them. That is a challenge to us because we need to convince them that the side effects are passing, she going to be fine.”* (Treatment supporter, Port Elizabeth)

#### **6.4 Socioeconomic, cultural and other contextual issues**

Socioeconomic and cultural issues formed part of the broader contextual experiences of patients on ARVs.

#### 6.4.1 Socioeconomic experiences of patients on ARVs

These related mostly to insufficient money to pay for both HIV-related and basic needs. Food, transport money to visit health facilities regularly, airtime for mobile phones, school fees and related expenses, shop accounts, and other debts formed part of these needs.

Specifically highlighted was money for food. Eating healthy food was associated with good health, but it was expensive. Unhealthy and insufficient food resulted in more side effects from the ARVs, and unwillingness to take treatment.

*“I request for grant because the drugs I am using require me to eat healthy food.”*  
(Patient, Mthatha)

*“Because of the food I am eating since it is not the same food I used to eat, I used to get social grant, but now that is no longer the case. Sometimes I would feel like something burning in my chest. I think it’s because I am not eating well, the treatment is not treating me well. Now I am afraid of using them but I do use them. I am unable to eat healthy food because I don’t have money.”* (Patient, Mthatha)

While some of the patients were willing to work, their illness made it difficult to meet the demands of the job that would have enabled them to earn money to meet their needs. The lack of income resulted in one of the participants depending on food donations, which was obviously not sustainable.

*When I get a job I only work for one month and my feet begin to swell until I am admitted to the hospital, and I end up losing that job. So it’s painful in my heart all the time. Even the food that I am eating, I got it through parcels that people gave me. I have no money and I am alone at home. The soup you [referring to the clinic] used to give us was so good, but you stopped now. If I happen to eat some healthy food, it feels better.”*(Patient, Mthatha)

Because of the country’s high rate of unemployment, rampant poverty and some patients being too ill to work, many of them depended on the government disability grant administered by SASSA through the Department of Social Development.

Those who were fortunate enough to get the grant generally appreciated it.

*“I do get it [social grant]. I started last November and they told me that it would last up to November. What I remember is that my CD4 count was very low so I got it on those grounds.”* (Patient, Lusikisiki)

Some of the patients depended on other types of grants, such as the child support grant, and used it for purposes other than what intended because of a lack of alternative sources of income.

*“I have three kids. I am not working and I depend on the social grant given to my two kids. At times I end up taking the drugs without having eaten. At times I do not have any vegetables and fruit to eat for a month or two. For me to be able to collect ARVs from the clinic I have to walk on foot since I don't even have money for transport.”* (Patient, Mthatha)

*“As I already said I am not working. I used to get some piece jobs [casual jobs] maybe twice a month, and that is so difficult for me. I am struggling, we both depend on the child support grant that my wife is getting for the child, and it is not enough because it is only R250. At times she would go and do some washing for the other people.”* (Treatment supporter, East London)

There were numerous complaints related to the administration of the social grant. These included the difficulties encountered in getting the grant, irrespective of how ill one might be; the inadequacy of the grant to meet people's needs; the grant being cancelled without informing the recipients; and a range of other unfair practices. Some health workers were perceived to be unhelpful in assisting people to get the grant. For those who had at some stage received the grant before was later taken away, it left a huge gap that resulted in them not being able to afford to buy food.

*“I appreciate the fact he is getting ARVs, but the problem is that he is not getting the grant. I tried to register him for the HIV grant, but he was not successful and I was told that I should register him for the foster care and I did, even though it was not*

*successful. I was told that there were things I had written wrongly since I was renewing the grant for other children as well.” (Caregiver, Lusikisiki)*

*“I did get it [the grant], but it was taken away in July last year. I have been trying to renew it but they tell me I am strong and fit.” (Patient, Port Elizabeth)*

*“Because I realised that my condition is very bad, I went to stay at the place called Santa [Santa operates similar to a hospice, and offers care to TB and HIV patients] I was struggling a lot with everything, they advised me to apply for a grant. I did, but I failed. They say I am being rejected by the computer, my CD4 count is not agreeing with me to get a grant.” (Patient, Mthatha)*

*“One of the ladies who died was from my town, she was without a sister like me. She used to say, ‘My home girl, let us look after each other so that the one who dies first will be buried by the one who is still alive.’ She did die first and I helped where I could. She did everything to get social grant but the computer rejected her. She would be carried on someone’s back since she was unable to walk, but the computer still rejected her.” (Patient, Mthatha)*

*“What is the problem with our virus? Because we take ARVs with those who got diagnosed, but we are not given grant. I wish the government would come here and take the list of those taking ARVs or with low CD4 count and take it to SASSA. Even though the nurses say we boast about the virus, we are not boasting about the virus, because we didn’t ask for it, but we need government to help us because we already have it.” (Patient, Mthatha)*

A patient related a story of a health worker who was perceived not to be helpful in assisting patients to get a grant.

*“The doctor at this clinic [HIV clinic at Mthatha Hospital] says that they are not handling grant things here, but they handled at SASSA. He also says that we should not ask him this question, because we are the ones who are corrupt and would influence the increase and decrease of the grant. He further said we would go to the extent of saying we are positive even when we are negative. I then asked the doctor*

*whether the list could not be made at the clinic and given to SASSA for them to verify who actually attends the clinic. They would know that so-and-so comes to this clinic every month since she or he has the virus and is receiving treatment here. Those who come to the clinic will receive grant, those who don't won't get it. The doctor didn't accept the suggestion.” (Patient, Mthatha)*

*“We are told that we are rejected by the computer, it is actually the doctor who does not recommend people to get grant.” (Patient, Mthatha)*

The government was lauded for making it possible for PLWH to access ARVs in the public health service, as they were expensive and beyond the reach of most people who were infected and affected by HIV. Despite the frustrations of not getting a social grant, one of the patients felt that the most important thing was to continue taking the ARVs. He appreciated the fact that ARVs were available and they made a lot of difference to one's health when taken as recommended.

*“The only thing that makes my heart painful is the issue of the grant, I did get it at first, it was stopped. I tried again but I didn't get it again. I eat the pills; I never stopped. This is the second card that I am using, but the grant stopped after a year. Even you go to the grant offices they tell you that you are well. They used to give us a soup and the DIVA [food parcel], but they are no longer giving us. It was very good and I liked it a lot. But despite all that, I thank the pills. Others have died because of not following the rules of the pills.” (Patient, Lusikisiki)*

Some felt that in the face of rampant unemployment, and added to that the discrimination by employers faced by PLWH in the labour market, those who were recommended to get the social grant should continue to receive it for life. As one of the patients put it, even if their health had improved, there was no guarantee that they would get an alternative source of income to take over where the grant had left off. Furthermore, they would remain HIV positive forever.

As opportunities for employment were limited for them, and the social grant could not be relied on as a long-term source of income, it was put forward that the government could assist PLWH to embark on some income-generating projects.

*“We are hungry and what is now going on is that at our homes and communities we are not given job opportunities, they are given to people who are literate. We are still people who want to work, though we are HIV positive. We would like to do things for ourselves, as we are not mentally ill. We do have some little education; we are not blank. We are always told about CD4 count, it hurts us because we are not old ladies who cannot do anything on their own, we can work and do something for a living. We would like to have our own projects – for example vegetable gardens and handwork like needlework and other crafts – so that we can have something to eat at the end of the day. The government should assist us with training, and money for the projects. It is difficult to take pills on an empty stomach.”* (Patient and treatment supporter, Port Elizabeth)

Home visits were suggested to identify those who were desperately in need of government assistance, but did not have an opportunity to put their case to the government.

*“The only thing I wish for is that the government should get in door to door and look for people who are suffering because other people do not even have money to come and see the doctor or take the pills. I am amongst the people who decided to die after hearing my status.”* (Patient, East London)

Mobile clinics were suggested to bring services closer to the people as travelling was a challenge because of poor roads, and were practically impossible to traverse when it rained.

*“If the government could bring back mobile clinics things would be better. It could be announced that the mobile clinic will be at a certain place on such-and-such a day so that we can go there and fetch our treatment. Sometimes it is difficult for us to get the bus and sometimes it is raining and impossible for the bus to go to the rural areas where there are no roads, so the mobile clinic can assist a lot.”* (Patient, Lusikisiki)

#### 6.4.2 Cultural experiences, with regard to traditional medicines, of patients on ARVs

The cultural issues mentioned were mostly in relation to the role of traditional medicine. Most of the participants had previously used traditional medicines, with a few of the patients being sceptical of them. Traditional medicines were at times used to alleviate specific symptoms experienced by the patients.

*“People said when you take ARVs while having shingles they would just disappear on the outside and still remain inside. I was taking traditional medicine to try and heal them from inside. So all in all I was drinking it.”* (Patient, Lusikisiki)

*“I was using something called masi.”*(Patient, Mthatha)

*“I was using masi too for pimples, mixed with other traditional medicines, but I was told I should not use the masi at all.”* (Patient, Mthatha)

Some side effects of the traditional medicines were dangerous.

*“Last month I had a painful ear and I took traditional medicine. This medicine was poured into my ear and I was given some to drink. I almost died.”* (Patient, Mthatha)

*“If you use them [traditional medicine] they put you down. In fact at home they are not in use.”*(Female treatment supporter Mthatha)

*“When I started being sick, I thought the poison which I got was through witchcraft. I then went to a person who deals with such poison. He wanted R200 from me, but I only had R100. I was given the medicine in a bottle. The medicine was mixed with long life milk. I drank it there and then I went to the toilet. I never slept that night. My eyes were black; I was using the white part to look. I was clueless about my status by then. I always thought that my blood system was dirty. I decided that I will never drink traditional medicine again.”* (Patient, Mthatha)

As part of HIV education, health workers often emphasised the need to avoid the use of traditional medicine when one was taking ARVs.

*“When I tested positive the nurses gave me some rules, they said do not use traditional medicine, do not do this and that. And I did exactly like that and that is why I am like this today.”* (Patient, Lusikisiki)

*“I was using traditional medicine called Magogota, but stopped after taking ARVs.”*  
(Patient, Mthatha)

*“We were advised by the nurses that they [traditional medicines] are not mixed or used simultaneously with ARVs.”* (Treatment supporter, East London)

Some of the participants were very sceptical of traditional medicines.

*“People still need to be educated concerning the issue of HIV/AIDS. They are blank, what they do is to use traditional medicine while they are dying.”* (Patient, Mthatha)

*“From where I come from we never used traditional medicine, I do not trust them. Another thing was that we saw the ARVs were helping on their own. The problem with traditional healers is that they do not test a person, and they do not know the complications caused by the traditional medicines inside the person. But with the ARVs we get checked after some months to assess how the pills are treating you.”*  
(Caregiver, Lusikisiki)

*“At home we are coloured so we never used traditional medicine.”* (Caregiver, Lusikisiki)

*“When I brought her here for the first time, her jaws were swollen, having chest pains, and wounds such that when I was talking about her wounds she would say, ‘Mama don’t embarrass me’. We were using traditional medicine but she was not getting any better. Now she is well after we stopped using them.”* (Caregiver, Lusikisiki)

Some patients were not candid about their use of traditional medicine. One of the participants was honest and informed the doctor about the traditional medicine he was

using, and the benefits he was deriving from them. He was contemplating persuading his doctor to continue using traditional medicines in conjunction with ARVs.

*“I do not want to lie, there is medicine that we add aloe to. I feel energetic when I take it. I am even thinking of negotiating with the doctor if he could allow me take it together with the ARVs.”* (Patient, Port Elizabeth)

## **6.5 Conclusion**

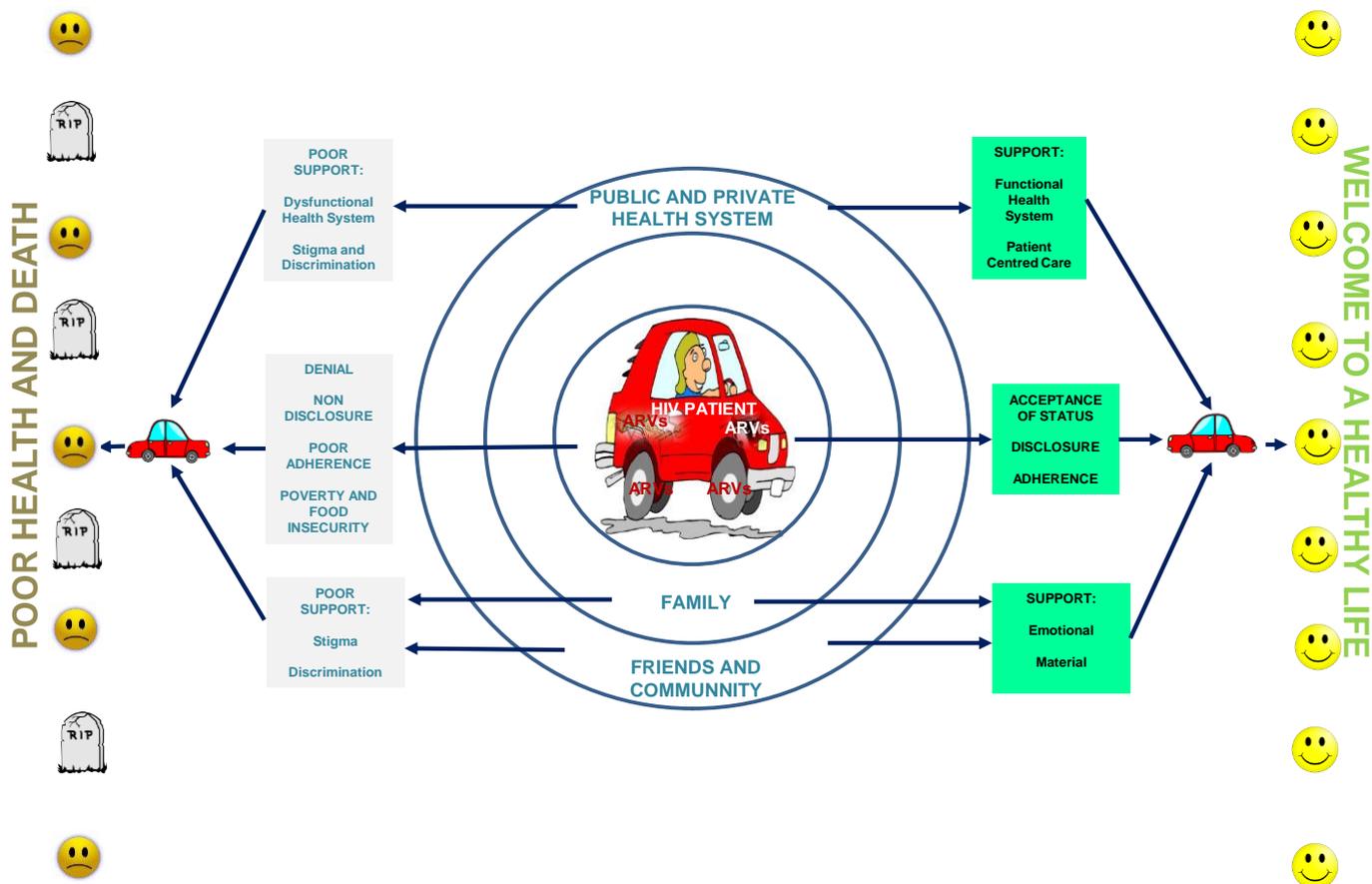
This chapter was about the contextual experiences of patients on ARVs. Positive experiences included support from family and other role players such as treatment supporters, community members, work colleagues or teachers. Support was needed at every stage – from HIV testing and acceptance of the positive results, to disclosure and the taking of ARVs. Stigma, discrimination and socioeconomic challenges were the main negative experiences. The sociocultural experiences mainly related to the use of traditional medicine in conjunction with ARVs. The majority of the patients who used to treat ailments with traditional medicines stopped doing so after commencing ARVs treatment as a result of health education.

The next chapter will examine the results of the thesis as presented in Chapters Four, Five and Six relating the findings to systems theory and the literature. The importance of the findings to the discipline of Family Medicine and the strengths and limitations of the study will also be highlighted.

## **CHAPTER SEVEN: DISCUSSION**

### **7.0 Introduction**

This chapter integrates the key findings and discusses them in relation to the available literature and current HIV policy. Limitations of the research are also discussed. The conceptual framework for the study (see Chapter Two) used systems theory to conceptualise the different systems that the PLWH are part of and which needed to be explored. The key findings can also be conceptualised using this same framework as shown in Figure 7.1.



**Figure 7.1 A diagram showing a summary of the study findings conceptualised using systems theory**

Figure 7.1 shows an HIV patient on a “journey” to a healthy life, which depends on his own internal effort to accept his status, disclose his status in order to elicit support, and to adhere to his ARVs. This is within the context of supportive experiences related to a functional health system with supportive healthcare providers on the one hand, and a supportive family and community on the other hand.

There was cross-pollination between the experiences related to the two arms of the context. For example, treatment supporters, who were a link between the health service and PLWH (to facilitate their care), were often members of the family or the community in which the patient they supported belonged. Moreover, some treatment supporters were also patients themselves. Conversely, the backward “journey” to ill health and death was facilitated by the patient’s negative feelings and practices in relation to denial of their

HIV status, non-disclosure, poor adherence to ARVs, and poverty and food insecurity. This was compounded by a context of poor support from the family, community and the health system, with stigma and discrimination particularly emphasised. A detailed discussion of the key findings related to these alternate “journeys” will follow.

## **7.1 The “journey” of the newly-diagnosed HIV patient**

### **7.1.1 The diagnosis of HIV**

Patients only mentioned HIV testing as part of antenatal care or in response to their partner testing positive. These reasons were far fewer than given in other studies (Campbell & Williams, 1999; Collinge, 2005). For example, responding to the National HIV Counselling and Testing (HCT) campaign, testing to recheck one’s status after an initial positive test, or testing for insurance purposes were not spontaneously mentioned.

The decision to be tested was not easy, as was reflected by the few reasons given for testing in this study. It is also possible that others chose not to give their reasons for testing or not to get tested at all because they feared being morality judged, including by the healthcare providers, or they anticipated stigma and discrimination.

Patients in this study, therefore, admitted to being only tested when prompted by antenatal care protocols or when confronted directly by an HIV positive partner. Proactive testing, in order to just know one’s status as recommended by the government’s campaign, did not appear to have had a significant impact. This would imply that a large number of people remained undiagnosed and continued to fuel the epidemic. Indeed, it has been reported that out of the 25 million people thought to be living with HIV in sub-Saharan Africa (UNAIDS, 2014), only 42% are aware of their HIV status. In Africa less than 20% of the girls between 15-19years are aware of their HIV status(WHO,2015,2016d)

The low uptake of HIV testing has been partly explained by widespread stigma and discrimination against HIV positive people. This is because of the shame associated with the perception that HIV infection is a disease that is acquired through immoral sexual behaviour or illicit drug injection (Sontag, 1990; Phillips & Sowell, 2000).

Stigma makes it hard for people to go for HIV testing, treatment, care and counselling for fear of being judged (Bell, Mthembu, O'Sullivan, & Moody, 2007; Bodenlos *et al.*, 2007; Aggleton & Parker, 2007). Stigma and discrimination have been reported as a major barrier to HIV testing across Africa (Wolff *et al.*, 2005; Babalola, 2007; Simbayi *et al.*, 2006; Pettifor, MacPhail, Suchindran, & Delany-Moretlwe, 2008; Koku, 2011). The reported complicity in this and other study of healthcare providers in reinforcing stigma (Bell, Mthembu, O'Sullivan, & Moody, 2007) is incongruous as they are the ones who encourage people to get tested in order to mitigate the pandemic.

It has been reported that the low uptake of HIV testing could also be due to ignorance about the benefits of knowing one's status – for protecting oneself and others from infection and re-infection, to access appropriate care, treatment and support, and to plan for the future. The benefits of testing for HIV are addressed in pre-test counselling (Jurgens, 2006). It is possible that pre-test counselling was effectively done for the participants in this study because there were no reports of anybody being coerced into testing. This would have violated the need for voluntary consent (UNAIDS & WHO, 2004).

In the light of stigma and discrimination against PLWH, it was important to provide privacy at the health facilities where the testing was done. This, however, was a challenge for some of the health facilities visited during the course of this study as limited space and overcrowding were observed. This made it possible for others who were not supposed to know the HIV results of other patients to do so by overhearing them, thus inadvertently disclosing the status of the person tested. Other studies have also reported similar occurrences of lack of privacy in public service facilities (Bell, Mthembu, O'Sullivan, & Moody, 2007). The lack of or limited privacy, given the rampant stigma and discrimination against PLWH, has the potential to discourage people from being tested.

This study reported on the breach of confidentiality by some health service providers who apparently talked about the HIV results of patients to colleagues and others. Other studies report similar occurrences (Paxton *et al.*, 2004; Bell, Mthembu, O'Sullivan, & Moody, 2007).

The participants reacted or reported others to have reacted in various ways following a positive HIV result. The reactions included indifference, crying, withdrawal from others, refusal to eat, suicidal ideation, attempted suicide and actual suicide. These reactions were similar to those found in other studies, with distress and isolation being the predominant reactions due to internalised-induced stigma (Olley, 2004; Olley, Zeier, Seedat, & Stein, 2005; Miles, Isler, Banks, Sengupta, & Corbie-Smith, 2010). These reactions could be explained by the fear of PLWH being stigmatised and discriminated against, or fear of death as a result of the previously perceived fatal nature of HIV infection before the advent of HAART (UNAIDS, 2015). The reactions could also be understood using the stages of loss or grief (Kübler-Ross, 1969). The loss could be related to the potential loss of life associated with HIV infection, or the loss of one's health and lifestyle. Some of the reactions experienced were symptoms of depression, which is known to have a higher prevalence in PLWH than the general population. Shisana et al. (2005) found that 29% of the general South African population reported feeling depressed in the past year, compared with 42% of PLWH. Given that HIV testing has the potential to incite serious and at times life-threatening reactions, it is important that it is done in the presence of professional support (Bell, Mthembu, O'Sullivan, & Moody, 2007).

This calls into question the safety of the practice of self-testing for HIV, which the public now has access to in South Africa by purchasing the home HIV self-testing kit from the pharmacy, following the recent approval by the South African Pharmacy Council (Gonzales, Polao, & Warby, 2016). Self-testing is increasingly gaining ground, in addition to the other methods, as one of the strategies to attain the Sustainable Development Goal of testing 90% of the global population who are not aware of their HIV status by 2020, and to achieve zero HIV incidence in the world by 2030 (UN, 2015). In countries such as France and the USA, where self-testing was introduced a few years ago, it was recommended that pre- and post-test counselling should always be done for access to care, whether the result was positive or negative (AIDES, 2013). The positive result has to be confirmed by an additional test. Indeed this has globally recommended in the latest WHO guidelines for HIV Self Test (WHO,2016a,UNAIDS,2016)

Apart from the concern about the absence of professional involvement in self-testing, there are benefits such as the opportunity to know one's status in privacy, particularly for those who prefer not to get tested in a health facility that lacks privacy. This could increase the uptake of HIV testing and ultimately have a positive impact on reducing the incidence of HIV infection. Self-testing for HIV thus has an important role to play in mitigating the HIV pandemic, but it needs to be managed carefully to maximise the benefits.

The participants were all aware of the benefits of testing for HIV as the gateway to access care, of which they were already beneficiaries. They thus encouraged others to get tested. They even suggested that in cases where people feared to be tested at their local health facility, they should attend elsewhere rather than not be tested at all. The suggestion for people to get tested elsewhere was due to the lack of privacy at the public health facilities, as well as the healthcare providers' complicity in reinforcing stigma and discrimination.

## **7.2 Acceptance and disclosure of HIV status**

### **7.2.1 Acceptance**

Acceptance of the positive HIV test result was an essential step before accessing the appropriate care, and for protecting others from being infected (Eustace & Ilagan, 2010). The participants in this study highlighted the importance of accepting one's HIV positive status. This made sense, as they could not access care for a problem they had not accepted. Acceptance was associated with adherence to ARVs and other lifestyle adjustments such as practising safe sex, and moderating alcohol consumption, getting regular exercise, and eating a healthy diet.

This study revealed that having HIV and also caring for a family member with HIV tended to promote the acceptance of one's status. This could have been due to the health education they received about caring for a PLWH giving them an opportunity to learn more about this virus they themselves were carrying. Delay in accepting one's status was associated in some instances with patients pursuing treatment for an alternative diagnosis – such as the kind provided by traditional healers – until they realised their condition was worsening. Similar experiences were reported in Uganda (Muhamadi, Tumwesigye, Kadobera, Marrone, Wabwire-Mangen, Pariyo, *et al.*,

2011b). Some of the patients chose not to seek any form of care, and ended up succumbing to HIV.

As a way of not accepting their results, some studies report that patients repeat their HIV test after being diagnosed with a positive result (Campbell & Williams, 1999; Collinge, 2005). This was not a finding in this study, although the knowledge about false positive results could have existed. This could have been fuelled by media reports of false positive HIV results emanating from some laboratories at the time. The existence of false positive HIV results is further supported by global evidence attributed to several factors (Johnson, 1996). Some of these factors that may be linked to false positive results are:

- TB infection (Kashala *et al.*, 1994);
- Renal failure (Schleupner, 1990; Jindal, Solomon, & Burrows, 1993; Cordes & Ryan, 1995);
- Influenza (Ng, 1991)
- Influenza vaccination (Kenzie *et al.*, 1992; Challakere & Rapport, 1993; Hsia, 1993; Profitt & Yen-Lieberman, 1993; Arnold, Slade, Jones, & Popovsky, 1994);
- Herpes simplex 1 infection (Langedijk *et al.*, 1992);
- Herpes simplex 2 infection (Challakere & Rapport, 1993);
- Pregnancy in multiparous women (Steekelberg & Cockerill, 1988; Ng, 1991; Voevodin, 1992; Profitt, 1993; Cordes & Ryan, 1995);
- Malaria (Biggar *et al.*, 1985; Charmot & Simon, 1990):
- Cancer (Pearlman & Ballas, 1994)
- Healthy individuals as a result of poorly-understood cross reactions (Bylund, Ziegner, & Hooper, 1992); and
- Receptive anal sex (Papadopulos-Eleopulos, 1988; Hammett, 1988).

Given that these factors are common in our population, the routine practice of a confirmatory test is justified. The repeating of the HIV test could also be because of denial of the positive result as part of a grief or loss reaction (Kübler-Ross, 1969; Ross, Tebble, Viliunas, 1977).

### 7.2.2 Disclosure

Following acceptance of one's HIV status, the next important challenge was to disclose one's HIV status to others. The ordeal was the tension between confidentiality and disclosure. The primary purpose of disclosure was for eliciting support (Hays, 1993; Battles, 2002; Degefa, 2003; Poppen, 2005). As has been reported elsewhere, patients readily disclosed their HIV status to health workers in the health facility, (Jefte *et al.*, 2000), because of the immediate need to access care. It also made them feel comfortable to take their ARVs, thus facilitating adherence; as well the use of adaptive coping strategies such as prayer, and the practice of safe sex. Similar benefits of disclosure have been reported (Bouillon *et al.*, 2007; M. W. Ross, Simon Rosser & Neuamaier, 2008; Préau, Bouhnik, Roussiau, Lert, & Spire, 2008; Simon Rosser *et al.*, 2008; Loubiere *et al.*, 2009; Wong *et al.*, 2009).

Although disclosure to healthcare providers was done from the premise of accessing care, this did not necessarily guarantee that the person would receive the appropriate treatment from the healthcare practitioners. The quality of care provided by the healthcare workers was generally not optimal. They were described as having negative attitudes, being judgemental, lacking in compassion, and on the whole being uncaring, with the exception of a few. With time, patients got to know the health workers who cared well for them. They made an effort to get attended to by them rather than those who perceived as uncaring. For the same reason, when they were down referred to their nearest clinic for continuation of care, some patients resisted because they did not trust the local healthcare providers to keep their status confidential, thus avoiding the local community knowing their HIV status. They pleaded to either continue with care at the hospital, or to be referred to a clinic far from their home, where the staff and the community did not know them. The stigma and discrimination practiced by the healthcare providers could have been a reflection of the perception of the community from which the staff originated (Bell, Mthembu, O'Sullivan, & Moody, 2007). The professionalism they espoused did not necessarily translate into practice. This was not surprising as South Africans generally regarded the public health services as poor compared with private health services, particularly with regards to patient-centred care (Matsoso, Fryatt, & Andrews, 2015). A study by the Office of Health Standards Compliance in 2010 revealed that only 34% of primary healthcare providers were described as being caring by patients. Similar experiences

about the uncaring service provided by health workers to people who have been diagnosed with HIV infection have also been reported from elsewhere (Wickramasuria, 1994; Bain, 1998; Norman, Carr, & Jiménez, 2006).

Beyond the health facility, the situation was even more complex for the person who had just been diagnosed with HIV infection. Choosing whom to trust when disclosing their status was difficult because of the rampant stigma and discrimination against PLWH. The decision to disclose was thus a process that needed time, and depended on individual circumstances to gauge the potential adverse consequences of disclosure. The consequences included being blamed for bringing HIV into a relationship (usually the female partner was blamed in this context of cultural gender power imbalances), loss of social support, physical harm, social ostracism and workplace discrimination. These are all similar experiences reported in other studies (Ogden & Nyblade, 2005; Ssali et al., 2010; Obermeyer, 2011).

When the patient's condition was not urgent, it was not unusual for them to give themselves time to make this decision. The amount of time varied depending on individual circumstances. Eustace and Ilangan (2010, pp. 2094) reported a similar experience of disclosure being a complex "process which included individual (e.g. self-esteem and self-efficacy), relational factors (being in relationship with others) and cultural factors. These were preceded by disease acceptance and knowledge, desire to support others or garner support, need to maintain secrets because of privacy concerns, socioeconomic status, and the time between knowing one's status and the decision to disclose." Black and Miles echoed this (2002).

Disclosure was open, selective and inadvertent. The immediate consideration for disclosure was the family because of their core function in providing social support, as also reported in other studies (Peretti-Watel *et al.*, 2006; Saali *et al.*, 2010). However, the reality was that there were those families who supported each other at all times; and there were those where this was not the case. Thus the participants opted for selective disclosure to family where total support was not envisaged.

The same principle was applied when disclosing to the community and other settings such as the workplace or school. The patients advocated for selective disclosure,

contingent on the expected outcome. Disclosure has been shown to occur when one is not coerced and one's autonomy is respected, and where acceptance by others is anticipated (Gillard & Roark, 2012). Where these conditions are not satisfied, disclosure does not normally occur. This supports the selective disclosure reported in this study and others. It also exposes the limitations of the public health approach where global disclosure is encouraged. The approach is a "one size fits all approach", which is not patient-centred. Little consideration is given for variation in individual circumstances.

The approach therefore needs to be reconsidered to favour the patient-centred approach. Indeed, this is in line with the WHO Health Report on Primary Health Care reforms, specifically on the need for the health system reform to include patient centeredness (WHO, 2008). However, it should also be remembered that selective disclosure was revealed in this study to pose a challenge to adherence as it necessitated the patients to take their ARVs secretly. When discretion could not be achieved, it caused patients to miss dosages or to take them late. Selective disclosure therefore needs to be tailored to individual circumstances and to be very carefully managed.

Inadvertent disclosure in this study was patient- or health-facility related. Unintentional patient-related disclosure was when visible complications of the infection – such as recognisable skin changes, shingles or TB, or because of side effects of ARVs such as lipoatrophy and lipodystrophy – gave away the patient's HIV status. Over time people have learnt to associate these disfiguring appearances with HIV infection. This led some of the patients to stop ARVs rather than suffer stigma and discrimination. Carr *et al.* (1998) report similar findings. Inadvertent disclosure also occurred when a person was seen in possession of ARVs. This made some patients discard the original packaging of the ARVs and use other containers to conceal the tablets. This had its own challenges as the people who were supporting the patients needed to identify the ARVs and discuss openly with the patient about the ARVs he or she was on.

The health-facility related inadvertent disclosure occurred as a result of the record system, which was colour coded according, thus identifying which people were HIV

patients. The management of the records in the health facility needs to be such that inadvertent disclosure is avoided. Having a separate HIV clinic also led to inadvertent disclosure because people assumed that whoever was seen in or near the vicinity of that clinic was HIV positive. This could lead to the person becoming stigmatised and discriminated against. This could be addressed by integrating the care of HIV patients into the general clinic service.

This recommendation, however, may be hindered by complications to do with privacy. Inadvertent disclosure is a universal challenge and has been reported elsewhere (De Wet & Kagee, 2016). Continued education of the public about HIV infection, including about the rights of PLWH, could form part of the solution to these adversarial outcomes. Advocacy groups for PLWH, such as the Treatment Action Campaign, have made a substantial contribution towards normalising the lives of PLWH, and they need to be commended and supported to continue with the good work they are doing. More importantly, PLWH need to come to terms with their condition and confront stigma, discrimination and other challenges they face head on.

## **7.3 Treatment**

### **7.3.1 Antiretrovirals (ARVs)**

Participants in this study largely accepted ARVs because of the health benefits of taking them. Reports of scepticism about ARVs related to their toxicity, although other negative perceptions about AIDS were scarce. Many PLWH on ARVs attested to how their health had changed for the better. This motivated them to continue with their ARV treatment. Participants in other studies confirmed this (Bell, Mthembu, O'Sullivan, & Moody, 2007).

Treatment supporters and caregivers in the case of children provided support for adherence. Though their role was primarily to ensure adherence to ARVs, they were also available to assist with any other problems the patient had. As many of them were HIV patients themselves, this made it easier for them as they drew on their own experiences to care for their patients. They received some training from the clinics and support groups to help them improve the quality of care they were rendering.

Most treatment supporters were family members or belonged to the extended family. Only a few came from the wider community.

Family members as treatment supporters were ideal because of the primary supporting function of the family. Couples where both were PLWH on ARVs supported each other particularly well after crossing the hurdle of who infected whom. The difficulty often related to power disparity between the couple in the marriage relationship, where the wife was subservient to the husband as reported in other studies (Katz, 2009; Maman, 2001; Maman, 2003). Caregivers who were either mothers or other women saw their role as that of ensuring that children in their care grew to adulthood. This nurturing role of women was a strong motivation for caring for children living with HIV.

Treatment supporters used mobile phones to remind the patients in their care about the time for taking ARVs. The patients also used mobile phones for the same purpose. The method worked well for facilitating adherence. Mobile phone text messages improved adherence from 50% to 68% for patients on medication for chronic diseases, according to a study by Thakkar *et al.* (2016), while Sabin (2014) reported 96% adherence, compared with 89% ( $p=0.003$ ) in the control group for patients on ARVs.

Use of mobile phone technology for facilitating health service delivery is gaining ground. It has already been successfully piloted for maternal care by the Department of Health through the Momconnect project (DOH, 2014). There have also been reported increases in uptake for male medical circumcision using mobile phone text messages. With such reported success stories that facilitate health service delivery, consideration could be given to formalising the use of mobile phones as part of the care package for PLWH. Mobile phones could form part of the communication toolbox for healthcare providers, and PLWH should be encouraged to own mobile phones and to use them to facilitate adherence.

### **7.3.2 The impact of poverty on PLWH**

The care given by the family was much more than that provided by the treatment supporter. It included providing food and money for basic needs of the patient,

including transportation to the health facility. The comprehensive support given by the family was a challenge when they failed to do so for reasons beyond their control, such as poverty. In situations where the patient had no source of income and the CD4 count was less than 100/ul, the patient qualified for a social grant from the Department of Social Development, administered by the South African Social Service Agency (SASSA). However, getting the grant was a challenge because not all who genuinely qualified for it were able to access the grant.

The situation was compounded by the fact that in addition to most PLWH being economically challenged, it was difficult for them to get jobs because of their status and the discrimination meted out in the labour market, or being too ill to work.

The main issue faced in terms of ARV adherence was lack of food as some treatments had to be taken after meals. Non-governmental organisations (NGOs) sometimes provided food parcels at the health facilities, and although highly appreciated by the patients, this was irregular and unsustainable. Public transport fare to access health facilities was another major obstacle, as well roads that were inaccessible in rainy weather.

The relationship between ARVs and food went hand-in-hand in this study. ARVs are sometimes associated with poor appetite and nausea due to interference of absorption and utilisation of nutrients (Ridder *et al.*, 2003). In addition, some ARVs should be taken after food to reduce side effects. A balanced diet with the necessary micronutrients is also necessary to restore intestinal function, gain weight and boost immunity (Tinnerello, 1998; Guarino, *et al.*, 2002). HIV is known to multiply most rapidly in malnourished individuals, hastening the progression from HIV infection to AIDS (Semba & Tang, 1999; Gillespie, Haddad, & Jackson, 2001; UNAIDS, WHO, WFP, 2008).

HIV is known to inhibit the absorption of nutrients, thus increasing the body's nutritional needs to fight infection. Low levels of micronutrients such as Vitamins A, C, D and B12; selenium; zinc; iron and carotenoids – which are important for the immune system to fight off opportunistic infections – have been found to be low in PLWH (Tinnerello, 1999). Hence PLWH have higher nutritional needs than people

who are not infected with the virus. Protein requirements are usually estimated at 30-50% more, and energy needs about 15% more (De Waal, 2003).

Good nutrition is therefore recommended for PLWH because it delays the progression from HIV infection to AIDS, and is essential for an effective ARV programme. Food insecurity is a national challenge in South Africa with about 13.3% (2.2 million people) of the population affected. Of which the Eastern Cape Province is the worst affected hosting 17.6% of the victims of food insecurity (Statistics SA, 2016). The challenge of food insecurity thus needs to be addressed as one of the national priorities in the management of HIV.

The government was blamed for the failure to provide social grants to PLWH who qualified for them. Alternative ways of PLWH generating income for themselves were suggested. Consideration needs to be given to this suggestion through inter-sectoral collaboration with the relevant government departments, and through the inter-ministerial committee for the management of the HIV pandemic (WHO, 2008; Matsoso, Fryatt, & Andrews, 2015). Mobile clinic services were also suggested to enable patients to access their ARVs easily. This suggestion contradicted the decision made by some patients to access care from health facilities that were far away from their localities to avoid the inadvertent disclosure of their status. These different preferences call for a patient-centred approach by the healthcare providers when they down refer the patients to the clinics after the initial three months of care in the HIV clinic at the hospital. The real underlying issue of widespread stigma and discrimination against PLWH needs to be addressed at both the health service and the community level.

### **7.3.3 Challenges faced by treatment supporters and caregivers**

Many treatment supporters were not employed and had no source of income to take care of their own needs as patients, as well their general needs. Now and again they were subjected to abuse by some patients, with others going as far as assaulting them. In contrast, some patients became over dependant on them such that they were not willing to do anything for themselves.

Treatment supporters also felt unequipped to deal with the side effects of ARVs because of their limited knowledge, and requested more training. Like the healthcare providers who are often affected by “burnt out” as a result of work overload and other challenges (Demmer, 2004), treatment supporters interviewed for this study reported similar experiences. This sometimes lead to a strained relationship between them and with the patients they were caring for, consequently impacting on the quality of care they were providing. Treatment supporters should not only be praised for doing a good job, which is largely voluntarily, they should also be given a care package.

With the number of PLWH on ARVs continuing to increase, particularly with the new policy that is moving towards a “treat all” on diagnosis policy (WHO, 2015), the burden of care by treatment supporters will increase. Consideration therefore needs to be given to formalising the role of treatment supporters – as is currently being considered for community health workers – to include them in the public health service workforce. They should also be provided with practical support to not only avoid “burnout”, but increase their resilience as well.

### **7.3.4 Other challenges experienced by PLWH in relation to ARVs**

#### **7.3.4.1 ARV stock outs**

The ARV supply at the health facilities was reasonably regular. However, stock outs were reported at some clinics, resulting in some of the patients preferring to get their ARVs from the hospital. The stock outs could have been due to a breakdown in the general supply chain management of medicines in the Eastern Cape. The problem is not unique to the Eastern Cape Province though. Nationally, stock outs of medicines have been cited as one of the service delivery challenges of the Department of Health (Matsoso, Fryatt, & Andrews, 2015). The same challenge occurs at a global level, and is one of the issues currently being tackled by the WHO (WHO, 2016c).

In the case of ARVs, it has very serious implications for patients, who risk not only developing a resistance to them because of the disruption to adherence, but also being exposed to morbidity and mortality. The state will also incur more expenses in caring for such patients when complications arise. The issue is being addressed by the National Department of Health through reviewing the drug policy in the “2009-2014

10-Point Programme” for transforming the health sector into a well-functioning health system capable of producing improved health outcomes.

To address the challenge, the Eastern Cape Department of Health in 2015/2016 successfully piloted in OR Tambo District a service to deliver chronic medication to patients at a location of their choice after the healthcare providers have stabilised their condition. The chronic conditions include HIV/AIDS, hypertension, diabetes mellitus, asthma and epilepsy. The points of collection are churches, community halls, private pharmacies, supermarkets, cafes and the nearest clinic or health centre. Mobile clinics are in addition used for facilitating the service. The pilot had a good uptake with about 50,000 patients registered within a period of about one year, as well as very positive feedback from the patients in terms of cutting down costs for accessing their medicine, the reduced waiting time, and the availability of their medicines. The plan is to include more chronic conditions and roll out the service to the rest of the province. This service needs to be commended and sustained. While the plan for improving access to chronic medicines, including ARVs, is explicit, there is still a need to clarify how the service addresses the issue of stock outs.

#### **7.3.4.2 ARV side effects**

ARVs all have a variety of side effects. The patients were usually informed of the side effects as part of their preparation. The study was done during the period when the use of ARVs for the management of HIV infection was relatively new in the public health service. One of the reasons for the delay was the fact that they were considered to be too toxic. However with time, PLWH realised that the benefits of taking ARVs (their health improved) outweighed the side effects. Therefore most continued to take their ARVs despite the side effects experienced or anticipated. The side effects were attended to when reported to the healthcare providers. The visible side effects of some ARVs, such as lipoatrophy and lipodystrophy, discouraged certain people from submitting themselves for HIV testing because of the fear of inadvertently disclosing their status. Other studies have reported similar findings (Kasper, Arboleda, & Halpern, 2000; Goetzenich, Corzillius, Maus, *et al.*, 2000; POZ, 2016). However, the situation has now changed with the replacement of Stavudine (D4t) – which was the main ARV causing lipoatrophy and lipodystrophy – with other ARVs such as Tenofovir. Educating the public about the benefits of knowing their HIV status to

access care, including the possible use of ARVs and the possible side effects in the management of HIV, could address the problem.

#### **7.3.4.3 Illicit use of ARVs to enhance recreational drugs**

Illicit use of ARVs to enhance the effect of addictive recreational drugs of such as marijuana has emerged as one of the challenges facing the ARV programme. The media has reported a lot on this; and the participants in this study also reported it. No formal study of the problem has yet been conducted. Participants in this study alleged that some of their peers were driven by poverty to sell their ARVs to the people involved in this unlawful trade. The same practice has been reported in Uganda (Esquivel, Rwechungura, & Bell, 2006; Rwechungura, 2006). This, leading to the consequences mentioned above, will compromise adherence. PLWH are also at risk of being attacked and harmed to obtain their ARVs. It is therefore imperative for PLWH to be aware of the danger so they can take the necessary precautions to keep themselves and their treatment safe.

The combination of the increasing numbers of people on ARVs; their being targeted for recreational drugs use; and persistent poverty constitute a challenge that needs to be addressed by an inter-sectoral task team. The South African government has a poverty alleviation programme in place that needs to prioritise the issue of indigence of PLWH because of the magnitude of the problem.

#### **7.3.4.4 Use of other medications in conjunction with ARVs**

Some participants had health problems other than HIV, or developed complications that needed additional treatment. Unfortunately, they had to go elsewhere in the hospital for such services. They appealed for comprehensive care at the HIV clinic, and provision of the necessary medications at the HIV clinic dispensary in order to reduce the time they had to spend at the hospital. This was a fair request that merited genuine consideration. All the HIV clinics at the regional hospitals the participants attended were run by medical officers with the support of a consultant in HIV medicine. Some arrangements could therefore have been made to accommodate their request. With the upsurge of non-communicable diseases such as hypertension and diabetes in South Africa (Bradshaw, 2003) the co-morbidity of HIV infection with the other chronic diseases is a reality. The health system needs to be reorganised to cater

for this and address the patients' needs and expectations. The vertical care of patients for HIV in special clinics is a classic example of fragmentation of health service delivery, which can result in poor health outcomes.

In response to the expressed needs of PLWH mentioned above, patient-centred comprehensive care is recommended so that all their problems can be addressed simultaneously. Primary health care that is accessible, continuous, well coordinated and comprehensive is ideally placed to offer across-the-board care to PLWH, especially those with multiple health problems. The adoption of the down referral policy of PLWH (whose ARV treatments are stabilised) to their local health centres for continuation of care, and the nurse-driven initiation of ARVs at the health centre level was therefore a move in the right direction in terms of comprehensive care for PLWH. Efforts need to be made to ensure that the necessary resources are provided at the health centres and clinics to safeguard the consistent rendering services. Healthcare providers at clinics also need to ensure that they provide an adequate quality of care so that PLWH do not have to resort to care at hospitals or other PHC facilities instead of their local clinics.

#### **7.3.4.5 Combining traditional medicine with ARVs**

The majority of the Eastern Cape population use traditional medicines for their health care needs (Broster, 1981), which are often sourced over the counter from *Amayeza* stores (African Chemists) – to use as self medication as the first line of treatment – or from traditional healers. Long waiting times at public health facilities, and the belief that the health problem may be culturally related; causes people to first pursue traditional medicine (Cock M, 2000). According to WHO (2003), 80% of the population of the world depend on traditional medicine for their primary healthcare needs. The practice is particularly common where access to western medicine is limited (Kanye, 2010).

Many of the PLWH interviewed for this study first tried traditional medicine before seeking allopathic care. The health workers discouraged mixing both types of medicine, and this advice seemed to have been accepted. Given the likelihood that PLWH could also have other health problems unrelated to HIV infection, there was a possibility that some continued to use traditional medicine. One such participant formally requested from his doctor to continue using the traditional medicine in conjunction with the ARVs. The concurrent use of traditional medicine and ARVs needs further investigation.

#### **7.4 The need for person-centred care by healthcare providers when dealing with PLWH**

The practice of patient-centred care defined as *“providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions”* by the Institute of Medicine (2001, p. 3) is one of the pillars of quality health care. There has been a move toward using the term “person-centred” rather than patient-centred to encompass the entirety of a person’s needs and preferences beyond just the clinical or medical. Various definitions of person-centred care have been proposed. One such definition is “an approach to improving the healthcare safety, quality, co-ordination and quality of life of a person in a way that assures the primacy of the individuals’ health and life goals in their care planning and actual care” (The American Geriatrics Society Expert Panel on Person-Centred Care, 2015).

In the interest of speaking the same language, a definition proposed by a multidisciplinary team under the auspices of the US-based Senior Care Action Network (SCAN) Foundation has been widely accepted: “Person-centred care means that individual values and preferences are elicited, and once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centred care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision making to the extent that the individual desires”.

The concept of having the person be the driving force in their health care decisions has evolved and gained momentum, and is now considered the gold standard for health care universally (Porock, 2014). It is a key component of Primary Health Care (WHO, 1978;

WHO, 2008). While the PLWH acknowledged the few instances when they experienced person-centred care from the healthcare providers, lack of person-centred care dominated their practice. They were complicit in stigmatising and discriminating against PLWH. Indeed, some PLWH expressed their concerns about the lack of sensitivity to their condition by the healthcare providers. The uncaring practice of healthcare providers in public health service is one of the challenges the Department of Health is currently addressing.

### **7.5 Stigma and discrimination**

Stigma and discrimination were anticipated and/or experienced at every stage of the “journey” of the PLWH on ARVs. This was an indication of the extent of the problem and constituted a serious challenge to the management of patients. Stigma and discrimination have been recognised as two of the greatest challenges in the management of HIV infection (Mann, 1987; Aggleton, 2000, Skinner & Mfecane, 2012). It is a global phenomenon with serious implications for the HIV pandemic and the lives of PLWH. The challenges relate to HIV testing, HIV prevention (Brooks, 2005), access to treatment and care (Aggleton, 2000), disclosure (Clark, 2003; Liu, 2006), support seeking (Flowers, 2006), social interaction (Varas-Diaz, 2005), identity (Hernandez, 2005; Flowers, 2006), and human rights (Aggleton, 2005).

Specific examples of stigma, discrimination and other uncaring practices by healthcare providers against PLWH included denying them their supply of ARVs for failing to keep appointments; disclosing their HIV status to others; poor communication; poor time keeping; negative attitudes; lack of respect; insulting behaviour; distrust of patients; and being judgemental. These findings were similar to a recent study done by Adeniyi *et al.* (In press) at Nelson Mandela Central Hospital in Mahatma, which suggests that little has changed in the last few years. Stigma and discrimination originate in the communities from which the healthcare providers also come (Bell, Mthembu, O’Sullivan, & Moody, 2007). The refusal of healthcare providers to care for PLWH because of stigma and discrimination is widely practiced and has been largely attributed to a lack of understanding of the mode of transmission of HIV and the precautionary measures (Elford, Ibrahim, Bukutu, & Anderson, 2007; Bebe & Anderson, 2009; Nostlinger, Rojas Castro, Platteau, Dias, & Le Gall, 2014; Douay, Toullier, Benayoun, Castro, & Chauvin, 2016).

The practice makes a mockery of the ethos of high quality care, including person-centred care, which would have been emphasised to the healthcare providers during their training. It also raises the issue of ambivalence between knowledge and practice in terms of the provision of treatment by healthcare providers. The uncaring behaviour of the healthcare providers reported by the participants was unprofessional, uncalled for and should be condemned. It stood in the way of a relationship of trust that is needed for the long-term management of patients on ARVs. The efforts made by the patients to counter stigma and discrimination – by using coping mechanisms which included acceptance of their status, ignoring those who stigmatised and discriminated against them, prayer (Winkler, 2010; Makoae *et al.*, 2008), and making an effort to adhere to the ARVs so that they looked healthy – need to be commended and encouraged. These could be used as strategies to enhance adherence to ARVs while the other efforts to reduce stigma and discrimination against PLWH still continue.

#### **7.6 Application of the chronic care model for the management of HIV infection in relation to the study**

With HIV infection joining the list of chronic diseases it is important to consider how the management of HIV fits into the Chronic Care Model (CCM) as developed by Wagner *et al.* (2001). This is particularly important, as the use of the CCM has attained widespread application. It should also be remembered that most of the chronic diseases for which the CCM was originally designed are non-communicable diseases (NCD), while HIV is a communicable disease (WHO, 2016b). Multimorbidity of HIV and the other chronic NCDs is on the rise in low- and middle-income countries undergoing a rapid epidemiological transition. Indeed, South Africa already has a burden of diseases that include significant contributions from both HIV and NCDs (Bradshaw, 2003).

The CCM was developed before HIV was declared a chronic disease. There are unique features of HIV infection, which it does not share with other chronic diseases, particularly related to the patients' psychosocial experiences as depicted by the patients in this study. One such experience, compared to other chronic diseases, is the fact that HIV is a highly stigmatised disease, which makes the PLWH very susceptible to discrimination. The experiences of patients on ARVs attending public sector health facilities in the Eastern Cape Province revealed the fear of stigma and discrimination against PLWH as a major

problem that cuts across the patient's whole life experience. It calls for a comprehensive approach to the care of PLWH that is patient-centred rather than provider-centred, with consideration for the bio psychosocial issues impacting on the patient's condition.

The growing complex multimorbidity of HIV with NCDs compounds the situation further. A critical look at the CCM suggests that it is not explicit enough in highlighting these issues related to HIV infection, and therefore falls short of addressing them. This calls for the amendment of the CCM to accommodate the features of HIV infection in general, and those related to the context of the PLWH. Published experience with the CCM and HIV care remains relatively rare. Some successes have been reported with the use of the CCM in the management of PLWH, but based on the measurement of a specified component of the model, such as improvement in the uptake of HIV testing (Anaya *et al.*; Goetz *et al.*, 2008; Sobo *et al.*, 2008), or improvement in the uptake of and adherence to ARVs (Sherer *et al.*, 2002).

However, the most comprehensive measurement of the impact of the CCM is in the study done by Tu *et al.* (2013) on PLWH in a marginalised aboriginal community in Australia. They reported that the use of the CCM led to improved disease screening, pneumococcal immunisation, increased ARV uptake and virological suppression rates, in addition to addressing underlying social determinants of health. In addition to the limitations cited, these studies were performed in the USA and Australia, where the prevalence of HIV infection is very low and the problem of multimorbidity of HIV infection and the NCD is not an issue. It therefore makes it difficult to transfer the results to a country like South Africa, which has a high HIV prevalence and NCD burden.

In western Kenya, a network of HIV clinics has based its ARV delivery system on the CCM, incorporating all its key components (Wools-Kaloustian *et al.*, 2006). The impact of the CCM has not been evaluated yet. The findings, irrespective of the outcomes, could be transferable to South Africa because of the similarity in HIV prevalence and the multimorbidity with NCD. These are encouraging efforts from the Kenyan and Australian settings, which call for more comprehensive studies to be done to assess the use of the CCM for the care of PLWH.

Indeed, Oni *et al.* (2014) have taken the challenge in South Africa and proposed an amendment of the WHO Innovative Care for Chronic Conditions (ICCC) Framework. It has similarities with the CCM, and does not significantly incorporate complexity associated with multimorbidity and co morbidity of non-communicable and infectious chronic diseases (CNCICD). The ICCC Framework incorporates community, patient, healthcare and policy environment perspectives and forms the cornerstone of South Africa's Primary Health Care re-engineering and strategic plan for chronic disease management integration. The amendment specifically includes the patient perspective in the framework relating to the effect of multiple chronic disease morbidity. Added to that are the other perspectives relating to the health system, health care provider and biological interactions related to multimorbidity.

### **7.7 Normalisation of the patients on ARVs**

As depicted by the analogy of the “journey” that PLWH have to travel, there are many challenges and obstacles along the way. However, with ARVs they had a chance to live a healthy life, which lifted them above many of the challenges. To ensure maximum benefit, people on ARVs restructured their lives to accommodate the need to take treatment. They devised counter measures to neutralise the challenges they were encountering in many facets of their lives because of their HIV status. They made efforts to strengthen relations with their providers, family, treatment supporters, caregivers and the community to the best level they could achieve under the circumstances, to enable them to continue with their lives. By normalising their lives the participants who did so achieved a state of dynamic balance in their health as explained by systems theory (Capra, 1982). Such was the process the PLWH who took part in this study used to normalise their lives. This is the collective difference that ARVs have made in the lives of PLWH, resulting in the notable reduction in morbidity and mortality since the advent of HAART (Egger *et al.*, 1997; Palella *et al.*, 1998).

### **7.8 The significance of the findings of the study for the practice of Family Medicine**

The “journey” that PLWH went through highlighted several principles of family medicine (McWhinney, 1997) which could be applied to their care. The need for the focus on the patient as a person was emphasised by the requirement for a patient-centred approach to some of the challenges expressed by the patients, such as their preference not to be referred to their local clinic for continuation of care because of stigma and discrimination.

The bio psychosocial impact of HIV highlighted in this study also affirms the need for a holistic or comprehensive approach to the patient and address co-morbidity and complications when they exist. This approach is in line with systems theory, which forms the backbone of the theoretical basis of the practice of Family Medicine/Primary Health Care. The need for continuity of care over time with a team of trusted health workers, and the need to co-ordinate care between local resources and different levels of care were also evident. The role of the family and the community in the care of PLWH was important. Referring PLWH to other providers for care was in line with a team approach to patient care as part of a network of healthcare providers. Advocating being sensitive to the patient's feelings, thoughts, worries and expectations, and avoiding being judgemental addressed the principle of taking into consideration the subjective aspects of the illness of the PLWH, and being patient- or person-centred. Family physicians whose practices are guided by the principles of family medicine are therefore in an ideal position to care for PLWH. On the whole, all healthcare workers involved in the care of PLWH should embody the principles of medical generalism or family medicine.

## **7.9 The strengths and limitations of the study**

### **7.9.1 Strengths of the study**

- The choice of qualitative study design was the most appropriate for this study because the key focus was on exploring the experiences of PLWH on ARVs. Experience is a variable that cannot easily be measured numerically.
- The selection of participants from four different settings spread widely over the province of the Eastern Cape was an attempt to explore a range of experiences and to increase the credibility of the study findings in relation to the province as a whole.
- The selection of the participants from different categories (patients, treatment supporters, care givers) and the gender balance increased the variation and range of experiences that could be triangulated, thus also adding credibility to the study findings.
- Use of multiple methods of data collection (individual interviews, focus group discussions, participant observation and patient diaries) also enabled triangulation

of data from different methods, as well as contributed to the credibility and dependability of the study findings.

- A detailed description of the study setting, participant selection and purposive sampling, together with methods of data collection and the findings themselves should allow readers to determine the transferability of the study findings.
- The researcher and two research assistants were the only people involved in the enrolment of the participants, data collection and cleaning. They were all trained before the inception of the study. The study was piloted before the actual study was implemented to iron out any methodological challenges. All these measures increased the credibility of the study findings.
- Given the large and miscellaneous quantity of data collected, it would have been a huge challenge to analyse the data manually. The use of Atlas t.i version 6.2 software to electronically analyse the data made it quicker, reduced the possibility of error, and thus also increased the credibility of the study findings.

### **7.9.2 Limitations of the study**

- The data for this study was collected between 2009 and 2011. It is possible that some of the experiences of PLWH on ARVs may have changed with time as the dynamics related to HIV management in general and the use of ARVs is continuously changing. This could compromise the validity of some of the study findings, rendering them obsolete in the current context. However most of the data collected on the experiences of PLWH is still relevant to date and can be used to guide improvement in the care of PLWH.
- This was a qualitative study with a very large volume of data collected from individual interviews, focus group discussions, patient diaries and participant observation involving 132 participants. The majority of the data, which was voice recorded, had to be translated from isiXhosa to English and transcribed verbatim. Despite all the efforts made to ensure the credibility of the results, some errors may have occurred along the line because of the large volume of data collected.
- The interviewers may have occasionally knowingly or unknowingly used the interview guide as a “questionnaire”, despite the training they had received, and in the process may not have explored the participants’ experience in sufficient depth. This could have reduced the depth of the data in some interviews.

- The influence of the phenomenon of reflexivity could not have been excluded as the subjective influence of the researcher and his assistants could have influenced the responses of the participants during the course of the data collection, thus impacting on the quality of data collected and reducing the credibility of the study findings. This could have occurred despite the efforts made to maintain objectivity during data collection through the rehearsal of the data collection process by the researcher and the research assistants in the pilot study.

## **7.10 Conclusion**

This chapter integrated and discussed the key findings using systems theory as a conceptual framework and the analogy of the journey that PLWH undertake to manage their illness. In light of the study findings, the application of the chronic care model in the care of PLWH was considered. How the principles of Family Medicine related to the study findings, and their significance to the discipline of Family Medicine were also explored. The strengths and limitations of the study were also highlighted. The next chapter presents the conclusions and recommendations.

## **CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS**

### **8.0 Introduction**

This chapter concludes the study and puts forward some recommendations. The conclusions are presented in relation to each of the objectives of the study. The recommendations look at the implications of the study findings in reference to policies for the care of PLWH in the Eastern Cape Province and beyond, and in terms of further research to address unanswered questions, as well as chart the way forward.

### **8.1 Conclusions**

#### **8.1.1 Objective 1: How patients incorporated the taking of ARVs into their lifestyle**

Strict adherence is a pre-requisite for the efficacy of ARVs, and PLWH had to devise various ways to achieve this. The patients incorporated the taking of ARVs into their lifestyles by being reminded by treatment supporters, some of who were on ARVs themselves, and were often family members. Patients also reminded themselves by using mobile phone alarms, clocks, watch alarms, regular radio programmes and calendars. Pillboxes were rarely used. Some believed that they could use symptoms such as headache and dizziness to gauge when they needed to take their ARVs, while others just had a “gut feeling” when their ARVs were due. These measures, combined with others such as food security, seemed to have worked well for them and are therefore important for ensuring adherence to the ARVs.

### **8.1.2 Objective 2: Beliefs and feelings of patients regarding their ARVs**

As the benefits of taking ARVs translated into better health outcomes, the belief in ARVs as lifesavers was strengthened. The fact that they had an opportunity to live longer gave them an opportunity to fulfil their life's dreams. The opportunity to care for their children to adulthood was cherished as it was often cited as one of the key benefits of adhering ARVs. ARVs gave them hope and the resilience to rise above any challenges that impeded on adherence. They believed that the ARVs effectively normalised their lives. The fact that the other PLWH on ARVs were also in good health further strengthened this belief. A smaller number of patients struggled to accept their HIV status, and therefore struggled to commit to their ARVs. Also noted were the problems of alcohol and substance abuse, as well as the involvement in the illicit trade of selling their ARVs to drug dealers and users, who used ARVs for the enhancement of recreational drugs.

### **8.1.3 Objective 3: The positive and negative experiences of patients attending ARV clinics**

ARV clinics provided a mixed bag of experiences for PLWH. These were related to the quality of care rendered by healthcare providers; how the services provided were organised; the clinic infrastructure; and the resources. Their experiences were broadly divided into positive and negative.

The positive experiences of PLWH in ARV clinics included person-centred care rendered by some of the healthcare providers; the provision of food; the reliable availability of ARVs; cleanliness and orderly service; the company of other patients in the clinic (with whom they shared experiences and exchanged knowledge); as well as education about ARVs and HIV in general. This ultimately culminated in the improvement of their health to such an extent that their physical appearance would no longer inadvertently reveal their HIV status.

Their negative experiences dominated and surpassed their positive experiences. These included poor attitudes; lack of respect; poor communication; poor time management and inequitable care offered by some healthcare providers. The stigma and discrimination against PLWH by some healthcare providers was of particular

concern. Many of the facilities had limited space, resulting in overcrowding; lack of privacy; inadequate toilet facilities; and poor cleanliness and hygiene in general. The poor co-ordination of services between the levels of care and the lack of comprehensive care were also a concern. Despite the fact that ARV supplies were generally regular, there was apprehension about the sustainability of the supplies because of the historical inconsistency in government policy towards the use of ARVs. Concerns about the toxic effects of ARVs that were fostered by the position of previous governments were diminished by the obvious benefits of ARVs and the availability of less toxic drugs.

#### **8.1.4 Objective 4: How others such as family and friends reacted to their taking of ARVs**

The reactions of family, friends and others to PLWH taking ARVs were both positive and negative.

The positive reactions were in the form of support, which could be emotional, material or both. Receiving support was preceded by acceptance of HIV by the PLWH, followed by disclosure of their status to family and others. Disclosure was selective and done when support was anticipated, and held back when the contrary was anticipated. Material support was mainly given by family members or close friends, and included money for transport, food and other essential needs.

The negative reactions included stigmatisation; insulting behaviour; being judgemental; having a negative attitude; isolation; discrimination; avoiding sharing items (such as eating and drinking utensils); name calling; gossiping, associating PLWH with sexual immorality (e.g. prostitution); and perceiving them to be terminally ill. The consequences of these negative reactions for PLWH included exclusion from work, school and other institutions; poor adherence to their ARVs as a result of taking them in secret to avoid inadvertent disclosure; difficulties in getting employment; loss of and difficulty in making friends; loss of life partners and others; changing jobs, workplace or school.

To counter the negative reactions of the family and others, PLWH developed coping mechanisms. These included selective disclosure of their HIV status; ignoring the negative reactions; working hard for the normalisation of their life through adherence

to ARVs; eating balanced diet; getting regular exercise; and other health-promoting measures to make them look healthy to avoid inadvertent disclosure of their status due to looking ill.

#### **8.1.5 Objective 5: The sociocultural and contextual issues that impacted on the patients' ability to take ARVs**

The social issues related to patients taking ARVs were poverty related due to their low socioeconomic status, inability to get employment, and difficulties with obtaining social grants from the government. As a result, they could not afford the basic needs related to the taking of ARVs, such as food and transport to the clinic. The widespread stigma and discrimination against PLWH was also a major social issue. The main cultural and contextual issues impacting on their ability to take ARVs included the cultural power disparity in the marriage relationship, where the wife is often submissive to the husband, and the challenges faced by the wife if she was the first to be diagnosed with HIV; as well as the concurrent taking of ARVs with traditional medicines.

#### **8.1.6 Objective 6: To elicit any other unanticipated issues that arise in the patient's context or experience that are important to their ability to take ARVs**

The importance of the role played by treatment supporters became evident. They served as a link between the patients and the health system. They played a key role in ensuring a positive experience for PLWH to enable them to get the maximum benefit from taking ARVs. Most of them were family members of the patient they were caring for. Some were married couples. This worked particularly well after any hurdles between them were sorted out. The treatment support included enabling adherence to the ARVs, attending to the patient's basic needs (e.g. food), helping with social problems, and general basic education about HIV. They also ensured that the PLWH were not confused by other healers and their claims that they could cure HIV infection. Some treatment supporters were PLWH who were also on ARVs. This augmented their role because they were able to share their own experiences with the patient they were supporting.

With all the demands their responsibility placed on them emotionally and physically, challenges emerged. These included becoming "burnt out", which at times led to

strained relations with the patient they were caring for. Some had to put up with aggressive, violent and uncooperative behaviour from the patient. Some had financial challenges of their own and were unable to meet their personal needs because they had no source of income. They were at times helpless when faced with some of the problems experienced by the patients in their care (e.g. the side effects of the ARVs) because of their limited knowledge about HIV. They appealed for some form of support from the government to enable them to do their work better. The suggestions included a stipend for the treatment supporters who had no other source of income, assistance with income-generating projects, and ongoing capacity-building training related to their work. With the implementation of the WHO “treat all” HIV management policy approved in principle for implementation by the public service in South Africa, the need for treatment supporters is bound to increase.

## **8.2 Recommendations**

### **8.2.1 Expanding use of mobile phone technology**

The use of mobile phone technology to enhance PLWH’s adherence to ARVs and other related care needs to be encouraged. The success of the mobile phone-based healthcare programmes such as “Mom Connect” for maternal care needs to be applied to other programmes, including HIV care.

### **8.2.2 Investigating illicit use of ARVs with recreational drugs**

The challenge of substance abuse is on the rise in the Eastern Cape and the country as a whole. The emerging illicit trade in ARVs for enhancing recreational drugs adds to the challenge. The current magnitude of the problem is mainly based on media reports. For an in-depth understanding of the problem, there is a need to conduct a scientific study to inform the strategies for mitigating the problem. Meanwhile the efforts of multidisciplinary role players (i.e. The Departments of Police, Social Development, Justice, Home Affairs, and Health) and the community to address the problem need to be commended and supported. The PLWH involved in the trade need to be counselled on the health risks they are exposing themselves and others to. They should also be assisted to improve their socioeconomic situations through involvement of inter-sectoral collaborations to enable them to find some source of income so that they do not have to engage in the illicit trade in ARVs.

### **8.2.3 Making healthcare more person-centred**

The healthcare providers need to practice person-centred care to improve the health outcomes for PLWH. This could be imparted through the training curricula for healthcare workers at all levels. The healthcare workers in employment need to be updated and refreshed on the practice of person-centred care on an ongoing basis. The training of primary healthcare providers should embrace the principles of medical generalism and family medicine, which have patient-centredness at the heart of everything they do. It should also focus on the importance of access, continuity, coordination and comprehensiveness of care.

Nurses should be trained to think and behave like generalist practitioners, rather than seeing primary care as a task that is driven by compliance to guidelines in a vertical disease programme. Doctors who support primary care clinics should receive postgraduate training in family medicine – such as the recently introduced national Postgraduate Diploma in Family Medicine. Currently none of our primary care providers receive training to work effectively as generalists, apart from those exiting the programmes that train family physicians. The practice needs to be regularly assessed by the Office of Health Standards Compliance (OHSC), and regular feedback should be given.

### **8.2.4 Improving corporate governance of the health system**

Systems issues such as infrastructural challenges (privacy for the patients, cleanliness of the health facilities, availability of water), human resources, and availability of medicines need to be addressed by the governance of the institutions as part of their core business. This should form part of their performance agreement, which should be regularly assessed.

### **8.2.5 Tackling stigma and discrimination**

Stigma and discrimination are major challenges in the care of PLWH. The causes need to be identified and addressed. As they cut across the whole “journey” of the PLWH and in all facets of their interaction with the population, a multidisciplinary approach to the problem may achieve better results. Education of the population about HIV infection in general is known to play an important function in reducing stigma and discrimination against PLWH. Inter-sectoral approaches involving the relevant

departments – such as Education, Health, Corporative Governance and Traditional Affairs, Justice and others – would be more effective than the Department of Health trying to tackle this alone.

Community health workers, through the ward based outreach programme, could play a key role in reducing stigma and discrimination against PLWH by educating the community about HIV infection. This would help to reduce the stigma and discrimination meted out by the rest of the population, including healthcare providers. The role of leadership in government, traditional leaders, faith-based leaders and other influential leaders in society to “preach” the same message is also necessary to change the attitude of the population about PLWH. The increased public awareness about HIV infection and its management will also assist in preparing the population for the WHO “treat all” policy – intended to manage all HIV positive people irrespective of their CD4 count – that is due to be implemented in the public service in South Africa soon.

#### **8.2.6 Recognising treatment supporters**

Given the value that treatment supporters bring to PLWH on ARVs, and the increasing need for their services, combined with the fact that many of them were socioeconomically challenged; calls for the Department of Health to review the needs of the treatment supporters and how they can be reimbursed or remunerated for their work. Their training needs should also be addressed.

#### **8.2.7 Addressing poverty in people living with HIV**

Poverty and food insecurity have a major impact in the care of PLWH. The government, through multi-sectoral collaboration of Departments such as Health, Labour, Social Development, Agriculture and Economic Development and others, needs to make a collective effort to address the problem as part of the national poverty alleviation and food security programme. The Department of Health could play a key role. The private sector, particularly NGOs, are already playing a significant role in addressing poverty, food insecurity and issues related to social deprivation in general. Their efforts need to be appreciated, and they need to work in collaboration with the government so that it is aware of their contribution. This will also reduce duplication and waste of resources.

### **8.3 Conclusion**

The experiences of PLWH on ARVs who attend public health service facilities are derived from interactions with a complexity of factors broadly conceptualised using systems theory. They have two interconnected arms – the health service on the one hand; and family, community and society at large on the other hand. The factors that make up the complexity are interconnected and operate in unison to culminate in the outcome of the experiences for PLWH on ARVs. In addressing the challenges related to their experiences, one therefore has to approach them with a holistic and collaborative strategy involving all the relevant role players to be able to achieve the desired results.

Chapter Eight brings the thesis full circle, having summarised the conclusions of the study in relation to each of the objectives, as well as listing a number of recommendations.

This chapter is followed by the references used in the thesis and a number of supporting documents contained in the appendices.

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## APPENDICES

### APPENDIX A: PATIENT MEDICATION DIARY REGIME 1a

#### Medication diary

1. Tick every time you take your medication.
2. Write down any side effects, problems or comments in the NOTES column.

		☀ MORNING		EVENING			NOTES
		d4T	3TC	d4T	3TC	Efavirenz	
							
<b>Dose</b>							
<b>Time</b>							
<b>ACTIVITY</b>							
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## APPENDIX B. PATIENT MEDICATION DIARY REGIME 1b

### Medication diary

1. Tick every time you take your medication.
2. Write down any side effects, problems or comments in the NOTES column

		☀ MORNING			EVENING			NOTES
		d4T	3TC	NVP	d4T	3TC	NVP	
								
<b>Dose</b>								
<b>Time</b>								
<b>ACTIVITY</b>								
Day	Date							
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## APPENDIX C. PATIENT MEDICATION DIARY REGIME 2

### Medication diary-2

1. Tick every time you take your medication.
2. Write down any side effects, problems or comments in the NOTES column

		☀ MORNING			EVENING			NOTES
		AZT	DDI	LPV/r	AZT	DDI	LPV/r	
<b>Dose</b>								
<b>Time</b>								
<b>ACTIVITY</b>								
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## APPENDIX D: PATIENT MEDICATION DIARY

### FOR NON-STANDARD REGIMEN

#### Medication diary

1. Tick every time you take your medication.
2. Write down any side effects, problems or comments in the NOTES column

		☀ MORNING			EVENING			NOTES
<b>Dose</b>								
<b>Time</b>								
<b>ACTIVITY</b>								
<b>Day</b>	<b>Date</b>							
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## APPENDIX E: PATIENT MEDICATION DIARY – XHOSA

### IDAYARI YAMAYEZA

- 1 Korekishanjaloemvenikokuthathaamayezaakho
- 2 Bhalaphantsiiziphumoezibiezingabangelwaliyeza, ingxaki, okanyeizimvozakhokumqolowokubhala

		☀ KUSASA		EBUSUKU			UMBHALO
		d4T	3TC	d4T	3TC	Efavirenz	
							
UMLINGA-NISELO							
IXESHA							
UMSEBENZI							
USUKU	UMHLA						
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## **APPENDIX F: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT:** The experiences of HIV positive patients on antiretroviral drugs attending public service health institutions in the Eastern Cape Province: A qualitative study.

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR: Dr J Chandia**

**ADDRESS:P.O.BOX 104 MTHATHA 5099**

**CONTACT NUMBER: Mobile:+27 827854256,+27 47 5311655(w),+27 47 5313617**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Committee for Human Research at StellenboschUniversity and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

This research will take place in the Eastern Cape province at HIV clinics in Mthatha, Lusikisiki, East London and Port Elizabeth. Twenty two (22) patients will participate in the project from each clinic. The aim of the project is to improve the care of HIV positive

patients on antiretroviral drugs by understanding your experiences while on the drugs and then making changes to improve the clinics or health service. You will be required to share your experience with taking antiretroviral drugs in an interview with the researcher or a research assistant. If you are a treatment supporter you may be asked to participate in a group discussion together with five other treatment supporters about your experiences. All interviews will be tape recorded with your permission.

**Why have you been invited to participate?**

You have been invited to participate in this study because you have experience of taking antiretroviral drugs or of supporting someone who is taking the drugs.

**What will your responsibilities be?**

Your responsibility will be to answer the questions honestly and to ask the researcher or any other person collecting information from you about anything which is not clear to you about this project.

**Will you benefit from taking part in this research?**

Once the project is completed and the recommendations implemented you should receive a better quality of care.

**Are there in risks involved in your taking part in this research?**

There are no direct risks involved in this research.

**Who will have access to your medical records?**

Only the researcher or his assistants will have access to information collected from you or any other confidential information.

**Will you be paid to take part in this study and are there any costs involved?**

No, you will not be paid to take part in the study, but your transport and meal costs will be covered for each study visit. There will be no costs involved for you, if you take part.

**Is there anything else that you should know or do?**

You can contact **Dr J.Chandia** at tel: **0827854256** if you have any further queries or encounter any problems.

You can contact the committee for Human Research at **021-9389207** if you have any concerns or complaints that have not been adequately addressed by your study doctor.

You will receive a copy of this information and consent form for your own records.

### **Declaration by participant**

By signing below, I ..... agree to take part in a genetic research study entitled “The experiences of HIV positive patients on antiretroviral drugs attending public service health institutions in the Eastern Cape Province: A qualitative study”.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) .....2008.....

.....  
**Signature of participant**

.....  
**Signature of witness**

## Declaration by investigator

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a translator. (*If a translator is used then the translator must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) .....2008.....

.....  
**Signature of investigator**

.....  
**Signature of witness**

## Declaration by translator

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/isiXhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....2008.....

.....

**Signature of translator**

.....

**Signature of witness**

## **APPENDIX G: INCWADANA ENGOLWAZI NGOMTHATHI- NXAXHEBA KUNYE NEFOMU YEMVUMELWANO**

**ISIHLOKO SEPROJEKTHI YOPHANDO:**

**INOMBOLO YONXULUMANO:**

**UMPHANDI OYINTLOKO:**

**IDILESI:**

**INOMBOLO YOQHAGAMSHELWANO:**

Uyamenywa ukuba athathe inxaxheba kwiprojekthi yophando. You are being invited to take part in a research project. Nceda thatha ixesha lokufunda ulwazi oluvezwe apha, oluzakuthi luchaze iinkcukacha zale projekthi. Nceda buza nayiphina imibuzo emalunga nayiphina indawo ongayiqondiyo ngokupheleleyo kubasebenzi besi sifundo okanye kugqirha. Kubaluleke kakhulu ukuba waniliseke ngokupheleleyo yinto yokuba uacelwe kakuhle ukuba yintoni ebangwa sesi sifundo kwaye ungabandakanyeka njani. Kwakhona, ukuthatha kwakho inxaxheba **kungentando yakho ngokupheleleyo** kwaye ukhululekile ukuba ungarhoxa ekuthatheni inxaxheba. Ukuba uthi hayi, oku akusayi kuchaphazela ukungavumi kwakho nangayiphina indlela. Ukwakhululekile ukuba uyeke kwesi sifundo naninina, nkqu nokokuba uyavuma ukuthatha inxaxheba ekuqaleni.

Olu phando luvunywe ziinqobo ezisesikweni **zeKomiti yoPhando Lomntu kwiYunivesithi yaseStellenbosch** kwaye luzakwenziwa ngokwemigaqo esesikweni lophando elamkelekileyo kwiSaziso seHlabathi sika-Helsinki, iMigaqo eLungileyo yoMzantsi Afrika yokuSebenza eKliniki kunye neBhunga lezoPhando ngamaYeza (MRC) iMigaqo yeNqobo yezoPhando.

**Simalunga nantoni esi sifundo sophando?**

- *Luzakwenziwa phi uphando; ingaba zikhona ezinye iindawo; bangaphi bebonke abathathi-nxaxheba abazakugaywa.*

- *Cacisa ngolwimi oluviwa ngumthathi-nxaxheba ukuba iprojekthi yakho ijonge ukwenza ntoni kwaye kutheni uyenza?*
- *Cacisa zonke iinkqubo.*
- *Cacisa nayiphina inkqubo engakhethiyo enokuthi ibekho.*
- *Cacisa ukusetyenziswa kwalo naliphina iyeza, ukuba likhona.*

### **Kutheni umenyiwe ukuba uthathe inxaxheba?**

- *Cacisa lo mbuzo kakuhle.*

### **Luyakuba yintoni uxanduva lwakho?**

- *Cacisa lo mbuzo kakuhle.*

### **Ingaba uza kuzuzisa ekuthatheni inxaxheba kolu phando?**

- *Cacisa yonke inzuzo ngokungaqhutywa luluvo. Ukuba akukho nzuzo bonisa ke ukuba ngubani onokuthi azuze kolu phando umz. Abazali bangomso.*

### **Ingaba zikho iingozi ezibandakanyekayo ekuthatheni kwakho inxaxheba kolu phando?**

- *Chaza naziphina iingozi ngokungaqhutywa luluvo.*

### **Ukuba awuvumi ukuthatha inxaxheba, loluphi olunye unyango onalo?**

- *Bonisa ngokucacileyo ngokubanzi loluphi olunye unyango alokhoyo kwaye lungafunyanwa phi, ukuba lukhona.*

### **Ngubani uza kufumana ingxelo yakho yamayeza?**

- *Cacisa ukuba ulwazi oluqokelelweyo luza kuba yimfihlelo kwaye luza kukhuselwe. Ukuba lusetyenziswe ekupapashweni okanye kwithesisi, umthathi-nxaxheba akasayi kwaziswa. Cacisa kakuhle ukuba ngubani oza kukwazi ukufumana ulwazi.*

**Kuza kwenzeka ntoni kwimeko yesiganeko esingalindekanga sokwenzakala ngenxa yokuthatha kwakho inxaxheba kwesi sifundo sophando?**

- *Cacisa imiba enxulumene nentlawulo ye-inshorensi ukuba ikhona. Ukuba kukho iindawo ezibandakanyekayo ezithengisa amayeza ingaba intuthuzelo izakuhamba ngokwemigaqo ye-ABPI? (Imigaqo yentuthuzelo enxulumene nokwenzakala kuphando lweManyano yaseBrithane yezoRhwebo lwamaYeza ethathwa njengekwizinga lehlabathi legolide). Ukuba ewe, nceda bandakanya iinkcukacha apha. Ukuba hayi, cacisa ke ukuba yeyiphi intuthuzelo eyakubakhona kwaye phantsi kweziphi iimeko..*

**Ingaba uza kuhlululwa ngokuthatha inxaxheba kwesi sifundo kwaye ingaba kukho iindleko ezibandakanyekayo?**

Hayi awusayi kuhlululwa ngokuthatha inxaxheba kwesi sifundo kodwa isithuthi sakho neendleko zokutya ziza kuhlululelwa kundwendwelo ngalunye lwesifundo. Akusayi kubakho zindleko ezibandakanyelwa wena, ukuba uthatha inxaxheba.

**Ingaba ikho enye into ekumele uyazi okanye uyenze?**

- Kumele wazise ugqirha wosapho okanye ugqirha oqhelekileyo nje ukuba uthatha inxaxheba kwisifundo sophando. *(sibandakanye ukuba sikhona)*
- Kwakhona kumele wazise inkampani yakho ye-inshorensi yamayeza ukuba uthatha inxaxheba kwisifundo sophando. *(sibandakanye ukuba sikhona)*
- Ungaqhagamshelana noGqr ..... kule inombolo yomnxeba ..... ukuba unemibuzo engaphaya okanye uhlangabezana neengxaki.
- Ungaqhagamshelana neKomiti yoPhando Lomntu kwa-021-938 9207 ukuba unenkxalabo okanye izikhalazo ezingasonjululwanga kakuhle ngugqirha wakho wesifundo.
- Uza kufumana ikopi yolu lwazi kunye nefomu yemvumelwano ukwenzela iingxelo zakho.

## Isifungo somthathi-nxaxheba

Ngokuyikitya ngezantsi, Mna ..... ndiyavuma ukuthatha inxaxheba kwisifundo sophando semfuzo esibizwa ngokuba (*faka ishloko sesifundo*).

Ndazisa ukuba:

- Ndilufundile okanye ndalufunda olu lwazi kunye nefomu yemvumelwano kwaye ibhalwe ngolwimi endiliciko nendikhululekileyo kulo
- Bendinalo ithuba lokuba ndibuze imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyakuqonda ukuba ukuthatha inxaxheba kolu phando kube **kukuzithandela kwam** kwaye andikhange ndinyanzelwe ukuba ndithathe inxaxheba.
- Ndingakhetha ukusishiya isifundo naninina kwaye andisayi kohlwaywa okanye uqal' ugwetywe nangayiphi indlela.
- Usenokucelwa ukuba usishiye isifundo phambi kokuba siphela, ukuba ugqirha wesifundo okanye umphandi ukubona kuyinzuzo kuwe, okanye ukuba andisilandeli isicwangciso sesifundo, ekuvunyelenwe ngaso.

Kutyikitywe e-(indawo) ..... ngo-(usuku) ..... 2005.

.....  
**Umtyikityo womthathi-nxaxheba**

.....  
**Umtyikityo wengqina**

## sifungo somphandi

Mna (*igama*) ..... ndiyafunga ukuba:

- Ndilucacisile ulwazi olu kweli xwebhu ku-.....
- Ndimkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.
- Ndiyaneliseka kukuba uyakuqonda ngokwanelisayo konke okumalunga nophando okuxoxwe ngasentla.
- Ndisebenzise/andisebenzisanga toliki. (*Ukuba itoliki isetyenzisiwe kumele ityikitye isaziso ngezantsi.*)

Kutyikitywe e-(indawo) ..... ngo-(usuku) ..... 2005.

.....  
**Umtyikityo womphandi**

.....  
**Umtyikityo wengqina**

## Isifungo setoliki

Mna (*igama*) ..... ndazisa ukuba:

- Ndicende umphandi (*igama*) ..... Ekucaciseni ulwazi olu lapha kweli xwebhu ku-(*igama lomthathi-nxaxheba*) ..... ndisebenzisa ulwimi lwesiAfrikaans/lwesiXhosa.
- Simkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.
- Ndimxelele eyona nto iyiyo malunga nokunxulumene nam.

- Ndiyaneliseka kukuba umthathinkxaxheba ukuqonda ngokupheleleyo okuqulathwe loluxwebhu lwemvumelwano eyazisiweyo kwaye nemibuzo yakhe yonke iphendulwe ngokwanelisayo.

Kutyikitywe e-(*indawo*) ..... ngo-(*usuku*) ..... 2008.

.....  
**Umtyikityo wetoliki**

.....  
**Umtyikityo wengqina**

# **APPENDIX H: TOPIC GUIDE FOR INTERVIEW WITH PATIENTS ON ANTIRETROVIRAL DRUGS OR CAREGIVERS OF CHILDREN ON ANTIRETROVIRAL DRUGS**

## **Introduction**

### **Introduction and background to the interview and obtain informed consent**

#### **Note demographic and background information prior to the interview:**

Age

Sex

Length of time on antiretroviral

Type of regime / names of drugs

Clinic attended

## **Opening questions:**

### **1. What has the experience of taking antiretroviral drugs been like for you?**

#### **Topic guide – issues that could be explored:**

Best and worse experiences

Remembering to take the drugs

Strategies used to improve adherence

Side-effects of the drugs

Beliefs about the drugs

Reactions of family, friends, colleagues at work

Expectations of the drugs

Motivation to take the drugs

Use of traditional medicines

**2. What has the experience of attending the clinic for antiretroviral drugs been like for you?**

**Topic guide – issues that could be explored:**

First visit to the clinic

Follow up visits

Negative and positive aspects

Relationship with health workers

Suggestions for improvement

# **APPENDIX I: TOPIC GUIDE FOR THE FOCUS GROUP INTERVIEW WITH TREATMENT SUPPORTERS**

## **Introduction**

### **Introduction and background to the interview and obtain informed consent**

#### **Note demographic and background information prior to the interview:**

Age

Sex

Relationship to the patient

Length of time as a supporter

Type of regime / names of drugs they are on

Clinic attended

### **Opening questions:**

- 1. What has the experience of supporting someone to take antiretroviral drugs been like for you?**

#### **Topic guide – issues that could be explored:**

Best and worse experiences

Remembering to take the drugs

Strategies used to improve adherence

Side-effects of the drugs

Beliefs about the drugs

Reactions of family, friends, colleagues at work

Expectations of the drugs

Motivation to be a treatment supporter

Use of traditional medicines

**2. What has the experience of attending the clinic for antiretroviral drugs been like for you?**

**Topic guide – issues that could be explored:**

First visit to the clinic

Follow up visits

Negative and positive aspects

Relationship with health workers

Suggestions for improvement

## **APPENDIX J: PARTICIPANT OBSERVATION AND FIELD NOTES GUIDE**

Observe and describe the following:

- \*The clinic setting and physical environment.
- \*The social environment.
- \*Capture any historical perspectives, e.g., history of the clinic as experienced by the participants.
- \*The structured /formal interactions within the clinic.
- \*The informal and unplanned activities and interactions.
- \*Any special “clinic” or “programme” language that has evolved.
- \*Nonverbal communication.
- \*Unobstructive indicators of what is going on (less effected by people being aware that they are being observed).

Comment on notable non-occurrences, i.e., what does not happen.

Construct mini case studies that can be used as units for later analysis.

Stay open. Gather a variety of information from different perspectives. Be opportunistic in following leads and emergent issues.

Observe oneself (reflexivity). Include your own experiences, thoughts and feelings in the notes. Consider how you may have influenced what was observed and how you may have been influenced by what you observed and reporting on the implications of your own perspective.

# APPENDIX K: UNIVERSITY OF STELLENBOSCH ETHICS APPROVAL LETTER



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
Jou kennisvennoot • your knowledge partner

## Ethics Letter

18-Feb-2016

**Ethics Reference #:** N06/10/197

**Title:** The experience of HIV positive patients on Antiretroviral drugs attending the public service facilities in the Eastern Cape Province. A qualitative study.

Dear Dr Jimmy Chandia,

The HREC approved the following progress report by expedited review process:

Progress Report dated 14/11/2014 - 15/11/2015

The approval of this project is extended for a further year

Approval date: 12 February 2016

Expiry date: 11 February 2017

If you have any queries or need further help, please contact the REC Office 219389819.

Sincerely,

REC Coordinator  
Ashleen Fortuin  
Health Research Ethics Committee 2

## **APPENDIX L: THEMATIC INDEX**

### 1. How patients incorporate the taking of ARVs into their lifestyle

- 1.1 Use of mobile phone alarm
- 1.2 Use of clock/watch alarm
- 1.3 Reminders from family members or treatment supporters
- 1.4 Intuition (they just feel it is the right time)
- 1.5 Carrying the medication with them
- 1.6 Keeping/taking medication elsewhere (to avoid disclosure)
- 1.7 Disclosing a different diagnosis (e.g., diabetes)
- 1.8 Take ARVs in secret
- 1.9 Follow advice from treatment supporter
- 1.10 Any other strategy for taking ARVs
  - 1.10.1 Acceptance of status
  - 1.10.2 Adherence linked to meal times
  - 1.10.3 Adherence linked to radio programme
  - 1.10.4 Bad health consequences of defaulting. ARVs is a motivation for taking them as prescribed.
  - 1.10.5 Using a pill calendar
  - 1.10.6 Reminded by patient
  - 1.10.7 Disclosure facilitates adherence
  - 1.10.8 Reminded by pillbox

### 2. Beliefs and feelings of patients / treatment supporter / care giver regarding their ARVs

- 2.1 Believe that they make them better (not get AIDS)
- 2.2 Believe that they increase life expectancy
- 2.3 Use of ARVs is form of unintended disclosure (that leads to stigma)
- 2.4 Feel angry about taking ARVs and HIV
- 2.5 Feel that ARVs increase their appetite/ make them hungry
- 2.6 Believe that ARVs have serious side-effects
  - 2.6.1 Rash
  - 2.6.2 Change of shape (e.g., back lump, swollen stomach, thin legs, loss of buttocks, face)
  - 2.6.3 Darkening of nails
  - 2.6.4 Loss of sensation in feet
  - 2.6.5 Painful feet
  - 2.6.6 Dizziness
  - 2.6.7 Nausea or vomiting
  - 2.6.8 Diarrhoea
  - 2.6.10 Visions, nightmares and insomnia
  - 2.6.11 Increased body temperature / night sweats
  - 2.6.12 Other side effects
- 2.7 Benefits outweigh harms
- 2.8 Increase CD4 count and/or decrease viral load
- 2.9 Effect on sex (libido)
- 2.10 Will lead to weight gain
- 2.11 Will enable them to complete parenting
- 2.12 Will improve quality of life
- 2.13 Timing of taking ARVs is too strict

- 2.14 Drinking alcohol reduces ability to take ARVs
- 2.15 Having mobile clinics would improve access
- 2.16 Any other belief / feeling regarding taking ARVs
  - 2.16.1 Taking ARVs is like any other chronic disease treatment
  - 2.16.2 ARVs are sexually transmitted
  - 2.16.3 Difficulty in swallowing ARVs
  - 2.16.4 They boost the immune system
  - 2.16.5 DO NOT USE CODE ( feeling unwell too non-specific)
  - 2.16.6 Effect of government policies
  - 2.16.7 Good effect of ARVs supplemented by eating healthy foods
  - 2.16.8 No side effects of ARVs
  - 2.16.9 Weight dropping
  - 2.16.10 Lump in the neck
  - 2.16.11 Headache
  - 2.16.12 Cramps
  - 2.16.13 Belief that we are greater than HIV/AIDS
  - 2.16.15 Benefit of early diagnosis

### 3. Positive experiences of patients/treatment supporters attending the ARV clinic at the Regional hospital

- 3.1 Caring and supportive staff
- 3.2 Sharing experiences with other patients
- 3.3 Regular supply of medication (vs. not regular at local clinic)
- 3.4 Information given about side effects
- 3.5 Good relationships with health workers
- 3.6 Less chance of being known (unintended disclosure) at the hospital (vs. local clinic)
- 3.7 Any other positive experience
  - 3.7.1 Advertising business/opportunities
  - 3.7.2 Having their own HIV clinic regarded positively
  - 3.7.3 Patients supporting each other at the ARV clinic
  - 3.7.4 Supportive staff even at the Primary Care Clinic
  - 3.7.5 Clinic is clean
  - 3.7.6 Clinic is spacious and has chairs
  - 3.7.7 Down referral reduces congestion at the clinic

### 4. Negative experiences of patients/treatment supporters attending the ARV clinic at the Regional hospital

- 4.1 Uncaring and unsupportive staff
- 4.2 Being blamed for having HIV (and giving staff work)
- 4.3 Long queues and waiting times
- 4.4 Poor work ethic amongst staff (e.g., long lunch breaks, tea times, telephone calls)
- 4.5 Insufficient or poorly maintained toilets
- 4.6 Lack of ventilation in waiting areas (concern about TB)
- 4.7 Being down referred to the primary care clinics
- 4.8 Geographic inaccessibility (i.e., long distance, poor public transport, cost)
- 4.9 Unintended disclosure by staff (e.g., reception, pharmacy) and processes (e.g., separate handling of files, mixing with common patient pool)
- 4.10 Distance between services in facility (e.g., consulting rooms and pharmacy)
- 4.11 Shortage of staff
- 4.12 Overcrowding

- 4.13 Conflict/fighting between patients
- 4.14 Favouritism shown to some patients
- 4.15 General lack of hygiene / cleanliness
- 4.16 No response to their feedback / suggestions
- 4.17 Not given food / snacks while they are waiting
- 4.18 No food parcels to take home
- 4.19 Poor diet provided when hospitalised
- 4.20 Fee for hospital service
- 4.21 Penalised for missing an appointment (regardless of reason)
- 4.22 No appointment system (times to be seen, coming early but seen late)
- 4.23 Not given their right to a choice over where they obtain ARVs (hospital vs. local clinic)
- 4.24 Care for children better than adults
- 4.24 Any other negative experience
  - 4.24.1 Having their own HIV Clinic regarded negatively
  - 4.24.2 Shortage of equipment
  - 4.24.3 Hospital care in the ward is poor
  - 4.24.4 Poor directions for new patients at the ARV clinic
  - 4.24.5 Stockout of ARVs/boosters

#### 5. Positive reactions of family and others to their taking of ARVs

- 5.1 Supportive with practical help (e.g., accompanying to hospital, giving food)
- 5.2 Supportive of emotions and feelings
- 5.3 Support from immediate family members (household)
- 5.4 Support from extended family members (not in household)
- 5.4 Support from people at work (e.g., colleagues, employer)
- 5.5 Support from friends
- 5.6 Support from church or religious community
- 5.7 Support from people in local community (not in any other category)
- 5.8 Any other positive reaction

#### 6. Negative reactions of family and others to their taking of ARVs

- 6.1 Stigmatisation
- 6.2 Isolating person by family (within household, not sharing utensils, not including them in activities)
- 6.3 Rejection of person by family (thrown out of household)
- 6.4 Isolation or rejection by community members
- 6.5 Blaming person for being a problem to the family
- 6.6 Conflict over having children
- 6.7 Discrimination by employers (e.g., when looking for work)
- 6.8 Any other negative reaction
- 6.9 Selective disclosure to family members.

#### 7. Socio-economic, cultural and contextual issues affecting ability to take ARVs

- 7.1 Health and body shape / weight
- 7.2 Traditional healers / medicines
- 7.3 Complementary / alternative medicines
- 7.4 Social grants
- 7.5 Lack of food at home
- 7.6 Poverty (lack of money)
- 7.7 Unemployment (lack of jobs)

- 7.8 Job creation (and up-skilling/education)
- 7.9 Migration (lack of opportunity to migrate elsewhere)
- 7.10 Any other issue
  - 7.10.1 Government to assist to get a cure for HIV infection
  - 7.10.2 Free ARVs with government support appreciated
  - 7.10.3 Government to provide mobile clinics to improve access for ARVs

## 8. Other experiences of treatment supporters

- 8.1 Resistance to treatment because of side effects
- 8.2 Negative reaction of patient (e.g., stubborn, angry, or aggressive)
- 8.3 Financial cost
- 8.4 Coping with immediate family, while offering support
- 8.5 Using their own experience of being HIV positive
- 8.6 Coping with/responding to side effects of ARVs
- 8.7 Helping with psychological issues (e.g., withdrawal from family)
- 8.8 Being supported themselves by patient (e.g., reminded to take their own ARVs)
- 8.9 Coping with one's own HIV positive status at same time
- 8.10 Making a difference is a positive experience (e.g., seeing the person get better)
- 8.11 Seeing people get better (e.g., gaining weight, eating better, etc.)
- 8.12 Being part of one's parental responsibility
- 8.13 Reinforcing how to take ARVs (e.g., not mixing with traditional medicines)
- 8.14 Positive change in patient's lifestyle
- 8.15 Other experiences of treatment supporters
  - 8.15.1 Difficulty in getting patients to accept their status
  - 8.15.2 Clear explanation of the role of the treatment supporter to the patient
  - 8.15.3 Do not listen to people who say HIV can be cured.
  - 8.15.4 Support because of love for the patient

## APPENDIX M: WSU REC PROTOCOL APPROVAL

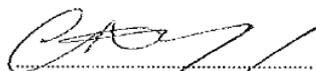


FACULTY OF HEALTH SCIENCES  
POSTGRADUATE EDUCATION, TRAINING, RESEARCH AND ETHICS UNIT

### HUMAN RESEARCH COMMITTEE CLEARANCE CERTIFICATE

PROTOCOL NUMBER : 00039 /08  
PROJECT : Experiences of HIV positive patients on antiretroviral treatment in the Eastern Cape Province.  
INVESTIGATOR(S) : J Chandia  
DEPARTMENT : Family Medicine  
DATE CONSIDERED : 01 October 2008  
DECISION OF THE COMMITTEE : Approved

**N.B.** You are required to provide the committee with a progress or outcome report of the research after every 6 months. The committee expects a report on any changes in the protocol as well as any untoward events that may occur at any time during the study as soon as they occur.

  
Professor CD Mwesigwa-Kayongo  
CHAIRPERSON

**Walter Sisulu University**  
Academic Health Service Complex of the Eastern Cape  
Postgraduate Education and Training  
Faculty of Health Sciences  
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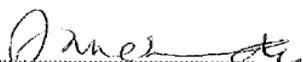
15/10/08  
Date

cc:

### DECLARATION OF INVESTIGATOR(S)

(to be completed in duplicate and one copy returned to the Research Officer at Office L311, 3<sup>rd</sup> Floor, Old Library Building, NMD Campus, WSU)

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Research Ethics Committee. I/We agree to a completion of a yearly progress report.

  
N.B. Please quote the protocol number in all enquiries.

9<sup>th</sup> August 2009

Prof CD Mwesigwa-Kayongo (Chairperson), Prof K Mfenyana (Exec Dean), Ms P Nakani (Secretary), Prof G Ekosse (Dean of Research), Prof EL Mazwai, Prof G George, Ms Z Dotwana, Rev Dr MW Guwa, Dr L Mpahlwa, Dr P Yogeswaran, Prof N Mijere, Prof JE Iputo and Prof GAB Buga.