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Perceptions and Experiences of Antiretroviral Treatment (ART) of Patients in Themba Lethu Clinic in Johannesburg: An Exploratory Study

By

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A research report submitted to the Department of Sociology- School of Social Sciences, the Faculty of Humanities at the University of the Witwatersrand, Johannesburg, South Africa.

In partial fulfillment of the requirements for the degree Master of Arts by Coursework and Research Report in Health Sociology

30 April 2012

Declaration

I declare that the work contained therein is my own, original work and that where I have made use of other's ideas I have referenced accordingly.

_____

Constance Mongwenyana

University of Witwatersrand, Johannesburg, South Africa

30 April 2012

Acknowledgement

First, I give glory to the mighty Lord for protecting, giving me strength and courage throughout the whole course.

I dedicate this to this to my beloved family, my father, my mother, my two brothers and my sister. I wish to thank my beloved fiancé Mr. Veli Zungu for being patient and understanding. He provided the support and encouragement that enabled me to finish the study. Special thanks to my lovely and understanding daughter, Tsholofelo Mongwenyana for taking over the domestic duties and responsibilities on my behalf when I was busy with my study.

I wish to acknowledge the long standing support and encouragement of my supervisors, Prof. Leah Gilbert and co-supervisor, Mr. Paul Steward of University of Witwatersrand. I'm humbled by their patience and guidance they gave me during the work of this report. Thank you very much; it was not an easy journey.

I would also like to thank Celeste Sauls for valuable support and technical assistance.

Thanks to my friends and colleagues at HE²RO who provided me with support and words of encouragement when I felt tired and not willing to continue.

Lastly, I wish to express my deep appreciation to the staff and patients at Themba Lethu Clinic at Helen Joseph Hospital for their willingness to assist and participate in the study.

Abbreviations

ART	ANTIRETROVIRAL THERAPY
HIV/AIDS	HUMAN IMMUNODEFICIENCY VIRUS/ ACQUIRED IMMUNODEFICIENCY SYNDROME
STI	SEXUAL TRANSMITTED INFECTIONS
TLC	THEMBA LETHU CLINIC
CAM	COMPLEMENTARY AND ALTERNATIVE MEDICINE
CEO	CHIEF EXECUTIVE OFFICER
PLWHA	PEOPLE LIVING WITH HIV/AIDS

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1. INTRODUCTION

With an estimated 5.6 million people living with HIV/AIDS, South Africa has the largest antiretroviral therapy (ART) programme in the world. According to the statistics released by South African National AIDS Council and Department of Health at the Programme Implementation Committee meeting in January 2011, currently there are 1,309,639 patients receiving ART in South Africa. ART has brought important benefits to HIV infected patients, such as increased survival, better quality of life, significant reduction in the incidence of opportunistic infections and lower costs related to ambulatory care and hospitalization (Guimaraes et al, 2007). The decline in deaths from 612 778 in 2006 to 592 073 in 2008(Statistics South Africa, 2010a) provide evidence that the treatment programme intervention has reduced mortality and morbidity of HIV/AIDS in South Africa.

This development of ART has shifted people's perception about HIV/AIDS as a fatal condition to that of a chronic one that can be managed (Basavaraj et al, 2010). Now, patients have to learn to live with HIV/AIDS as a manageable disease. Therefore, their perceptions of ART have to be taken into consideration in order to maintain adherence with the prescribed drug regimens. There are also concerns about ART by HIV positive patients which include the need for additional food, travelling costs, stigma and side-effects (Fox et al, 2010; Weiser et al, 2003). People living with HIV/AIDS face everyday problems related to the disease, the therapy, and a persisting social stigma which inevitably influences their perceptions and behaviour (Martini et al, 2000). Based on this, patients' perceptions of the disease and therapy are important in influencing the level of adherence by patients to treatment and better quality of life as well as to the potential encouragement of other HIV positive people not yet on treatment to take it up. Since 2004, the South African

government has worked hard on the awareness and general education about HIV/AIDS prevention. The ART roll out in 2004 was a big step toward the fight against HIV/AIDS but the consensus is that now HIV programmes in South Africa, that target the general population should include educational messages about ART and address the changing beliefs about HIV in the era of greater ART availability (Cohen et al, 2009). The education and changing of beliefs about HIV/AIDS and ART at this moment are particularly important after the widespread misconceptions about HIV/AIDS and treatment related to the previous President Thabo Mbeki's government which doubted the effectiveness of treatment. Since the 'AIDS denialism' approach, delayed and slow paced the delivering of public ART programme (Muula, 2008), there is a greater need for education about issues related to treatment.

The problem is that a wide variety of negative perceptions and experiences of ART leads to decreased concern about HIV, non-adherence to available therapies and to increased sexual risk taking. Therefore, patients may feel emotionally unprepared for treatment due to lack of understanding and/or belief in ART, leading to increased difficulties with everyday treatment management. This exploratory study, therefore, has the potential to add to our understanding of these perceptions and experiences and incorporate it in future educational programmes. In light of the above, this study aimed to investigate the perceptions and experiences of ART mainly because of the limited nature of such research in sub-Saharan Africa.

1.1 THE AIM OF THE STUDY.

- To explore the perceptions and experiences about ART of those currently on treatment at Themba Lethu clinic(TLC) in Johannesburg in order to establish strategies to decrease the high level of non-adherence to Antiretroviral therapy (ART).

1.2 RESEARCH QUESTIONS

This study aimed to answer the following research questions:

- What are patients' perceptions and experiences of ART?
- What factors contribute to their perceptions and experiences?
- How are these perceptions shaped by the various factors such as stigma, side-effects, etc?

1.3 RATIONALE

The study will facilitates a better and more nuanced understanding of how patients perceive and experience ART and provides us with more clarity with regard to the factors which shape these perceptions and experiences. This knowledge has the potential to contribute towards the enhancement and the effectiveness of ART programmes being rolled out by the government and non government organizations in South Africa, to develop a clear strategy on reducing the number of patients that are non-adherent on treatment; to reduce the numbers of patients who become resistant to ART regimens and who are susceptible to opportunistic infections and to reduce the number of clinic loss to follow-ups. Lastly, the findings provide health care workers with valuable information in order to identify and predict factors that may lead to non-adherence and thereby provide material for more appropriate education about ART. Since the literature on this topic in the South African context is limited, this study has the potential to fill in the existing gaps.

2. LITERATURE REVIEW

2.1 Lay belief about health

Health is generally understood in different ways based on different sets of beliefs, educational disciplines and culture. There is no doubt that health professionals and patients perceive or understand health differently. The differences are based on their knowledge, social groups, socio-economic status and more generally, the information available to them (Curtis & Taket, 1996; St Claire, Watkins & Billinghurst, 1996). According to Wei-Ti Chen et al (2008), most negative attitudes towards ART expressed by patients are derived from their experiences, their socio-economic status and cultural health beliefs. Regardless of the differences between the health care professionals and researchers are also becoming increasingly aware that effective treatment of diseases and health promotions in culturally diverse societies, such as South Africa, requires sensitivity to the patients' cultural beliefs and customs which form the bases of their lay beliefs about health (Beuster & Schwar, 2005). Cultural customs and beliefs can significantly impact on the patients' attitude towards treatment procedures.

In South Africa, even though there is access to information about health in general and ART through media, television, awareness and education campaigns, and so on, the society still has their own beliefs about health for example, that ART cures AIDS (Nachega et al, 2005). However, it has been suggested that qualitative studies may assist in improving our current understanding of, and provide insight on patients' own perceptions and experiences about illness (Sidat et al, 2007). This study thus aimed to contribute towards that by getting more information and understanding about these perceptions and experiences on ART, which will help to increase the level of adherence to treatment.

2.2 Experiences of ART

ART is the main type of treatment for HIV/AIDS. It is not a cure, but it can stop people from becoming ill for many years. The treatment consists of drugs that have to be taken every day for the rest of a person's life. The aim of ART is to keep the amount of HIV in the body at a low level. This stops any weakening of the immune system and allows it to recover from any damage that HIV might have caused already. The benefits of ART for people with HIV/AIDS are actually far outweigh their risks. According to the WHO ART guideline (2010) all HIV positive patients with a CD4 count of ≤350 cells/mm3 and for those with WHO clinical stage 3 or 4 if CD4 testing are to be initiated for ART including those who has TB and pregnant women. The South African ART guideline (2010) says the same but with CD4 count of ≤200 cells/mm3. A circular dated 28 August 2011 was sent by Dr. Y Pillay (Deputy Director-General: HIV/AIDS, TB and MCWH) that all HIV positive patients with a CD4 count of ≤350 cells/mm3 should be initiated for ART. This new policy directive aims to improve the quality of life and health outcomes of all HIV positive South Africans.

Although ART leads to a sustained reduction of virus load in many patients, it can also be associated with adverse side-effects. Because of the low tolerability of these drugs patients, who receive long-term ART often become less adherent to the regimens, which in turn may result in the development of multidrug-resistant virus. Factors that could impede the success of ART as a prevention and a treatment tool include factors such as adherence to treatment, stigma and discrimination, development of drug-resistance, economic constraints included additional medical expenses, travelling cots to the clinic and changes in sexual behaviour as a result of the availability of treatment (Alcorn, 2010; Weiser et al, 2003).

Different people have different experiences taking medications and lead different lives. Lipodystrophy syndrome derived from the ART side-effects and is defined as a set of changes that includes less fat in peripheral areas (Giudici et al, 2010). The development of lipodystrophy may lead to problems relating to stigma towards people who are taking ART hence the change of their body shape. This study's particular interest is in the meanings of their medication practices, views regarding ART, and why and how they comply and fail to comply with medications, what are their experiences with ART, how do patients on ART cope with side effects and what do they do to cope with the side effects.

Side effects occur when the drugs affect the body in ways other than those intended. Most of the antiretroviral drugs have known side effects, but this does not mean that everyone who takes the drugs will experience them. Some people only experience mild side effects and find them easily manageable. But for some the side effects occur so strongly that they have to consider alternative drugs. Many people who are HIV positive still use traditional medicines to treat opportunistic infections and offset side effects from ART (Chinsembu, 2009). This happens because of less knowledge that side effects often get better after a person has been on treatment for a while, as the body starts to adjust to the antiretroviral drugs. Doctors can usually prescribe some treatment to help with the most common side effects such as nausea and diarrhea.

Given the above literature, it is important that patients are made aware of known side effects so they maintain their treatment adherence whenever possible. There are conflicting messages about the benefits of ART and its side effects. Ongoing education to patients on their disease, including any new diagnoses, unexplained symptoms or opportunistic

infections needs to be done to increase the level of adherence. For this reason, this study focuses on how are patients' perceptions and experiences about ART are shaped by these side effects. A high level of adherence to medication is required for patients to realise the benefits of antiretroviral treatment.

Clinical and treatment-related factors were found to be barriers for good adherence among HIV treated patients. According to Wei-Ti Chen et al (2008), negative attitudes towards ART derive from patients' experiences. Studies also concur that appearance-related changes or side effects have a significant impact on the daily life of HIV infected patients (Cabrero et al, 2010; Sidat et al, 2007; Guimaraes et al, 2007; Wei-Ti Chen et al, 2008).

High level of stigma is experienced by people who are taking ART because of the appearance-related changes, and this is consistently associated with lack of social support, poor physical and mental health and poverty. In South Africa, infected individuals have been shunned, abandoned, isolated, expelled and even killed by horrified neighbors and kin. Therefore, intensive on-going education about ART, counseling and support is needed, a task that might be easier if we had a better understanding of experiences of people on ART.

However, ART is a dynamic phenomenon which changes over time, as patients tend to adapt their daily routines to regimen scheduling and mostly learn how to identify and deal with the side effects (Guimaraes et al, 2008). Sidat et al (2007), state that a good knowledge of side effects is regarded as an important tool in gaining sense of control over patients' health. A complete understanding of the complexity of the regimen may also help patients deal with their medication with less difficulty. In addition, earlier access to care and

counseling before initiating ART may help prepare patients for long-term treatment effects and reinforce the need for high level of adherence.

Poor health professional-patient relationship may be more likely to increase the difficulties with treatment (Guimaraes et al, 2007). Therefore, health care professionals and AIDS referral services must develop focused interventions to address modifiable factors such as compliance with medical visits, counseling, improved physician-patient relationships and better ART orientation to achieve immediate and sustainable adherence (Guimaraes et al, 2007). In this study, the understanding of patients' perception and experiences raises the feasibility of improving patient experience of care in general, and the ability to improve upon the health professional's ability to make a patient feel known "as a person" in particular. According to Beach et al (2006), such interventions can improve provider behavior and adherence to ART.

2.3 Perceptions of ART

According to Cohen et al (2009), since the availability of ART, the prevalence of unprotected sex and the incidence of sexual transmitted infections (STI) and HIV has increased. In their study they found that men who are taking ART believed that it cures HIV/AIDS. In another study conducted by Nachega et al (2005) on the beliefs about HIV/AIDS and ART among HIV positive patients in Soweto, South Africa, participants' impression of ART were overly optimistic but there was 49% who also believed that ART can cure HIV/AIDS. That belief was associated with a low level of education. In this study of Cohen et al, 2009, which was conducted in Kenya, knowledge that missing one's ART dose can lead to disease progression was significantly higher among those not taking ART compared with those on ART (Nachega et al, 2005). Therefore, there is a need to reinforce education messages about ART

particularly to those who are taking treatment. Nachega et al., study was conducted just after the ART roll-out in South Africa and during the government of President Thabo Mbeki which denied the effectiveness of ART. Therefore, the importance of the findings in this study that investigates the perceptions and experiences of ART in an era where there is a greater availability of and people are more knowledgeable about HIV/AIDS.

Basset et al (1999) maintain that the most common reasons for patients discontinuing treatment are actual side effects or the fear of side effects and this occurs because of the perceptions and conflicting information from different sources and beliefs about ART. Most studies deal more with side effects as a factor that influences the perceptions on ART by patients. According to Guimaraes et al, (2007) factors associated with non-adherence include characteristics related to the antiretroviral regimen (e.g. complexity of therapy, pill burden, adverse reaction), a patients' perception of the treatment, interference of ART in daily life, symptoms of AIDS and level of education.

In a study by Agnerson et al (2010) about the challenges to ART scale-up in rural district in Tanzania, it was found that there are a negative attitudes and perceptions about ART care HIV testing and the ART programme. There was lack of trust in ART's sustainability and HIV positive individuals on ART reported risky behaviours with the aim of revenge and were feared by community members. There is an immense need to build awareness among ART patients so they understand how risky behaviours affect their personal well-being and the community at large.

According to Wei-Ti Chen et al (2009) complementary and alternative medicine (CAM), is used to replace the prescribed ART or as a complement to ART. The factors which influence

this act are the increased pain the perception that CAM is generally being “safe” and patients “know that it works”.

According to Chinsembu (2009) HIV/AIDS patients rely on current ART programme but there are some who still have faith in traditional medicines In general, HIV/AIDS patients are open in their choice of treatments, such as that they want to have the best of both worlds. Patients should be aware of potential toxicities and drug interactions related to the use of CAM and ART (Hsiao et al, 2003 in Wei-Ti Chen et al, 2008). Since patients who are on ART need to be made aware that alternative medicine can lead to drug resistance and other problems, this study’s concern is to expose the factors that contribute to the belief in alternative medicine by patients who are on ART.

This study is more interested in a better understanding of the perceptions and experiences of ART of patients on treatment and gets more factors which influence these perceptions and experiences of ART. It seems that people perceive ART as a cure for HIV/AIDS and this perception is associated with low level of education and low level of knowledge about ART. This, also comes from the sources of information people have access to such as the media, radio, newspapers, magazines, friends, relatives, traditional healers, political leaders, etc. The fear of side effects also contributes to the perceptions of ART and this occurs because of the perceptions and conflicting information from different sources and beliefs about ART. Perception of illness severity also influences HIV clinic attendance (Wringe et al, 2009; Baumann & Trinicard, 2002). This ultimately leads to loss to follow ups in the clinic and requires further exploration.

Side effects, depression, anxiety and stigma are the core of the experiences of patients who are on ART according to the literature. As indicated, people who are on ART also use alternative medicine to deal with the opportunistic infections or side effects. The outcome of perceptions and experiences on ART are risky sexual behaviours, non-adherence, patient loss to follow up, treatment resistance or failure, depression and poor mental health. On-going education, counseling and support may help to reduce these outcomes.

3. THEORETICAL CONCEPTUAL FRAMEWORK

The concepts of 'Illness experience' and 'adherence' and the social complexities associated with them form the framework of this study.

3.1 Illness experience

Most people do have ideas about how illness occurs and it is very likely that this will in turn, shape their views about health and how to maintain it (Annandale, 1998). As indicated in the literature review, people have ideas about ART and use the alternative medicines with ART to reduce the side effects. Patients on ART need to be explained on how to avoid adverse drug-drug interactions. Herbs and other over the counter preparation can lead to renal and liver toxicity, complicating the clinical picture of adverse events, and may have unknown drug interactions affecting antiretroviral drug levels (Department of Health, 2010). The patient should understand the possible consequences of unknown content and the danger of over-the-counter drugs and traditional medicines.

According to Seeman & Kleinman (2000), illness experience connects the social and cultural context and the biography of a person but a highly specific one to the disease process. Illness experience is a given shape and pattern by the shared categories of culture, gender, ethnicity, social position, and age cohort, but it is also unique in each particular case. Illness experience can be considered as a site for the infolding of the social world onto the body but in a way that interacts complexly with rather than effacing the contingency of individual lives.

This study uses Parsons (1951) concept of the sick role for understanding the ART experience. He perceives illness as a societal entity rather than physical entity. According to

Parsons, illness disrupts normal life functions and relationships (Young, 2004). It is a social role, the 'sick role' which is characterized by duties of the parties to the doctor-patient relationship. In this relationship, the doctor has to restore wellness to the sick person while the sick person has the duty to try to get well. He used the term 'sick role' which involves winning patients trust and access to their body and obligation to apply highest levels of competence in caring for the patients. He emphasized that individuals should seek help and at the same time they have the obligation to cooperate with physicians (Young, 2004). This concept assists in countering some deficiencies of an alternative empowerment ethos by bringing social structural factors into play. Patients who are supported in their adherence efforts are much more likely to maintain viral loads that are undetectable. The Department of Education Guideline(2010) emphasize that health officials needs to spend time with the patient and explain the disease, the goals of therapy and why the need for adherence that ensures virological suppression as often as it is needed.

3.2 Adherence to treatment

Adherence to ART means how correctly a person is managing to take his/her medication. It means taking the correct dose of medication at the right times, every day, for as long as ART is required (Orrell, 2004). Adherence is crucial in order to sustain virological and clinical benefit of ART. The more the doses are taken correctly the more the virological suppression is achieved and therefore maintained (Orell, 2004; Chesney, 2000).

In a country where the prevalence of HIV is very high, and the disease presents a heavy burden on public health resources, as in South Africa, it is particularly important that optimal treatment outcomes are achieved in order to realize the long-term goals of public

health programmes. It is in this context that treatment adherence assumes importance (Bhat et al, 2010).

Since 2004, ART has been provided by the South African Department of Health to patients who need it as part of the national ART roll-out but it is unclear that adherence to ART is optimal among the patients receiving treatment in the context of the national roll-out. In the context of the ART roll-out, however, high levels of health literacy cannot also be assumed and vigorous efforts will be needed to ensure optimal ART-related literacy (Kagee, 2007). Kagee further emphasized that, in the absence of properly designed interventions aimed at enhancing treatment literacy among patients in the South African roll-out, predicting ART adherence levels is difficult.

It is clear from the literature reviewed that the perceptions and experience of patients play a crucial role towards adherence. Therefore, this study explores these areas. The literature states that, a good patient–health-care provider relationship may be an important motivating factor for taking and adhering to complex combination drug therapies. Thorough pre-treatment and on-going education is also vital in order to develop a full understanding of HIV/AIDS and the benefits of ART.

4. METHODOLOGY

The researcher used the descriptive survey design. This means learning a large population by surveying a sample of that population. An exploratory approach was used to conduct the study. This method is used in attempt to gain insight into a particular area of a problem. It is considered relevant since the study attempts to get insight into what are the perceptions and experiences of people on ART. For the purposes of this study, the researcher employed

a combined - qualitative and quantitative - research approach. Qualitative research is a method of conducting research that produces findings not arrived at by means of statistical procedures. It takes place in the real life of the participants and consequently the researcher had a direct contact with HIV positive patients who were the most feasible option. Qualitative research also helped the researcher to uncover and understand what lies behind the perceptions and experiences of the respondents. Quantitative research is about numbers and the counting and measuring of things. It is objective hard data. This method involves the use of structured questions with a limited number of predetermined response options (Strauss & Corbin, 1990).

4.1 Study site

The researcher conducted the study at the Themba Lethu clinic at Helen Joseph Hospital. The Themba Lethu Clinic (TLC) was established in October 2000, and began large-scale ART provision alongside the South African government's ART rollout in 2004. TLC is an urban public-sector clinic at the Helen Josephs Hospital in Johannesburg and is believed to be the largest HIV treatment site in South Africa with 28, 000 patients in care and nearly 18,000 patients actively on ART. TLC is one of the busiest ART clinics in the country which sees about 400 to 500 patients on daily basis. However, the researcher conducted interviews in a private room in a clinic to ensure privacy of participants.

4.2 Sampling procedure

Themba Lethu clinic has been on existence since April 2004 and it is the largest ART clinic in South Africa. This study included 30 HIV positive patients on ART who came to Themba Lethu clinic for their regular clinic visit. Participants were recruited on voluntary basis and were informed about the purpose of the study. Participants were recruited from the pharmacy area where patients normally sit while waiting to pick up their ART's. The

researcher approached the patients and requested to do an interview with them after they have collected their medication or when they have done with their clinic chores. The researcher used the **purposive sampling** procedure which is used when we want to target particular individuals and categories of individuals for investigation (Greenstein, 2003). In this study the researcher targeted the HIV positive patients on ART. These participants were purposively selected because of their experience in taking treatment and their ability to give more information about their perceptions about ART. The researcher made use of own judgment to select a sample of respondents that she believes are information rich and are going to provide relevant information needed to complete this study. This is supported by Patton (1990) as cited in McMillan and Schumacher (2001) who maintains that the logic and power behind purposeful selection of informants is that the sample should be information rich.

4.3 Data Collection

Interviews and questionnaires were used as a method of collecting primary information. Data were collected trough **face-to-face in-depth interviews** using guide with **structured and semi-structured questionnaires**. In a structured interview, the researcher asked a standard set of questions and in semi-structured interview, the researcher followed the standard questions with one or more individually tailored questions to get clarification or probe a person's reason. The researcher posed a series of questions to willing participants about their characteristics, opinions, attitudes, or previous experiences by and tabulates their answers. The researcher also summarized their responses with percentages and frequency counts. Face-to-face interviews were useful to help the researcher gain cooperation from the participants, clarify ambiguous answers and seek follow up answers. That helped to get information which is secretive as the researcher was able to detect if the

participant is hiding any information.These methods were used to assist the researcher to probe participant's views, opinions, ideas and perception about ART in order to gain in-depth information. Qualitative element includes **in-depth interviews** as a method of collecting information that is regarded sensitive to participants.

4.4 DATA ANALYSIS

According to Patton (1990), qualitative data analysis is the process of systematically organizing the interview transcript, field notes and other accumulated material until they are understood in such a way they address the research question and present the result that create an understanding to others. Data analysis is the process of bringing order and meaning to the collected data. The researcher captured data in CSPro 4.0 data tool and use SAS 9.0 software package to code and analyze the data. The descriptive statistics was used by using frequencies as a method of data analysis. According to Greenstein (2003), the descriptive statistics method is used to organize and describe the characteristics of data about the population**.** Frequencies break down the overall data into categories and present them as a percentage of the total.

4.5 ETHICAL CONSIDERATIONS

The researcher doesn't think any issues of unethical practice have arisen. In research involving humans, the ethical principle of beneficences expressed in researchers' responsibility to minimize risks of harm or discomfort to participants in research projects. Patient autonomy must be respected. Endeavors to promote autonomy should be pursued through seeking opinions of representatives of vulnerable communities, including persons living with HIV/AIDS (Department of Health, 2004).

Prior to involving the participants into the study the researcher first obtained their consent voluntarily and there were no use of coercion. Informed consent entails informing the participants about the overall purpose of the investigations and the main features of the design, as well as of possible risks and benefits from participating in the research project. It further involves obtaining the voluntary participation of participants and informing them about their right to withdraw from the study anytime. Participants were informed in advance of their right of choice to participate and they were given time to make such a decision. Refusals and withdrawal from the study did not lead to any discrimination. The researcher gave the participants an assurance that the data will be kept confidential and anonymous.

Permission to conduct the research was already been obtained from Themba Lethu medical manager and CEO of Helen Joseph Hospital as well as the Wits Ethics Committee before the data were collected. Ethical clearance was obtained from the University of Witwatersrand Committee for Research on Human Subjects (medical) for permission to carry out this study (Protocol number M111115, approved 16/01/2012), Appendix F. The Themba Lethu Clinic at the Helen Joseph Hospital and the Helen Joseph Hospital has also granted approval for the conducting of the study (Appendix D and E).

5. ANALYSIS OF FINDINGS

The purpose of this section is to present and analyse the results which were obtained primarily from face-to-face interviews held with patients at Themba Lethu clinic. Patients were interviewed in their preferred language by the researcher.

Themba Lethu clinic operates from Monday until Thursday from 7h30 until 4h30. Patients start to queue for their medication from as early as 6h00, the reason being their eagerness to be the first on the queue or to finish early so they are able to go to their work or daily activities. The researcher targeted the participants from 6h00 in the morning before the pharmacy starts to operate and in the afternoon after they have collected their medication. The purpose was not to interrupt the movement of their queue. Interviews were done in a private room next to the pharmacy and lasted for 15 to 30 minutes.

In analyzing the perceptions and experiences of ART of patients in this study, it is important to describe some of the factors that according to the literature might play a role in shaping and influencing these experiences and perception despite the fact that this study did not seek to establish statistical correlations between these factors but was rather descriptive and explorative. These factors include their social background, social support, stigma, side effects, etc. The identified themes were categorized and classified in order to understand the experiences and perceptions of patients on ART. The findings are also presented in a form of tables as well as summaries

Table 1 below shows the description of socio-demographic characteristics or the social background of patients which were interviewed in the study and gives an indication of the characteristics of the study population.

5.1 Socio-demographic characteristics of respondents

Table 1

Variables	Frequency	%
Gender		
Females	15	50
Males	15	50
Age categories		
26 – 35	10	34
36 – 45	14	47
46 – 55	4	13
56 – 65	1	3
Refused	1	3
Name of suburb		
Johannesburg	21	70
Soweto	8	27
Orange farm	1	3
How long have you lived in this suburb		
<1 year	2	6
1-5 years	5	17
>5 years	23	77
Original place (province) of birth		
Gauteng	12	40
Natal	5	17
Limpopo	3	10
North West	2	7
Free State	2	7
Eastern Cape	1	3
Mpumalanga	1	3
Non-South African	4	13
Level of education		
Some primary school	2	7
Completed primary	2	7
Some high school	11	36
Matric	14	47
Post-Matric training	1	3
University degree	0	0
Marital status		
Single	13	43
Engaged	1	3
Married	8	27
Divorced or separated	8	27

Out of 30 patients interviewed at TLC 15 were males and 15 were females. All patients were on ART and gave their informed consent. Their ages ranged from 26 – 62 years (*M* = 39.4). The participants stay in the suburbs around Johannesburg in Gauteng and 77% of them have been living there for more than 5 years. Only 40% of these patients were originally born in Gauteng while others come from different provinces in South Africa including some of the sub-Saharan countries (13%). The participants were less likely to have completed secondary education but were more likely to have completed Matric. Only 3% had post-Matric qualification. The analysis showed that patients interviewed were not well educated and this could influence their perceptions on ART. This echoed the findings of Wei-Ti Chen et al, (2008) that most patients who express negative attitudes towards ART are derived from their experiences and their socio-economic status. Other researchers found that lower education increases one's risk of not understanding of treatment (Wringe et al, 2009; Baumann & Trinicard, 2002).

5.2 Perceptions and concerns about ART

Table 2 Perceptions, concerns and benefits of taking ART

Perceptions and Concerns about ART	**YES**	**NO**
The ART clinic is not open at convenient times for me	**40%**	**60%**
I am afraid of stigma or abuse	**30%**	**70%**
I am concerned about side effects	**40%**	**60%**
ARTs will make me sick	**16.67%**	**83.33%**
People taking ART die	**13.33%**	**86.67%**
I do not want to take medicine for life	**20%**	**80%**
I do not have enough food to take ARTs	**30%**	**70%**
If I take ART with alternative medicine I might get better	**13.33%**	**86.67%**

My family doesn't want me to take ARTs	**6.67%**	**93.33%**
Benefits of taking ART	**YES**	**NO**
If I take ARTs I will feel better/stop being sick	**93.33%**	**6.67%**
If I take ARTs I will be happier	**80%**	**20%**
If I take ARTs I will be able to take care of my family	**96.67%**	**3.33%**
If I take ARTs I will be cured of AIDS	**33.33%**	**66.67%**
If I take ARTs I will live longer	**96.67%**	**3.33%**
If I take ARTs I will be able to work	**96.67%**	**3.33%**

Table 2a indicates perceptions and concerns about ART by patients. The researcher used the questions based on information coming from the literature. The participants were asked to express their agreement or disagreement with the statements in the table. However, they were also allowed to express themselves beyond the structured questions. The findings of Table 2 shows that out of the six patients who do not want to take ART for the rest of their lives and who says if they take ART they will not be happier, four of them are the same patients.

5.2.1 Time of the clinic

Forty percent of the participants (Table 2a) have a concern that the clinic is not open at a convenient time for them, that the clinic is always overcrowded and that they spend a lot of time in the clinic only to collect medication. One of the participants said:

> 'I wish that the clinic could open until 8 o'clock in the afternoons or maybe open on Saturdays because of my working time. My employer does not allow me to often take the day offs for clinic visit or come to the work late. The clinic is always full and this is makes my life difficult.'

This might be one of the reasons behind the high number of defaulters in the clinic. According to Wanyenze et al, 2010, increased volume of patients has contributed to having

HIV clinics that often are congested and struggling to meet the demand of high patient volume. This could also affect patient satisfaction and retention.

5.2.2 Stigma or abuse

Even in this era of greater availability of ART and knowledge of HIV, the findings show that 30% of patients are still afraid of stigma, as reflected in some of their quotes:

> 'I am afraid to be stigmatized because people don't have enough knowledge about HIV and ART'.
> 'We are just being stigmatized because people are ignorant'.
> 'People stigmatize and judge me because ART has changed my body'

Most of the participants (83%) feel that they are being judged negatively or treated badly because they are taking ART. The participants noted the negative judgments and tried to explain why this is the case by stating that:

> 'People judge me negatively because they think I was sleeping around'.
> 'They have no information and knowledge about ART'.
> 'They are not educated'.
> 'They don't know their status and think that they will not be infected'.
> 'They fear death'.

Whether, these are plausible reasons behind the negative judgments or not are beyond the scope of this study. However, it is important to expose how patients on ART feel with regard to these judgments.

5.2.3 Do not have enough food to take medication

In the study by Nachega et al (2004) of adherence to antiretroviral therapy in HIV-infected adults in Soweto, it was found that one of the reason for not adhering to ART was difficulty with meal requirements. This study was done immediately after the South African roll-out of ART of which we can assume that, people had less knowledge about ART. Several studies have also recently identified food insecurity as a key structural barrier to ARV adherence and as a contributor to ARV treatment interruptions (Weiser et al, 2009; Weiser et al, 2010).

Their findings also suggest that food insecurity may compromise treatment efficacy even in well-resourced settings. The studies found that food insecurity and hunger not only interfere with day-to-day adherence but that fears about hunger and food insecurity may also cause people to delay initiating or to discontinue ARV therapy.

In this study, the table 2a also shows not having enough food (30%) as being the other barrier to ART and a potential increase of non-adherence. Participants were concerned that they don't have enough food to take ART. They perceive that ART increases appetite and lead to intolerable hunger in the absence of food. This finding is of major concern and should be taken into consideration by the relevant authorities.

5.2.4 ART will not make me happier

The analysis shows that 20% of participants believe that ART will not make them happier. As expressed by one patient mentioned:

> 'I hate these pills; I only drink them just to satisfy the people that I live with them. I don't want them to blame me when I'm dead.'

This is consistent with other studies where patients expressed dissatisfaction with having to take their medications for the rest of their lives (Gilbert & Walker, 2010). It also highlights the relevance of Parson's 'sick-role' in understanding that the patients do what is required of them by society

5.2.6 Do not want to take ART for the rest of the life

Some of the patients interviewed in this study have been taking ART for longer period ranging from 1 to 10 years. Even when patients fully understood the need to take ART throughout their lives, 20% of the patients do not want to take the medication for the rest of their lives. The patients complained that

> ‘The medication is taking over my body’.
> ‘I have a concern of taking ART every day; I wish I could take it once in six months’.
> 'ART is a powerful drug that is not good for your body and it drives you crazy. ‘I wish that one day we could stop taking ART and have a solution to this disease’

These sentiments portray the complexity of taking life-long medication. However, this is not an experience unique to patients on ART but characterizes medical regimens of most chronic patients who are on medication for the rest of their lives. They also, once again, bring to light the inadequacy of Parson’s model of the ‘sick-role’ since despite the patients’ best intentions, they will not be cured even if they do take the medication – they will however ‘get better’

5.2.7 ART cures AIDS

Despite the knowledge that ART does not cure AIDS but can stop people from becoming ill and suppresses the viral load so that the immune system should not be weak, 33.33% of participants believe that ART cures AIDS (Table 2b). This finding strongly suggests that patients still need to get more education about ART and HIV/AIDS. The analysis also shows that from the group 9 patients who believe that ART cures AIDS, 7 of these patients were born and grew up in rural areas which are far away from Johannesburg (Lesotho, Limpopo, Natal and Malawi) while only 2 were born in Gauteng. This might suggest that the correct information about the merits of ART has not been disseminated adequately in the rural areas. It also brings to our attention the movement of patients from rural areas to clinics in Gauteng and as revealed in a study conducted by Gilbert and Walker (2009) where patients chose to come to the inner-city clinic in order to maintain anonymity and avoid stigmatization.

Burnett et al (1999) in Pretzel et al (2010) found that 51% of traditional healers believe that there is a cure for HIV/AIDS. This might influence patients' perceptions; however, this study did not seek to establish the differences in perceptions between the patients who believe that ART cures AIDS and the ones who go to traditional healers when sick – this is a task that can be achieved in a study of larger scope. Nevertheless, the traditional healers also need to be trained about the disease and care as some patient turn to traditional healers for help for the cure.

5.3 Experiences with ART and help seeking

5.3.1 Experiences

Patients who were interviewed in this study started taking ART from 2002 to 2011. The analysis focused on the patients' personal experiences with ART since they started treatment. Patients acknowledge that before they started ART they were very ill and that they now have recovered from their illness and they are well. The quality of life has improved and opportunistic infections are lowered since they started ART. ART is the means by which they survive as acknowledged in other studies (Gilbert & Walker, 2009).

Four themes emerged from the data analysis. The themes cover the *side effects, adherence, social support and stigma* as experienced by the patients who are taking ART.

5.3.2 Side-effects

Some participants were concerned about the side effects of ART. Not surprisingly, this finding is consistent with those in other studies. Carios et al (2010) found that side effects were the most frequently discussed barriers to adherence. The *side effects* mentioned by participants included, drowsiness or dizziness, skin problems, sore feet, big stomach or disfigured body, strange dreams or sleepless nights, vomiting, diarrhea, headaches, fatigue,

swollen glands, too much acid in the body, mental disturbance, as well as losing of appetite and weigh loss.

When asked on how they are coping with side effects, 10 participants indicated that it is very difficult to cope with side effects while 2 mentioned that they have accepted the condition. Gilbert & Walker (2009) indicated that side effects are sometimes difficult to understand because they vary from one person to another. There is a need for the patients to have a good level of understanding, which is often difficult to achieve despite the efforts of health workers.

The analysis also shows that 14% of patients agreed that they would take any treatment other than medical treatment when they get ill. One patient mentioned that

> 'I believe that cure for HIV/AIDS will come with somebody thus I will continue to look for that somebody. I would take anything that is said to be helpful in curing AIDS'.

According to Taylor (2010) there is a pattern of shopping around for a more effective treatment based on the belief that there is always some more effective medicine out there and that the challenge is just to locate it. . As mentioned earlier, some people choose to go to the traditional healers than to the clinic or the hospital because of discriminatory treatment that some nurses give to AIDS patients. The above-mentioned patient continued

> 'Nurses in the clinic do not treat us right, its better if I seek help somewhere when I get ill.'

This is not an uncommon complaint in the context of the South African health care services and no doubt shapes patients' experiences and impacts negatively on the implementation of ART. However, further investigation is beyond the scope of this research report.

5.3.4 Adherence

Patients are also still experiencing difficulty in adhering to the drug regimen. The findings of the study show that as much as 70% of patients are not fully adhering to treatment. The main reason for being non-adherent is that they are sometimes travelling or away from home and do not have tablets with them, forgot to take treatment, too busy, too many pills, traditional healer advised not to take the treatment or the patient could not read or understand the instructions. As reflected in some of their expressions:

> 'I am trying to adhere to my regime but sometimes I miss my pills when I'm drunk.'
> 'I've just started taking treatment and I'm not used to it, so I forget'
> ' Could not read or understand the instructions well'
> 'When time to drink the pills has passed for I just don't drink them'

This reveals an unsatisfactory scenario with regard to effective education and adherence counseling in this clinic.

5.3.5 Help seeking

The analysis shows that 83.33% have the final say about their health while 16.66% depend on parents, spouse, siblings and friends to decide about their health. Patients felt happy and proud of the decision about their health. The results also show that 50% of the patients haven't been seeing other type of healthcare worker in more than a year. This is a positive sign that most of the patients who are taking ART might not be getting sick often and are feeling much better.

However, the analysis also shows that 20% of patients who were interviewed visited the traditional healers while on ART. The response they got from traditional healers was that they have been bewitched, that they have to do some traditional rituals like slaughtering a goat to get healed and was promised that the muti (traditional medicine) will heal AIDS. Mixing ART with CAM is believed to be one of the leading factors that impact on patients'

defaulting on ART and can also cause drug resistance. Health professionals are concerned about the possibility of traditional healers undermining the ART roll out programme through providing untested substance that could interact adversely with ART (Mall, 2005 in Gilbert et al, 2010) Patients mentioned that

> 'The traditional healer promised to cure me; I got hurt when I realized that I was not healed because I have spent a lot of money. So, I tried to commit suicide.'
> 'I only stopped taking the 'muti' when my traditional healer died of AIDS'.
> 'I only went to the traditional healer because my family took me there as I was sick all the times. This happened because I did not disclose to my family that I was HIV positive'.

Families go to traditional healers for traditional remedies as symptoms recur or continue for their patients and they have common beliefs about seeking help from healers. People also go to traditional healer not as a substitute but as a complementary method for the management of disease and sickness. The common belief is that people with conditions or symptoms related to HIV/AIDS have spiritual or supernatural forces and not HIV/AIDS (Hatchett et al, 2004; Taylor, 2010) . They also believe that patients are bewitched and traditional healers will help them.

5.3.6 Social Support

Lack of support from the clinic was also mentioned as a negative aspect experienced by patient who are taking ART. Patients mentioned that they are not getting enough counseling and education about ART when they are already on treatment. Two patients mentioned that they got mentally disturbed and the other tried to commit suicide because they were still in denial, could not cope with side effects and did not have knowledge about ART. Another patient responded.

> 'I was referred to this clinic from the private doctor and was not given any education about ART. Without any knowledge, I drank my pills at anytime because I was not told that this treatment is supposed to be taken at the same time every day.'

All the participants shared with somebody close to them that they are taking ART. This is a positive reality since as Weiser (2003) mentioned and others, non disclosure to friends and family serves as one of the factors that negatively affect adherence. It seems that 40% of people living with them in the same household are taking ART while 60% of their friends are also on ART. This no doubt is a direct reflection of the high prevalence of HIV/AIDS in their community.

It is, therefore surprising that at with such a high number of PLWHA at this time of ART availability people who are taking ART are still judged negatively by other people. The findings show that 80% of people on ART feel that they are negatively judged a lot. Patients interviewed gave the reason that people who are not on ART do not have knowledge, information, and education about ART and also they fear death.

People living with HIV/AIDS (PLWHA) are confronted by many factors that strongly discourage both public and private disclosure such as moral judgment and blame; ostracism by household or community; relationship termination; verbal and/or physical abuse and discrimination (Gilbert & Walker, 2010). However, it seems that in this study all respondents made full disclosure to somebody.

The results also show that 70% of the patients who are already on ART never received education about ART since they started treatment, while 66.67% of them never received any counseling. At TLC, patients attend several classes of ART adherence before they initiate on ART, but after initiation, there are no extra classes to educate or counsel patients about

ART. This could be a problem as patient experience complications when they started ART. All patients interviewed expressed their need to have education about ART after initiation.

The South African government has been trying hard to promote health. The challenge has always been the shortage of staff. According Cullinan (2005) in Gilbert et al, 2010, the ART treatment plan desperately needs more staff itself to expand. Patients further explained that they get the source of information about ART from the clinic but only if they ask the clinicians during their clinic visit and also from media. There are number of programmes used by South African government to educate people about HIV/AIDS through media for example, Khomanani, Soul City, Brothers of Life, Love Life, etc. Less is done on the education about treatment.

5.3.7 Stigma

Once again stigma still emerged as one of the negative experiences by patients taking ART. As explained earlier, 30% of patients are afraid of being stigmatized or abused. Two of these participants indicated that they are afraid of being stigmatized because their body changes which is caused by ART. This is what was explained by Goffman (1963) in Gilbert and Walker(2010) that there is a stigma of the body such as blemishes or deformities. As mentioned earlier, fear of stigma may have a positive effect on adherence. Mahajan et al, 2008 in Gilbert and Walker 2010 also stated that stigma may prevent those who are HIV positive from accessing much needed ART. It affects disclosure and hence the taking of treatment. Some of the participants mentioned

> ‘ I miss my tablets when I’m gone to my homeland because I don’t want them to know that I’m taking HIV treatment.’

Scrambler (2009) described different types of stigma, the 'felt' (internal stigma) and 'enacted' (external stigma). 'Enacted' stigma refers to actual experiences of discrimination. This may include the experience of domination, oppression, the exercise of power or control, harassment, punishment, blame, exclusion, ridicule or resentment. While 'Felt' stigma is associated with the fear of PLHA to be discriminated against. Both type of stigma appear to be experienced by the patients interviewed in this study.

6. GENERAL DISCUSSION AND CONCLUSION

This study set out to explore the experiences and perceptions of patients who are taking ART. It is evident from the results of this study that patients who are taking ART at TLC think that the opening time of the clinic is not convenient for them, they do not have enough food to take ART, that ART does not make them happy and do not want to take it for the rest of their lives and they also believe that ART cures AIDS. Patients also experience stigma from the people who are not on ART, they are concerned with side effects, some are not fully adherent to treatment, they seek help from traditional healers while on ART and also expressed that they don't get enough support through counseling and education from the clinic. In the discussion of the results, the abovementioned will be discussed.

Treatment options come with choices, and this cannot be easy with limited knowledge. The patient's knowledge and understanding of treatment, which has been recognized as a factor that influences adherence of ART, can be improved through educational programmes. This was proved in a study conducted by Goujard et al (2009) where patients who had educational intervention had better adherence and knowledge of ART than those who were not. However, educational programmes must be carried out early in the course of treatment, before drug resistance arising from non-adherence develops and alters the ultimate therapeutic prognosis in an irreversible way. There must also be an on-going education, counseling and support to increase clinic attendance and reduce clinic loss to follow ups (Wringe et al, 2009). The findings of this study show that 70% of the patients who are already on ART do not get education about treatment. Due to lack of education on ART and lack of on-going counseling, one participant reported that he tried to commit suicide because he did not have enough knowledge and understanding of medication. Education

about ART should also be extended to traditional healers because some patient seek help from the traditional when they ill.

This study also found that 33.33% of participants believe that ART cures AIDS. The literature reviewed showed that in another study conducted by Nachega et al (2005) on the beliefs about HIV/AIDS and ART among HIV positive patients in Soweto, South Africa, participants' impression of ART were overly optimistic but there was 49% who also believed that ART can cure HIV/AIDS. That belief was associated with a low level of education. Nachega et al's study was conducted during the era where ART was not knowledgeable. This study shows that there is still a need for on-going education about ART.

Policies and public health programmes need to focus on comprehensive strategies to address continuing transmission risk behaviours as well as improve psychological well being and social circumstances.

Recent surveys have been suggesting that there is low level of stigma in South Africa (Shishana et al, 2005. The HSRC Study of HIV/AIDS in Stein (2003) suggests that the majority of South Africans express attitudes of acceptance towards people living with AIDS and that the levels of HIV/AIDS knowledge in South Africa has increased and the levels of expressed stigma decreased. This is because of the national health education campaigns and the AIDS policies which promote the rights of people living with HIV/AIDS. However, Stein argues that the measures used to measure stigma are not enough as it does not include the 'hidden truth' about the 'dirty secret' . Exposure to health education does not necessarily mean that individuals will not maintain wrong beliefs about transmission. For example, participants in

surveys tend to answer questions designed to assess knowledge regarding HIV transmission according to the information they got on public health but not really according to their attitude and belief or actual behaviour. People are just not willing to admit to total strangers that they hold discriminatory attitudes and access to information may be insufficient to eliminate 'false beliefs' about transmission (Stein, 2003). This opens a question of whether studies which suggest that the level of stigma in South Africa is low use adequate measures.

The reality as reflected in this study and others (Gilbert & Walker, 2010) is that 30% of participants are afraid of stigma. Patients experience what Scrambler (2009) describe as 'enacted' stigma whereby patients who are taking ART are discriminated by other because of their deformity and the 'felt' stigma in which they blame themselves for the disease. Participants in this study feel that they are still stigmatized by people who are not on ART because people don't have enough knowledge about ART and HIV/AIDS. The solution is to have public education campaigns to emphasize the unfairness of ostracizing people with HIV who are taking ART from areas of life in which they fully participate. This might alleviate or reduce the felt stigma and increase the level of adherence.

Intervention to improve care and treatment should utilize the role of traditional healers to reduce the disease progression and to improve adherence to ART. Traditional healers could also work more closely with modern health professionals to provide AIDS information and evaluation of HIV/AIDS symptoms. Healers can continue to refer patients for modern treatment and reduce the delay and symptom progression(Hatchett et al, 2004). However, this requires a level of cooperation and further training of traditional healers about ART.

Simmons (2011) also suggest that collaborating with traditional healers could also offer another option for shoring up general health promotion efforts in the country

This study was limited by its use of a convenience sample of people living with HIV/AIDS in an urban population of Johannesburg. The participants in this study cannot be considered representative of people living with HIV/AIDS throughout Johannesburg, South Africa. However, one of the strengths of this study is that the researcher is confident that the saturation was reached because a number of the themes were similar among participants. In conclusion, in order to make recommendation to the clinic to increase patient adherence, the researcher recommend that the health workers be trained to keep a continuous education of ART to patient who are already on ART.

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Appendix A

Information Sheet and Patient consent form

INFORMATION SHEET

Study title: Perceptions and experiences of Antiretroviral treatment (ART) of patients in Themba Lethu clinic in Johannesburg: an exploratory study

Hello,

My name is Constance Mongwenyana. I am studying towards a Master's degree in Health Sociology at Wits University. The purpose of the study is to find out how patients who are taking treatment understand ART and how are they coping with it.

I am inviting you to take part in a research study and would be very grateful if you would agree to answer a few questions about ART. The questions will include, the medication you taking, your perceptions, experiences and personal information.

By gathering this data, I'm hoping to assist government or non-government organizations to reduce the number of non-adherent patients, clinic loss to follow-ups as well as reduce the number of patients who are resistant to ART. I am approaching you for interview because of your knowledge of ART. I believe that your ideas and thoughts are important and can contribute to this study. The interview will take around 30 minutes to complete during which I will be asking you a few questions and will like you to tell me what circumstances are really like, not what they should be. If you feel that a question is inappropriate or too sensitive, you are free not to answer it.

There might be unknown risks/discomforts involved. I will be very careful to prevent this from happening. You may find some of the questions difficult for you to answer. While answering all the questions will be most useful for out study, you can decide not to answer any questions if you wish. You can stop the interview at any time.

You will receive no direct benefit from your participation in this study. However, your participation may help the investigators better understand what is needed to help keep people in ART care which may benefit the entire community.

Your participation in this study is completely voluntary. If you agree to take part, you can stop at any time if you do not want to carry on being involved. If you refuse to take part or stop at any point during the study, you will not be affected in any way and you will not be discriminated against.

All the information you choose to give me will be kept confidential. I will not use your name in the research report and no one will be able to link you to the answers you give. Only I and my supervisor will have access to the linked information which will be kept in a secure place. All efforts will be made to keep personal information confidential.

If you have any questions about this study, you can contact me on 073 837 8682, by fax on 086 510 7943 or by email at cmongwenyana@heroza.org . My supervisor, Professor Leah Gilbert on 011 717 4440/29. Should you feel that the interview has emotionally disturbed you or that the questions are uncomfortable and you need any counseling, you can contact the clinics senior counselor, Nonhlanhla Dlamini on 011 276 8850 extension 123 / 073 263 7264. The email address is nonhlanhla.dlamini@righttocare.org .

Appendix B
Consent form

I understand the procedure described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form

Signature
Respondent ……Date……

Signature
researcher ……Date…….....

Appendix C

Questionnaire for:

Perceptions and experiences of Antiretroviral Therapy

To be read by the interviewer to the subject:

Thank you for agreeing to participate in this study. I appreciate your time. The information you give me is confidential. I will ask you questions and then write down your answers to the questions. The questions will take about 30 minutes to answer. Please ask me (the interviewer) if you do not understand any question. While I hope you will answer all the questions, you are free to stop answering the questions at any time or to skip specific questions that you do not want to answer. If you are not feeling well enough to answer questions at any time we can stop the interview.

This questionnaire has 6 parts.

Part A. Interview Details
Part B. Demographic Information
Part C. Perceptions and concerns about ART
Part D. Treatment experience and Help Seeking
Part E. Social Support and Stigma
Part F. Closing of Interview

Part A. Interview Details

A1. Has the consent process been administered?

____ 1 = Yes ____ 2 = No → END INTERVIEW

A2. What is today's date?

Day:____ ____ / Month:____ ____ / Year:____ ____

A3. In what language is the interview being conducted?

____ 1 = English
____ 2 = isiZulu
____ 3 = isiXhosa
____ 4 = Setswana
____ 5 = Afrikaans
____ 6 = siSwati
____ 7 = Sesotho sa Leboa
____ 8 = Sesotho
____ 9 = Tshivenda
____ 10 = Xitsonga
____ 11 = isiNdebele
____ 12 = other (specify _____)

A4. Date of birth Day:____ ____ / Month:____ ____ / Year:____ ____

Part B. Demographic Information

B1. Gender:

____ 1 = Male
____ 2 = Female

B2. What is the name of the suburb, township, or community in which you currently live (e.g. Diepsloot, Soweto, Parktown)?

B3. For how long have you lived in this suburb, township, or community?

____ 1 = < 1 year ____ 2 = 1-5 years ____ 3 = > 5 years

B4. What is your original place of birth and where you grew up?

……..

B5. What language do you usually speak at home?

____ 1 = English
____ 2 = isiZulu
____ 3 = isiXhosa
____ 4 = Setswana
____ 5 = Afrikaans
____ 6 = siSwati
____ 7 = Sesotho sa Leboa
____ 8 = Sesotho
____ 9 = Tshivenda
____ 10 = Xitsonga
____ 11 = isiNdebele
____ 12 = other (specify_____)

B6. What is the highest education level that you have reached?

____ 1 = Never attended school
____ 2 = Some primary school
____ 3 = Completed primary school
____ 4 = Some high school
____ 5 = Matric
____ 6 = Post-matric training (technical degree, etc.)
____ 7 = University degree (BA or higher)

B7. What is your marital status?

____ 1 = Single
____ 2 = Engaged
____ 3 = Married
____ 4 = Divorced or separated
____ 5 = Widowed

Part C. Perceptions and concerns about ART

Which of the following concerns do you have about ARTs?

		Yes	No
C1.	The ART clinic is not open at convenient times for me	1	2
C2.	I am afraid of stigma or abuse	1	2
C3.	I am concerned about side effects	1	2
C4.	ARTs will make me sick	1	2
C5.	People taking ARTs die	1	2
C6.	I do not want to take medicine for life	1	2
C7.	I do not have enough food to take ARTs	1	2
C8.	If I take ART with alternative medicine I might get better	1	2
C9.	My family doesn't want me to take ARTs	1	2
C10.	Other _____		

C11. Would you like to tell more about your concerns about ART?

……

……

……

What do you think are the benefits of ARTs?

		Yes	No
C12.	If I take ARTs I will feel better/stop being sick	1	2
C13.	If I take ARTs I will be happier	1	2
C14.	If I take ARTs I will be able to take care of my family	1	2
C15.	If I take ARTs I will be cured of AIDS	1	2
C16.	If I take ARTs I will live longer	1	2
C17.	If I take ARTs I will be able to work	1	2
C18.	Other _____	1	2
C19.	Other _____	1	2
C20.	Other _____	1	2

C21. Can you tell more about the benefits?

……

……

……

Part D. Treatment experiences and Help Seeking

D1. Tell me about you experiences with ART

……

……

……

……

D2. Do you have negative experiences with ART?

____ 1 = Yes
____ 2 = No
____ 3 = Don't know/not sure

D3. List your negative experiences

1.
2.
3.
4.

D4. Tell me more about them

……

……

D5. How do you cope with side effects?

……

……

D6. Would you take any treatment other than medical treatment when ill and why?

……

……

D7. Have you ever visited a traditional healer/Sangoma because you are on ART

____ 1 = Yes
____ 2 = No
____ 3 = Sometimes
____ 4 = Never
____ 5 = Don't know/not sure

D8. What did he / she tell you?

……

……

D9. What was your reaction?

……

……

D10. Please tell me the whole story?

……

……

……

……

D11. Do you miss taking any of your antiretroviral tablets?

____ 1 = Yes
____ 2 = No
____ 3 = Sometimes
____ 4 = Never
____ 5 = Don't know/not sure

D12. Why, how will you explain it, please give me more details?

……

……

……

D13. If the answer to D11 was YES, what was the most important reason for missing these tablets?

____ 1 = Forgot
____ 2 = Ran out of tablets
____ 3 = Travelling or away from home, didn't have tablets with me
____ 4 = Bad side effects from tablets (they make me feel sick)
____ 5 = Too busy
____ 6 = Elder or traditional healer advised me not to take them
____ 7 = Couldn't read or understand instructions
____ 8 = Misunderstood doctor or nurse
____ 9 = Didn't want others to see me (stigma)
____ 10 = Couldn't take with food as instructed
____ 11 = Felt better, didn't need the tablets
____ 12 = Didn't think they would work
____ 13 = Stresses at home/work
____ 14 = Too many pills to take
____ 15 = Don't know
____ 16 = Other (specify:

D14. In general, what are the most important problems or difficulties you have in taking your tablets?

Interviewer: write down the exact answer.

No difficulties ☐

D15. Who in your family usually has the final say on decisions about your own health (check all that apply)?

____ 1 = Myself
____ 2 = My parents
____ 3 = My spouse
____ 4 = My sibling(s)
____ 5 = Someone else (_____)

D16. How do you feel about it?

D17. How long ago was the last time you went to any type of healthcare worker or health facility for medical care, even a traditional healer, for any reason?

____ 1 = Less than 6 months ago
____ 2 = 6-12 months ago
____ 3 = More than one year ago

D18. Explain the reason
……
……

D19. What type of healthcare worker or facility was it (CHOOSE ONE)?

____ 1 = Government or public hospital or clinic
____ 2 = Traditional healer
____ 3 = Private hospital or clinic
____ 4 = Private doctor (GP) or specialist

Part E. Social Support and Stigma

E1. Have you shared with anyone that you are taking ART's?

____ 1 = Yes
____ 2 = No (skip to G3)

E2. If YES, who have you told? (mark all that apply)

(1) my spouse or partner (one or more)	☐	Yes
(2) my mother or father (or both)	☐	Yes
(3) my brother or sister (one or more)	☐	Yes
(4) my child (one or more)	☐	Yes
(5) another person in my family (one or more)	☐	Yes

(6) someone else, specify: _____

E3. Is anyone currently living in your household taking ARTs?

____ 1 = Yes ____ 2 = No ____ 3 = Don't know

E4. Do you have any friends who are taking ARTs?

____ 1 = Yes ____ 2 = No ____ 3 = Don't know

E5. How often do you feel people with HIV are judged negatively or treated badly because they are taking ART's?

____ 1 = None or little
____ 2 = Some
____ 3 = A lot

E6. Why do you think this is the case?

……
……

E7. How often do you get education about ART from your clinic since you started taking ART's?

____ 1 = Sometimes
____ 2 = Never
____ 3 = Don't know/not sure

E8. How often do you get counseling from your clinic since you started taking ART'?

____ 1 = Sometimes
____ 2 = Never

____ 3 = Don't know/not sure

E9. Where do you usually get information about ART's?

____ 1 = Clinic / Health care services
____ 2 = Media i.e. radio, TV, newspapers
____ 3 = Friends / relatives
____ 4 = Church / Religious leaders
____ 5 = Other _____

Part F. Closing of Interview

<u>Interviewer reads:</u> Thank you for participating in this survey. I appreciate your time. The information you have given me is confidential and will not be identifiable to anyone outside the Wits authorities. If you have any questions about the research I'm doing or your participation in this study, you may contact one of my supervisors whose names and telephone numbers are shown on the Information Sheet you were given.

_____

Interviewer Comments

H2. Interviewer's signature: _____

Study ID

Gauteng Department of Health

Helen Joseph Hospital

PERMISSION FOR RESEARCH

DATE: 21/06/2011

NAME OF RESEARCH WORKER: Ms Constance Mongwenyana

CONTACT DETAILS OF RESEARCHER (INCLUDE ALTERNATE RESEARHER):

073 837 8682

TITLE OF RESEARCH PROJECT Perceptions and experiences of ARVT of Patients on ART in Thembalethu Clinic in JHB

OBJECTIVES OF STUDY (Briefly or include a protocol):

SEE ATTACHED PROTOCOL

METHODOLOGY (Briefly or include a protocol): SEE ATTACHED PROTOCOL

CONFIDENTIALITY OF PATIENTS MAINTAINED: YES

COSTS TO THE HOSPITAL: NIL

APPROVAL OF HEAD OF DEPARTMENT: Leah Gilbert

APPROVAL OF CRHS OF WITS UNIVERSITY:

SUPERINTENDENT PERMISSION:

Signature: [signature] Date: 21/06/11

health and social development
Department: Health and Social Development
GAUTENG PROVINCE

Themba Lethu

Date: 30 May 2011
Enquiries: Dr T. Maotoe
Tel: 011 276 8843
Email: Thapelo.maotoe@righttocare.org

To Whom it may Concern

Dear Sir/Madam

This letter serves to confirm Ms Constance Mongwenyana has been granted permission to conduct a study titled: *"Perceptions and experiences about Antiretroviral Treatment (ART) of patients on Antiretroviral Treatment (ART) in Themba Lethu clinic in Johannesburg: An exploratory study"* in Themba Lethu Clinic.

During the study period, Ms Mongwenyana will abide and follow at the requirements as stated out in the SOP for conducting studies in a health facility.

Yours sincerely

.....

Dr Thapelo Maotoe| Medical Manager| Right to Care — *Treating AIDS Seriously*
Helen Joseph Hospital, Perth Road, Westdene, Johannesburg, 2092
Tel: 011 276-8850 | Direct: 011 276-8843 | Fax2Email: 086 692 0091 | Mobile: 079 494 4539 |
Email: thapelo.maotoe@righttocare.org

Themba Lethu Clinic Helen Joseph Hospital, Pvt Bag X 47, Auckland Park

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

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Constance Mongwenyana

CLEARANCE CERTIFICATE	M111115
PROJECT	Perceptions and Experience of Antiretroviral Treatment (ART) of Patients in Themba Lethu Clinic in Johannesburg: An Exploratory Study
INVESTIGATORS	Constance Mongwenyana.
DEPARTMENT	Department of Sociology
DATE CONSIDERED	25/11/2011
M1111150DECISION OF THE COMMITTEE*	Approved unconditionally

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

DATE 16/01/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Prof Leah Gilbert

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

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...