

**Cultural Factors Influencing the Management of HIV/AIDS in Patients on Anti-Retroviral Therapy in Ekurhuleni North Gauteng**

by

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## **DECLARATION**

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## **ABSTRACT**

The aim of the study was to identify cultural factors influencing the management of HIV/AIDS patients in order to raise awareness and improve management of patients within the community of Ekurhuleni North in Gauteng. A qualitative study was conducted using a semi-structured questionnaire and 60 patients from Dan Kubheka Clinic in Ekurhuleni were interviewed. The findings of the study revealed that there are cultural factors that influence the management of patients on ART and that such factors do have an impact on the management of patients.

## **OPSOMING**

Die doel van die studie was om die kulturele faktore te identifiseer wat die bestuur van MIV/Vigs pasiënte beïnvloed, om sodoende meer bewustheid te werf en die bestuur van pasiënte in die Noordelike Ekurhuleni gemeenskap in Gauteng te verbeter. 'n Kwalitatiewe studie was uitgevoer deur middel van 'n semi-gestruktureerde vraelys waar onderhoude met 60 pasiënte van die Dan Kubheka kliniek in Ekurhuleni gedoen was. Die bevindinge het onthul dat daar wel kulturele faktore is wat die bestuur van pasiënte op ART beïnvloed en dat sulke faktore wel 'n impak het op die bestuur van pasiënte.

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## **LIST OF ABBREVIATIONS**

ACSM= Advocacy, Communication and Social Mobilization

AIDS = Acquired Immune Deficiency Syndrome

ART = Antiretroviral Therapy

ARV = Antiretroviral

EHD= Ekurhuleni Health District

EMM= Ekurhuleni Metropolitan Municipality

HIV = Human Immunodeficiency Virus

NDOH=National Department of Health

NIMART=Nurse Initiated Management of Anti-Retroviral Therapy

NSP= National Strategic Plan

PHC= Primary Health Care

PLWHA =People Living with HIV/AIDS

STIs= Sexually Transmitted Infections

TAC= Treatment Action Campaign

TCMA= Traditional Complementary and Alternative Medicine

UK= United Kingdom

ZCC=Zion Christian Church

## GLOSSARY

**Culture** – is a particular form, stage, or type of intellectual development. (The Concise Oxford Dictionary, 1981)

**Cultural factors** – cultural factors may include behaviour, beliefs, moral values, traditions, language, religion, gender roles, occupations, dietary practices and laws that are being practices by a certain nation, community or any defined group of people.

**HIV/AIDS Management** – is a comprehensive care, management and treatment of people who are infected with HIV/AIDS

**Primary Health Care (PHC)** – is an essential health care based on practical, scientifically sound and socially acceptable methods and technology that is made universally accessible to individuals and families in the community.

**Ekurhuleni Metropolitan Municipality (EMM)** – “Ekurhuleni is a Tsonga word meaning a place of peace. Ekurhuleni Metropolitan Municipality is the local authority and government for Gauteng, South Africa's former East Rand area”. (<http://www.ekurhuleni.gov.za>)

**Ekurhuleni Health District (EHD)** – According to Kellerman & Thomas (2013) EHD is one of the three metropolitan areas in the Gauteng province South Africa and constitutes of two health authorities that provide health services, namely the local government municipality and the provincial health authority.

**Anti-retroviral therapy(ART)** – According to WHO Standard ART consist of a combination of at least t three drugs in order to maximally suppress the HIV virus and stop the progression of HIV disease.

## **1. CHAPTER 1: RESEARCH ORIENTATION**

### **1.1 INTRODUCTION**

HIV/AIDS was declared an epidemic in most countries globally and it is managed as a priority programme. Increasing access to antiretroviral therapy is one of the strategies towards addressing the issue in order to reduce its impact within communities. The success of the HIV programme is determined by good implementation strategies. This study is looking at cultural factors that have an influence on the management of HIV in patients that are on ART. According to The Concise Oxford Dictionary (1981) cultural factors may include any particular form, stage, or type of intellectual development.

Culture encompasses behaviour, beliefs, moral values, traditions, language and laws that are being practices by a certain nation, community or any defined group of people. Cultural characteristics may include the language spoken, religion, customs, gender roles and occupations, dietary practices and other aspects of behaviour. Even though strategies have been put into place by governments to expand HIV services and improve access to ART, the management of HIV still depends on the commitment an individual patient and the surrounding circumstances. Because of the fact that the HIV suppresses the immune system, the main purpose of ART is to suppress the virus in order to prevent fast progression to AIDS. With the use of ART morbidity and mortality due to HIV/AIDS related diseases is reduced. Non compliance by HIV/AIDS patients that are on anti-retroviral therapy (ART) is a challenge at Ekurhuleni North in Gauteng and therefore posing difficulties in managing the disease and controlling the epidemic.

Accessibility to HIV service points was initially a major concern which is why even the government of South Africa took a stand and made means to address the issue and HIV/AIDS services were scaled down to all public PHC facilities within the country in order to meet the objectives in the National Strategic Plan (NSP). The NSP objectives is to reduce new HIV infections by 50% and that 80% of HIV positive patients who are eligible have access to ART. Regardless of all the efforts in increasing accessibility to HIV services as well as accessibility to ART, it is noted that there are still barriers within communities which are brought about by various cultural issues. It is believed that amongst other factors, individual

factors such as age, gender, literacy level also contribute and that is why it is necessary to do proper pre and post test counselling as well as proper adherence counselling prior to ART initiation. Lack of support is said to be one other cause coupled with non-disclosure of status, which puts some people under pressure of being involved in some risky behaviours under an influence of their significant others.

The importance of disclosure should be emphasized during pre and post-test counselling. Socio-economic and cultural factors also play a role in patients adherence to ART. “Challenges such as human resource shortages, poverty and limited infrastructure are common in most settings and these are being addressed through the provision of integrated comprehensive services”, ( Koenig, Ivers, Pace, Destine, Leandre, Gdandpierre , Mukherjee, Farmer & Pape, 2010), however it is still necessary to emphasize prevention activities, including safe sex, management of STIs, promote gender equality and improve education for women. According to National Institute of Health 2010, social support must also be emphasized as treatment is rolled out, including strategies to improve nutritional and economic status, and to assist patients in adhering to therapy.

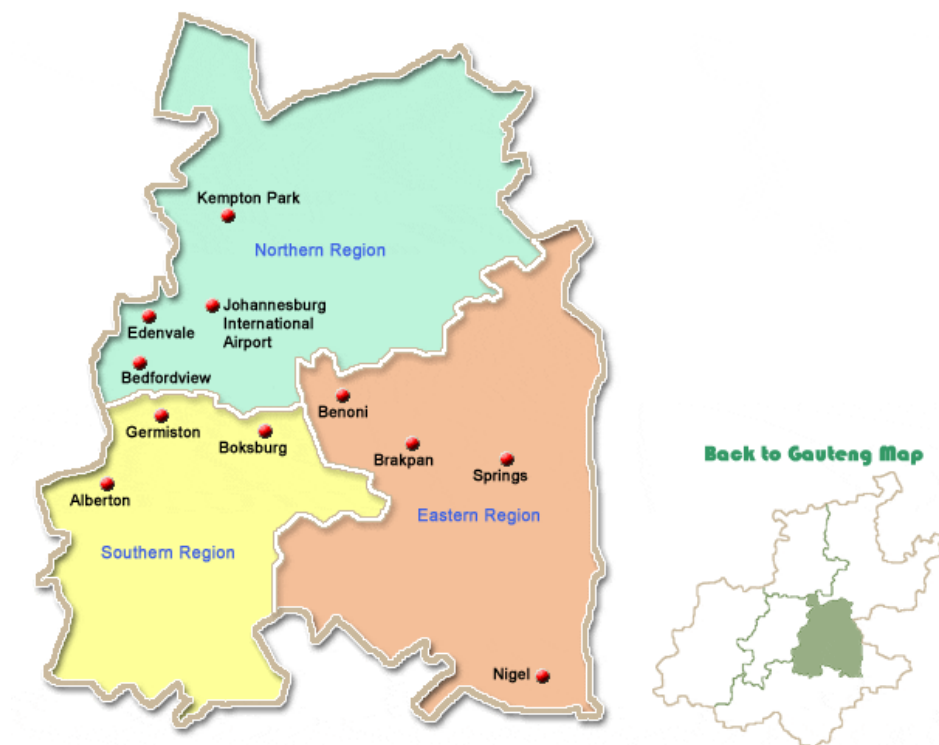


Figure 1 : Map of Ekurhuleni showing the North, South and East Regions Source: (<https://www.google.co.za>)

## **1.2 RESEARCH QUESTION**

Which cultural factors influence the management of HIV/AIDS patients that are on ART in Ekurhuleni North-Gauteng?

## **1.3 SIGNIFICANCE OF THE STUDY**

The findings of the study will be made available to Ekurhuleni Municipality and Ekurhuleni Health District so that it contributes to the knowledge that already exists on ART adherence. The findings should hopefully encourage Ekurhuleni management together with the Department of Health to review current strategies and design programmes directed at dealing with cultural issues that are influencing the management of HIV/AIDS, such as providing health workers with more training on adherence counselling and cultural issues and development of some education material for patients so that they can be more informed on such issues.

## **1.4 OBJECTIVES OF THE STUDY**

### **Study objective:**

To identify cultural factors influencing the management of HIV/AIDS patients in order to raise awareness and improve management of patients within the community of Ekurhuleni North in Gauteng.

### **Specific objectives:**

- To identify cultural factors that influences the management of patients on ART.
- To describe how cultural factors influence the management of patients.
- To recommend strategies to improve management of patients on ART

## **1.5 CONCLUSION**

This chapter gives a general overview of the study. It entails an introduction of the chapter and gives background of the population that is being studied. The chapter includes the research question, significance of the study, definition of concepts, aim and objectives, data collection methods and data analysis as used in the study.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 INTRODUCTION**

This chapter presents a review of literature by other researchers based on the research topic.

The chapter is presented as outlined below:

- HIV/AIDS prevalence
- ART initiation
- Adherence to ART
- Cultural factors contributing to HIV management
  - Traditional and religious rituals
  - Traditional medicine
  - Gender inequality
  - Cultural beliefs and rituals
  - Witchcraft
- Conclusion

### **2.2 HIV/AIDS PREVALENCE**

According to UNAIDS Global Report (2012), sub-Saharan Africa is said to be mostly affected with the HIV/AIDS epidemic. In sub-Saharan Africa about 1 in every 20 adults (4, 9%) is living with HIV and sub-Saharan Africa amount to 69% of people living with HIV in the whole world. According to STATS SA (2013) the midyear estimates the estimated number of people living with HIV in South Africa is approximately 5, 26 million in 2013 and about 15, 9% of the population of adults aged 15-49 are living with HIV. Gauteng Province has a population of about 11.19 million people which makes about 22.4% of the whole South African population. According to the latest ANC survey, Ekurhuleni district municipality had the highest HIV prevalence of 33.8%, compared to all other districts in Gauteng province.

With the expansion of HIV/AIDS services to all primary health care facilities it is expected that 80% of HIV positive patients that are eligible for ART should be initiated, as a result there was even task shifting from doctors and nurses are now trained to initiate patients on ART to facilitate the process. According to UNAIDS Global Report (2012) scaling up of antiretroviral therapy resulted in a decline in HIV incidence and HIV/AIDS related deaths. A

comparison was done in relation to deaths where it was found that deaths due to HIV/AIDS related causes in 2011 was about 1,7 million and in 2005 about 2,3 million deaths occurred. There was a marked decline of about 24% due to the fact that there was an increase in the number of people who are on ART. In order to attain good adherence one has to adapt to a lifestyle of taking medication on daily basis. The management of HIV/AIDS in patients can be influenced by a number of factors, and such factors must be addressed in order to achieve optimum level of ART adherence.

### **2.3 ART INITIATION**

There's a criteria for ART initiation according to the to the HIV/AIDS guidelines of the National Department of Health (NDOH) of the Republic of South Africa. In the strategy to increase access to ART, there was a directive from the NDOH that there should be task shifting from doctors and that nurses should be trained on ART initiation in order to facilitate the process hence Nurses Initiated Management of Anti-Retroviral Therapy (NIMART) was introduced. At PHC level patients are initiated on ART by Professional Nurses based on the set criteria and only those complicated cases are referred to doctors.

### **2.4 ADHERENCE TO ART**

Issues such as religion, culture, gender, poverty, education and many more others are predictors of ART adherence. Poor adherence lead s to poor outcomes. Even though patient's initiation on ART is done on the larger scale by health workers, patients should also contribute to the success of the program. Increased access and good adherence will lead to prolonged life and reduction of new infections. Poor adherence to treatment may lead to failure to suppress viral replication which may put the patient at risk of developing viral resistance. Effective adherence can be achieved by allowing patients to choose options to suit a range of needs and settings.



## **2.5 CULTURAL FACTORS CONTRIBUTING TO HIV MANAGEMENT**

### **2.5.1 Traditional and religious rituals**

There are a number of religions existing among communities. In the study that was conducted by Wasti, Simkhada, Randall, Freeman & van Teijlingen, in Nepal in 2012, it pointed out that people live in a community and need to abide by their local traditional and religious rituals, which can influence adherence to ART. It was found that “health care providers noticed that some PLHIV did not take their morning ART because their culture required fasting from sunrise to sunset” (Wasti et al., 2012). In the study that was conducted in KwaZulu-Natal by Peltzer, Friend-du Preez, Ramlagan & Fomundam, ( 2008 ) on the use of traditional complementary and alternative medicine (TCAM) they found that “One of the main types of TCAM use was that of prayer (no cost) and faith healing methods, which on average was lower in cost than herbal remedies. Studies amongst Black African HIV-positive patients in the UK have found that religion, as well as providing a spiritual coping mechanism for dealing with difficult life events, also provided practical support as a family might”, (Peltzer et al., 2008).

According to Okonkhor (2011) people tend to abandon their treatment and rely on ‘divine healing’ through prayers and studies have found that religious and spiritual beliefs may conflict with mainstream HIV treatment and care, particularly if patients believe that prayer alone may cure them. Previous studies confirm that tradition and religious beliefs do have an effect on ART adherence, as alluded to above. This study is also aiming at identifying factors in religions that influence the management of HIV/AIDS and which makes patients vulnerable to ART non-adherence.

### **2.5.2 Traditional medicine**

“Traditional medicine and religion remain important in many people’s lives after ART initiation, but these issues are rarely addressed in a positive way during ART counselling. Many patients found traditional medicine and their religious beliefs to be in conflict with clinic treatment advice. Patients described a decisional process, prior to the actual drop-out

from the ART program that involved a trigger event, usually a specific religious event, or a meeting with someone using traditional medicine that influenced them to take the decision to stop ART” (Wasti et al., 2012). Most African cultures believe more traditional medicine than western medicine because there is a belief that if a person is sick he or she must have eaten something which is called ‘sejeso’ in Sesotho or ‘isidliso’ in isiZulu which needs to be flushed out by the use of traditional medicine which induces vomiting or diarrhoea.

According to Dahab, Charalambous, Hamilton, Fielding, Kielmann, Churchyard & Grant, (2008) use of traditional medicines is a result of “lack of belief in the existence of HIV and/or one's own status”. In the study that was conducted by Dahab et al., (2008) in South Africa, it was found that traditional medicine use appeared to affect adherence negatively. “Patients reported that both clinic providers and traditional healers advised them not to "mix" ART with traditional medicines, leading to ART interruptions. Given that traditional medicine use is common in this setting, a deeper understanding and clarification to providers of how to counsel patients on the use of traditional medicines while on ART is critical” (Dahab et al., 2008).

In the study conducted by Peltzer et al., (2008) in South Africa, KwaZulu-Natal, on the use of traditional complementary and alternative medicine (TCAM) they found that traditional medicine use has been reported and is common among individuals with moderate and advanced HIV disease. Their study also pointed out that traditional herbal therapies and TCAM are commonly used by HIV treatment naive outpatients of public health facilities in South Africa and in some cases TCAM use may have interactions causing a decrease in ART effectiveness or even toxicity”.

In the study that was conducted by Van Dyk (2010, 2011) she found that only 40, 1% of the patients on ARVs could not reach optimum adherence levels of 90% or above, while 49% reached levels between 70% and 90%. Another 10, 9% could not even reach adherence levels of 70%. She found that one of the other factors contributing to ART non-adherence is “using medicines from traditional healers with ARVs without disclosing to healthcare worker” (Van Dyk, 2012, p. 122).

### 2.5.3. Gender inequality

Different status of men and women within families sometimes impact negatively on ART adherence. For instance in a case where a woman is submissive to a man, it will be difficult for that particular person to even attend a health care facility because she has to take care of the household chores at all times. Sasaki, Kakimoto, Dube, Sikazwe, Moyo, Syakantu, Komada, Miyano, Ishikawa, Kita & Kai, (2012) in their study that was conducted in Zambia found that there are gender related barriers in relation to ART adherence. “However, other studies have also shown that HIV positive females often experience gender-related barriers to accessing health services, thus affecting ART adherence. For example, many females have to obtain permission from a male spouse or a relative to seek HIV care, which is difficult when females have to ask for money and take time away from household chores. In addition, where costs for treatment are involved, families may prioritize paying for male’s treatment.

Gender based violence has also affected female’s access and ART adherence” (Sasaki et al., 2012). According to Susser, 2009, as referenced from a recent United Nations Development Program study from India which found that “a significant proportion on new infections is found in women in monogamous relationships but has been infected by partners who have taken multiple sex partners”. It is culturally also believed that to be real man one has to have multiple sex partners. As it was proven by the United Nations Development Program as cited by Susser, (2009), in her literature, this study will find out the extent to which that contributes to ART non-adherence. The partner will come back and demand sex from his wife without even using protection and that will result in biological markers showing signs of non-adherence which may be due to re-infection on the partner who is already on ART.

“Unfortunately, laws establishing women’s new constitutional rights have proved easier to implement in the public sphere and slow to be enforced in the domestic or extended family environment (Susser, 2009, p. 152). According to Susser (2009) there are difficult situations where women have little autonomy with respect to important HIV related right such as sexuality and therefore it will be difficult for a woman to take treatment or disclose her status. HIV/AIDS affects mostly women across all communities. According to UNAIDS Global Report on HIV/AIDS (2012) in sub-Saharan Africa which is mostly affected by HIV/AIDS, women represent 58% of the people living with HIV and bear the greatest burden of care. On the other hand gender norms within different cultures encourage high risk behaviours among

men which increase their vulnerability to HIV infection. They also believe that health services are for women and they therefore lack knowledge about HIV. According to UNAIDS (2012) the vulnerability to HIV is increased in transgender people due to the fact that they are scared to attend health facilities due to stigma and discrimination even adherence to ART will be a challenge if someone is already initiated.

#### **2.5.4. Cultural beliefs and rituals**

“Ideas alone do not mobilize people, as anthropologists have long pointed out. From a conservative point of view, involvement in mass rituals and collective emotional experiences help to generate loyalty an action with relation to the state or hegemonic common sense”. Like for instance in South African people that are participating in activities of the Treatment Action Campaign will find it easy to adhere to ART than a person who is not because it is their culture to engage “in the ritual process of protest, demonstrations, prayer vigils, and, for AIDS, near –death experiences that the emotions and commitments are built among activists (Robins, 2006)” (Susser, 2009, p. 208). According to Susser (2009) the TAC has had an enormous impact, not only in inspiring people with respect to treatment but also in redefining AIDS away from sexual shame. “Cultural and traditional beliefs can severely undermine an ART programme. Dr Tshabalala-Msimang, South Africa’s health minister, promoted garlic, beetroot and African potatoes as an alternative to ARVs (McGreal, 2006). A Ugandan newspaper article disapproved of the increase of pastors who convinced patients to pray instead of taking the ARV drugs (New Vision, 2006)” (Susser, 2009, p.18).

“One experienced counsellor said that in Uganda there is a cultural barrier to taking western drugs. Traditionally Ugandans consult the traditional healer for all matters, who often lives locally to them and serves the village. The healer mainly gives out herbs, and people fear them due to the mystery surrounding these medicines and the preparation of them. It is customary for the healer to appear to spit, or as some people believe, cast a spell, as they prepare the ‘mumbwa’, which is mud mingled with herbs” (Susser, 2009, p. 34). According to Susser (2009) research revealed that patients who are within the hospital system and regularly consult medical personnel when ill are perceived to be putting their trust in the ‘western’ system. Those who do not normally attend a hospital when ill are unlikely to consult doctors but will go to the traditional healer and with no experience of hospitals, and

have little education and knowledge outside their village, fear them and even if the patients are on ART they could still be consulting the healer and so the ‘mumbwa’ could be interacting negatively with the ART.

### **2.5.5 Witchcraft**

Some people especially in African cultures still believe in witchcraft. Like it happened with the famous South Africa disc jockey that after dying of AIDS it was reported by the journalist Liz Mc Gregor that his family was accusing his wife of bewitching him. Some people especially those who believe in witchcraft, they stop taking ART and the resort to “traditional healing practices” by seeking “alternative healing” (Susser, 2009). Witchcraft believed to be one other factor which influences the management of HIV/AIDS which can also be due to denial of the HIV positive status. This study will identify factors related to witchcraft that may have an effect on the management of HIV.

## **2.6 CONCLUSION**

In the above discussion there is evidence by different researchers that cultural factors do have an impact in the management of HIV. The researcher in this case is eager to find out the extent to which factors like cultural and religious beliefs, practice an attitudes contribute to the management of HIV/AIDS in the population that is being studied.

## **CHAPTER 3: RESEARCH METHODOLOGY**

### **3.1 INTRODUCTION**

This chapter entails a detailed discussion of the methodology that was used in the study. It explains the research problem that was formulated, study design used together with the research area and target population, sampling method and criteria, data collection method and instrument used, validity and reliability, data management and data analysis, ethical considerations and the conclusion of the chapter.

### **3.2 PROBLEM FORMULATION**

Previous studies proved that cultural factors have an influence on the management of HIV/AIDS in patients as alluded to under the literature review. Accessibility to HIV/AIDS services has been increased however the management is still a challenge regardless massive accessibility. There are other determining factors to the management of HIV as well as ART adherence and previous studies proved that but this study is particularly looking at cultural factors as it was conducted in an area where culture still have a great influence on peoples behaviour.

### **3.3 THE RESEARCH DESIGN**

This is a quantitative study whereby semi-structured interviews are conducted. Participants recruited from a PHC facility in Ekurhuleni North, Benoni. Dan Kubheka Clinic was chosen to conduct the study the target population being HIV/AIDS patients that are on ART. “A research design is reviewed as a comprehensive plan of study meant to map out necessary directions to be followed during the research process in order to come up with expected and orderly outcomes. It is sometimes referred to as a blueprint for conducting a study. The purpose of research design is to ensure that there is no interference with the validity of the results by maximising the control of factors. Research design includes clear and organised activities with specific purpose to meet specific needs of the study. As the process of research involves observation and analysis, planning is imperative in order to put in place what will be observed and analysed including the direction to be followed as dictated by the plan to the study” (Babbie & Mouton 2001:75).

## **SAMPLING**

### **3.3.1 Sampling method and size**

Patients were interviewed using semi-structured questionnaire. Patients are registered on ART in the same facility and the selection of participants was random. Patients were recruited during their visit to the clinic. Patients meeting the criteria were selected to a total of 60, and the selection done until the required sample size was obtained.

### **3.4.2 Sampling criteria**

The eligibility criteria for patients are adults above the age of 18 and who has been registered on ART for more than 12 months. The literacy level within that population is low so the participants were selected based on the level of understanding of the study that is being conducted. Though not all of them could understand English since that was the language used on the consent and the questionnaire, thorough interpretation and explaining was done by the researcher. The population is predominantly Zulu speaking and the interpretation was done in isiZulu and a little bit of Sesotho and isiXhosa. All the participants reside around the clinic in Kingsway which is mainly RDP houses and Lindelani informal settlements. The researcher followed all data protection protocols in order to produce valid information.

## **3.4 DATA COLLECTION**

### **3.5.1 Data collection method**

Data is collected through semi-structured interviews of patients that are on ART. A semi-structured questionnaire with open ended questions is used, requiring information on participant's background, the aspect of knowledge, attitude, perception and practice on the use of ARVs. The interview solicit cultural information, general assessment of adherence, report of adherence and reasons for non- adherence. Participants were randomly selected and interviewed during their visit to the clinic as they are waiting to be seen. Data was collected by the researcher.

### **3.5.2 Data collection instrument**

A semi-structured interview questionnaire containing close and open ended questions was used for data collection. The questionnaire contained clear questions that could be easily answered by respondents and the researcher was able to clarify any questions during an interview. The interviews were conducted by the researcher so that relevant information could be solicited and the respondents were assured that confidentiality on the collected data will maintained.

The questionnaire contained five sections as outlined below:

Section 1: Demographic information

Section 2 Pre diagnosis

Section 3 Post HIV infection

Section 4 Cultural factors

Section 5 Management and treatment

## **3.5 VALIDITY AND RELIABILITY**

The questionnaire was first piloted by the researcher before data collection in order to maintain consistency in data collection and interpretation of the questions to the respondents so that the collected data is valid.

### **3.6.1 Validity**

Validity is a way of finding out if the instrument used is indeed fulfilling the purpose it is meant for. According to Kothari (2004) “validity is the extent to which differences found with a measuring instrument reflect true differences among those being tested” meaning that correct procedures have been applied to find answers to a question”. Validity was tested in this study.

### **3.6.2 Reliability**

Reliability in a study yields accurate and consistent results. The reliability as well as the validity of the study was tested by piloting of the data collection instrument before being utilized and the result showed that the questionnaire was well structured.



### **3.7 DATA ANALYSIS**

Descriptive statistics will be used in analysing the data and data categorized, summarized and presented in graphs and percentages. According to Kothari (2004) the analysis of data involves a number of closely related operations which are performed with the purpose of summarising the collected data and organising these in such a manner that they answer the research question.

### **3.8 ETHICAL CONSIDERATIONS**

#### **3.8.1 Permission to conduct the study**

Application for ethical clearance from Stellenbosch University Ethics Committee was done and granted. Permission to conduct the study was requested from Ekurhuleni Metropolitan Municipality and was granted by the Municipality together with Ekurhuleni Health District.

#### **Informed consent**

An explanation about the research was done and objectives discussed with each participants and written consent was obtained from each of them. It was explained to participants that there will be no incentives for participating in the study. Participants were told about the right to refuse to participate at any point during the process and they may not respond to questions they don't feel comfortable with care in the facility.

#### **3.8.2 Confidentiality**

Selected participants were each interviewed and privacy and confidentiality was strictly maintained. All the data collected from this study was safely stored to ensure that no other person has access to them. Participation was voluntary and no person was forced to participate. The information collected was kept safe and confidential and anonymity was maintained. No patient's personal information was used on data collection instrument only a study number was assigned to each and the information was safely stored in the box and put in a lockable cupboard.

## CHAPTER 4: RESULTS

### 4.1 INTRODUCTION

The present chapter outlines the results of the quantitative study as described and presented in a form graphs and percentages. The chapter is presented as below:

Section 1: Demographic information

Section 2: Pre-diagnosis

Section 3: Post HIV infection

Section 4: Cultural factors

Section 5: Management and treatment

### 4.2 DEMOGRAPHIC INFORMATION

#### 4.2.1 Gender distribution

In a total number of 60 patients who participated in the study 35 are females and 25 males.

Females 35 (58%)

Males 25 (42%)

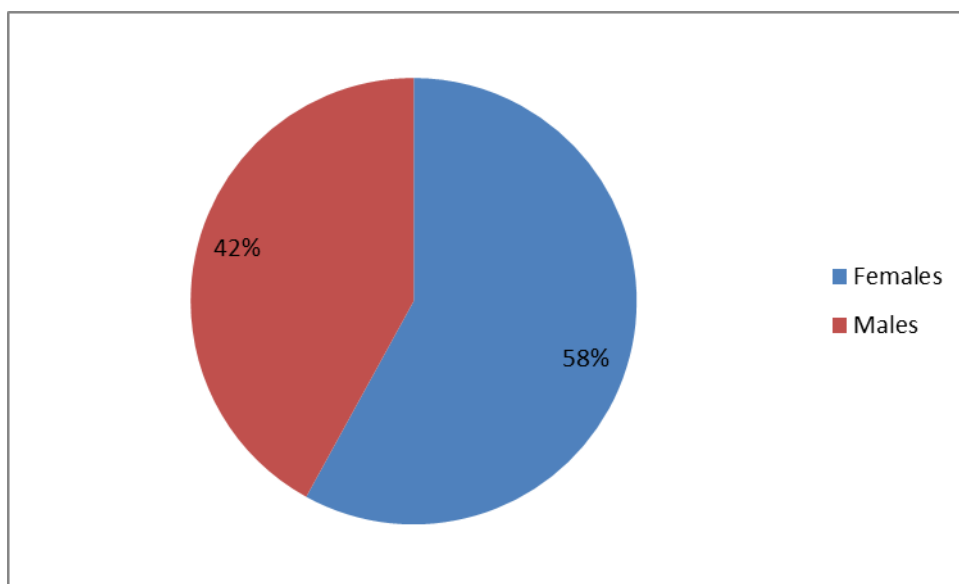


Figure 2 : Gender distribution

#### 4.2.2 Age distribution.

The ages of respondents range from 19-74. This is an indication that HIV affects all ages in the studied population, but the majority is between ages 30-49.

19- 29 = females 4 and males 4 (13%)

30 - 39 = females 14 and males 8 (37%)

40 - 49 = females 11 and males 9 (33%)

50 - 59 = females 4 and males 3 (12%)

60 - 69 =females 1 and males 1 (3%)

70 - 79 =females 1 and males 0 (2%)

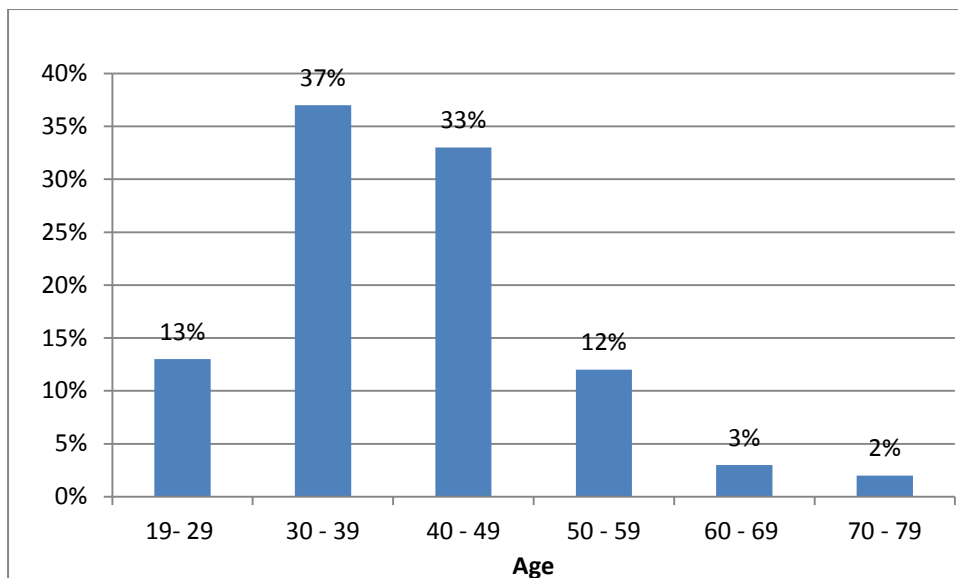


Figure 3 : Age distribution

### 4.2.3 Ethnic group

The majority of the respondents are Zulu speaking (83%)

Zulu – 50 (83%)

Sotho – 5 (8%)

Xhosa – 3 (5%)

English – 2 (4%)

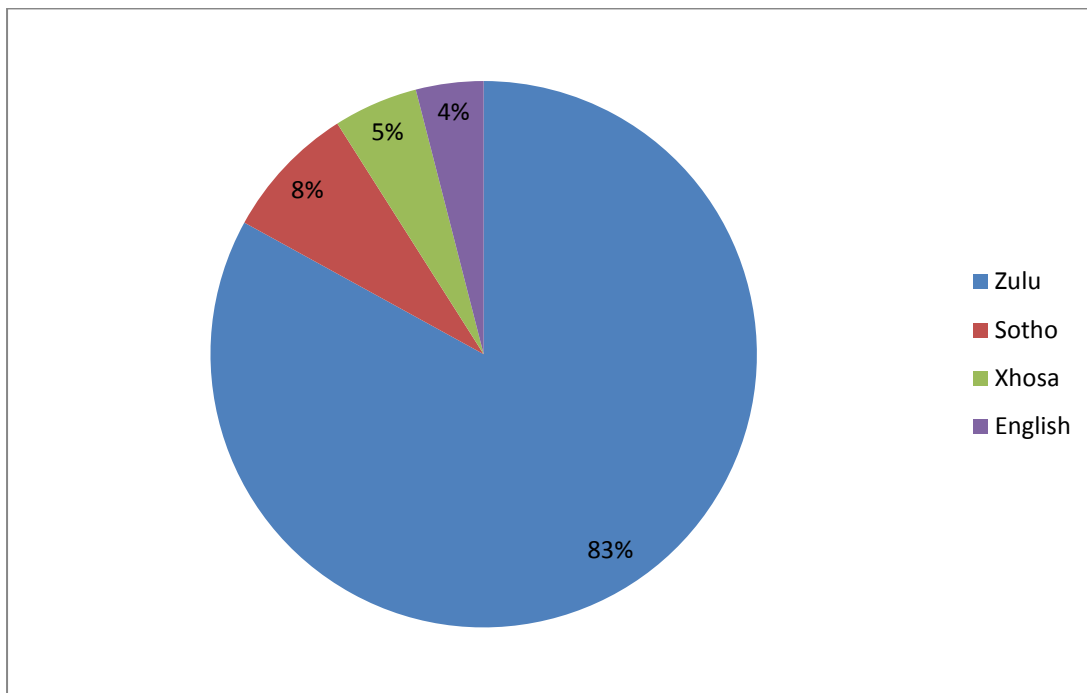


Figure 4 : Ethnic group

### 4.2.4 Religion

Christian: 53(88%)

Moslem: 1 (2%)

None: 6 (10%)

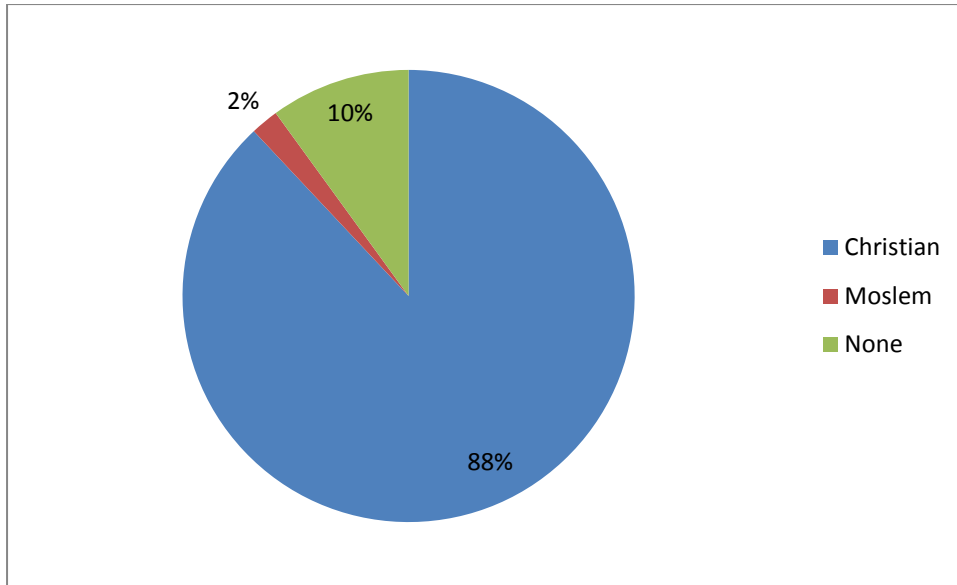


Figure 5 : Distribution according to religion

Christian are of different church denominations including the Zion Christian Church(ZCC) and the Nazareth Baptist Church popularly known as ‘Kwa-Shembe’ by the population, which are African traditional churches to name but a few.

#### 4.2.5 Marital status

Single: 46 (77%)

Married: 14 (33%)

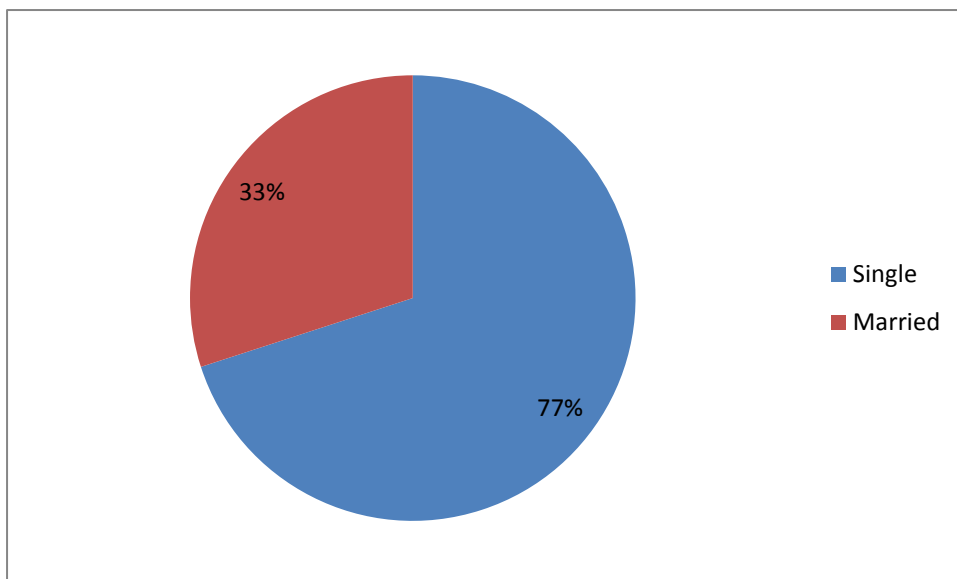


Figure 6 : Distribution according to marital status

#### 4.2.6 Type of dwelling

RDP house: 32 (53%)

Shack: 28 (47%)

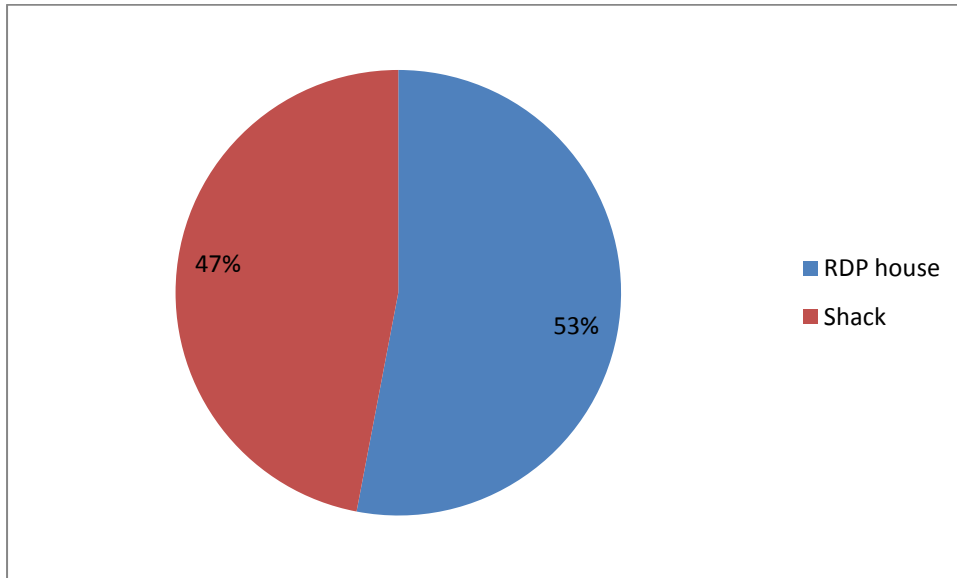


Figure 7 : Distribution according to type of dwelling

As mentioned in the background that the catchment area consists of RDP houses and shacks (made of zinc and others made of wood) and the population is mainly of low socio economic class, 32 (53%) of participants stay in houses and 28 (47%) of them in shacks.

#### 4.2.7 Number of dependents

None: 7 (12%)

1 - 5: 49 (82%)

>5: 4 (6%)

Most of the study participants have dependants ranging from 1-5. Seven of them have no dependants and only four of them have more than 5.

#### 4.2.8 Occupation

Employed: 28 (47%)

Unemployed: 32 (53%)

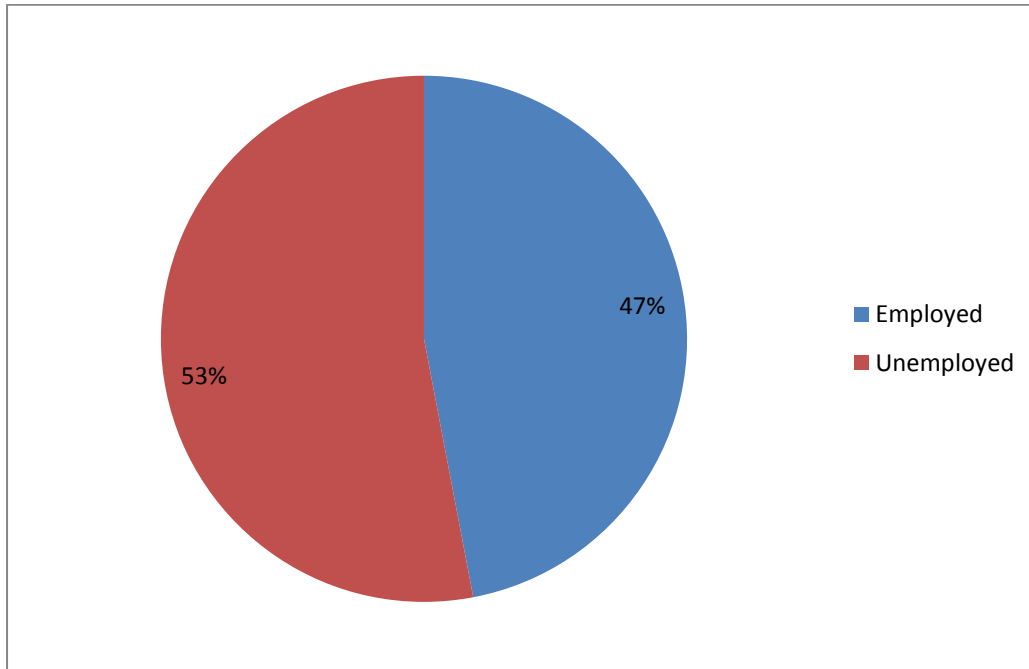


Figure 8 : Distribution according to Occupation

#### 4.2.9 Education level

None: 9 (15%)

Primary level 13 (22%)

Secondary level 37 (61%)

Tertiary/vocational level: (2%)

Out of all 60 participants 9 of them never went to school, 13 went up to primary level, 37 to secondary and only 1one up to tertiary level

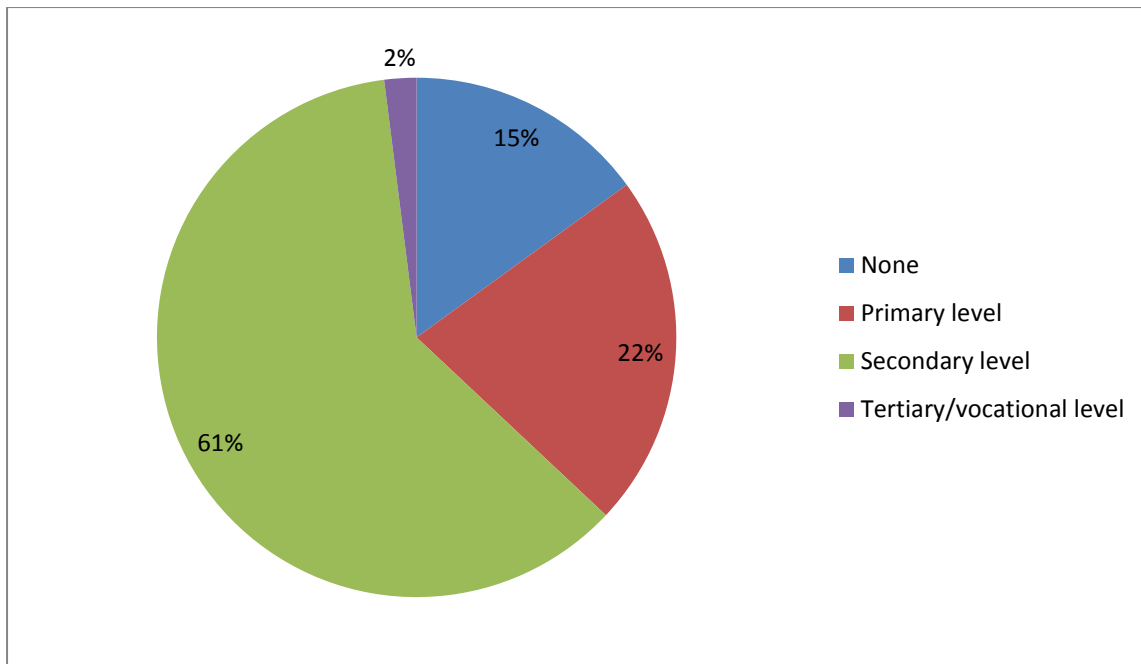


Figure 9 : Distribution according to education level

### 4.3 PRE-DIAGNOSIS

4.3.1 Knowledge about HIV: 13 (22%)

4.3.2 The cause of HIV: 13 (22%)

4.3.3 HIV transmission: 53 (88%)

4.3.4 HIV prevention: 53 (88)

4.3.5 HIV treatment: 60 (100)

4.3.6 HIV cure: Yes – 10 (17%)

: No – 47 (78%)

: Don't know – 3 (5%)

Most of the participants don't know what HIV is what cause causes it but they know how is it transmitted and how it can be prevented. Very few patients know what HIV is and causes it some have different views and opinions. The say HIV is dirty blood, a killer disease. One of the participants said HIV is a disease that is caused by witchcraft. Only 13 participants know exactly what HIV is and what causes it, and 8 have misconceptions.

Two (2) participants said HIV is transmitted though food and one (1) said HIV is a disease that is transmitted to human beings my monkeys. Four of the participants don't know how



HIV is transmitted. Most of the participants (53) know how HIV is transmitted and prevented.

All the participants (60) know that the treatment for HIV is antiretroviral therapy, 47 of the participant say that the treatment does not cure HIV but only suppresses the virus, 10 say if one takes the treatment well they become cured and only 3 don't know if HIV is curable.

#### **4.4 POST HIV INFECTION**

##### **4.4.1 Year diagnosed**

1-2 years: 15 (25%)

3-5 years: 28 (47%)

>5 years: 17 (28%)

Out of all the 15 participants were diagnosed with HIV 1-2 years ago, 28 diagnosed between 3-5 years ago and that was during the time of the massive HCT campaign which was a presidential mandate following announcement done by the president of the republic of South Africa on the World Aids day on 1<sup>st</sup> December 2009 with the objective of scaling up HIV services and 17 participants were diagnosed with HIV more than 5 years ago.

##### **4.4.2 Year treatment started**

1-2 years: 38 (63%)

3-5 years: 12 (20%)

>5 years: 10 (17%)

##### **4.4.3 Health condition with ART**

Well: 56 (93%)

Unwell: 4 (7%)

The majority (56) of the patients feel much better and they are well since started taking treatment, 2 of the participant say the treatment is making them feel more sick, one says she

does not notice any difference because she still feel sick and the other one respondent said “I still feel sick and every time I am told that my CD4 count is low and my viral load is high.”

### **Knowledge of other symptom reliever**

Yes: 2 (3%)

No: 58 (97%)

Most of the respondents (58) say nothing can make HIV/AIDS symptoms better except taking of ART, 1 from the Nazareth Baptist church said that she applies fats from her church and every time she had the fats on she feels better but if she does not use the she becomes sick so she beliefs the fat application makes her symptoms better; and 1 said that she always uses forever medicines and they make her feel better more than ART.

## **4.5 CULTURAL FACTORS**

Out of all 60 respondents 31 do not believe HIV has anything to do with culture and vice-versa and do they do not perform any of the cultural practices that are discussed below; and 29 believe that HIV is a cultural issue and therefore culture and tradition should be considered in its management have performed some:

### **4.5.1 Traditional and religious rituals**

Yes: 11(18%)

No: 51 (82%)

When participants were asked about their experiences on traditional and religious rituals 11 responded by saying they do practice some religious rituals, 6 of them who are members of the Zion Christian Church said that in their church they routinely drink tea in order to clean the blood and flush away all the disease and participants from the Nazareth Baptist Church responded by saying they are given water which is prayed foe at the church and that water cure all the diseases including HIV/AIDS

#### **4.5.2 Traditional Medicine**

Yes: 17 (28%)

No: 47 (72%)

When asked about experiences on traditional medicine, 17 participants admitted to the use of traditional medicine. Some have used previously and other are still using it. Among the seventeen one participant is a traditional healer and he said that as a traditional healer he can not dish out the medicine without tasting it so he does that with every medicine that he gives to his clients.

#### **4.5.3 Gender inequality**

Yes: 2 (3%)

No: 58 (97%)

Most participants (58) believe that both partners are responsible for HIV infection. Only 2 participants are blaming their partners that they are HIV infected.

#### **4.5.4 Cultural beliefs and rituals**

Yes: 1 (2%)

No: 59 (98%)

Only one of the participants says and believe that she is being possessed by ancestors that is why she is HIV positive and therefore she needs to go to an initiation school in order to become a 'sangoma' then the HIV will be cleared.

#### **4.5.5 Witchcraft:**

Yes – 8(13%)

No – 52 (87%)

Out of 60 participants 8 strongly believe that HIV is witchcraft. They say HIV is ‘isidliso’, ‘umegqo or umbhulelo’, ikhubalo.

#### 4.5.6 Other

Yes: 1 (2%)

No: 59 (98%)

Only one of the male participants believe that if you a man is circumcised HIV transmission is not possible to both partners therefore the use of condom is not necessary when a man is circumcised.

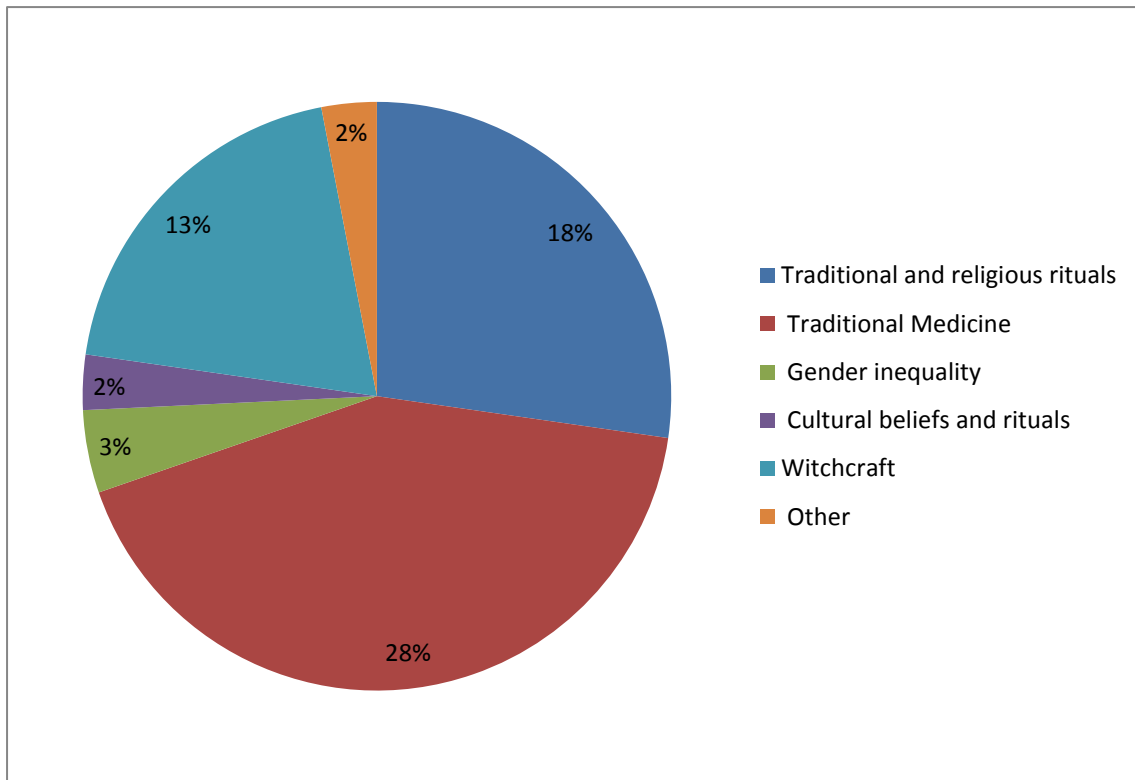


Figure 10 : Cultural factors (Beliefs and practices)

## 4.6 MANAGEMENT AND TREATMENT

### 4.6.1 Use of other medication

Yes: 8 (13%)

No: 52 (87%)

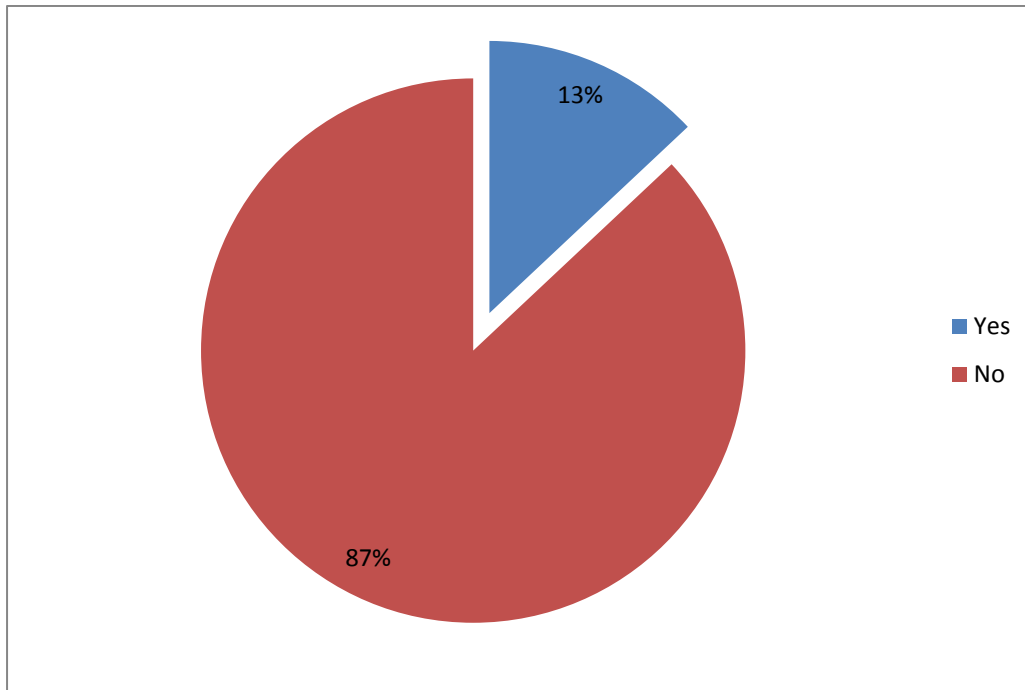


Figure 11 : Use of other medication

Other medicines used were named as Vukahlale, Uzifozonke, Isiwasho (water mixed with ash), Forever, Traditional Medicine, CD4 max.

### 4.6.2 Missed of doses

Yes: 23 (38%)

No: 37 (62%)

### 4.6.3 Reason for missed doses

The following are given the reasons for missed:

- Forgetfulness

- Work
- Alcohol
- Use of other medications
- Being away from home
- Tired of taking medication

#### **4.6.4 Thought of stopping treatment**

Yes: 11 (18%)

No: 49 (82%)

## **CHAPTER 5**

### **DISCUSSION, RECOMMENDATIONS AND CONCLUSION**

#### **5.1 INTRODUCTION**

This chapter presents a discussion and recommendation based on the findings that are presented in the above chapter. The aim of conducting the study was to establish the relationship that exists between cultural factors and the management of HIV/AIDS in patients that are on ART. The discussion is an interpretation based on the data that was collected and analysed under the following headings

- Demographic information
- Pre diagnosis
- Post HIV infection
- Cultural factors
- Management and treatment
- Recommendations

#### **5.2 DEMOGRAPHIC INFORMATION**

The study sample consisted of 60 HIV/AIDS patients that are on ART. Female In a total number of 60 respondents 58% were females and 42% males. The ages of respondents range from 19-74, but the majority in the studied population between ages 30-49 which makes 70% of the total sample. The majority of the respondents are Zulu speaking totalling to 83% and the minority speak other languages which are English, Sesotho and isiXhosa, 88% are Christians of different church denominations including the Zion Christian Church (ZCC) which makes 7% and the Nazareth Baptist Church popularly known as 'Kwa-Shembe' by the population 10%, which are both African traditional churches to name but a few, 10% are non-Christian and 2% Moslem. Most of the respondents are single 77% and only 33% is married. The study area consists of RDP houses and informal settlements 53% of participants stay in houses and 47% in shacks, with only 47% employed and 53% unemployed. The education level of respondents ranges from primary to secondary level, only 2% went up to tertiary level and 15% never went to school.

### **5.3 PRE-DIAGNOSIS**

HIV/AIDS information is still lacking within the population. There are a lot of misconceptions about the disease, especially on what HIV/AIDS is and the cause thereof. Out of the whole group only 13 which is 21% know exactly what HIV is and what causes it and the rest of the respondents have different views and misconceptions and some of them call it a 'killer disease', 'dirty blood' and some even say its witchcraft. Most of the participants 88% know how HIV is transmitted and prevented and only 7% do not know, 2% says HIV is transmitted to human beings by monkeys and 3% say HIV transmission is through food. All the respondents (100%) know that HIV is treated with ART and most of them (78) know it is not curable.

### **5.4 POST HIV INFECTION**

The respondents diagnosed with HIV 1-2 years ago are 15 (25%), 28 (47%) diagnosed between 3-5 years ago and that was during the time of the massive HCT campaign which was a presidential mandate following announcement done by the president of the republic of South Africa on the World Aids day on 1<sup>st</sup> December 2009 with the objective of scaling up HIV services and 17 (28%) participants were diagnosed with HIV more than 5 years ago. The respondents are on treatment for  $1 \geq 5$  years and 93% of the them say they are doing well on treatment, 2 of the respondents say the treatment is making them feel more sick, one says she does not notice any difference because she still feel sick and the other one respondent said "I still feel sick and every time I am told that my CD4 count is low and my viral load is high". Most respondents (96%) say nothing can make HIV/AIDS symptoms better except taking of ART, 1 respondent (2%) from the Nazareth Baptist church said that she uses fats from her church and every time she apply fats on she feels better but if she does not use the she becomes very sick so she believes that fat application makes her symptoms better; 1 respondent (2%) uses herbal medicine from 'forever' and that makes her feel much more better than ART.

### **5.5 CULTURAL FACTORS**

In this study it was it was found that people from the ZCC and Kwa-Shembe practice traditional rituals in their churches. When they were asked about their experiences on traditional and religious rituals they responded by saying they do practice some religious



rituals, of the ZCC they said that in their church they routinely drink tea in order to cleanse the blood and flush away all the disease and those from Kwa - Shembe responded by saying they are given water which is prayed for at the church and that water cure all the diseases including HIV/AIDS.

When asked about experiences on traditional medicine, 17 (28%) responded admitted to the use of traditional medicine. Some have used previously and other are still using it. The respondents that used traditional medicine said that they stopped using traditional medicine because they got sicker instead of getting better. Among the seventeen one participant is a traditional healer and he said that as a traditional healer he can not dish out the medicine without tasting it so he does that with every medicine that he gives to his clients.

Gender inequality also does have an effect on the management of HIV the responses of the participants proved that. One female respondent said that she got HIV from her partner who is drinking a lot and have other sexual partners. The other female respondent said she understands well that she's got HIV and wants to take treatment, but the partner whose status is unknown refuses to use a condom and she abuses her physically to an extent that she is sometimes scared to even go to the clinic because of bruises and the partner always insults her about her HIV status. Only one of the participants says and believe that she is being possessed by ancestors that is why she is HIV positive and therefore she needs to stop taking ART and go to an initiation school in order to become a 'sangoma' then the HIV will be cleared.

Out of 60 participants 8 (13%) strongly believe that HIV is witchcraft and they use traditional medicine together with ART. They say HIV is 'isidliso', 'umeqo' or 'umbhulelo', ikhubalo. They believe that HIV is 'umeqo'(something you jump over) they say that it is some traditional medicine that is placed on someone's gate or door as a trap, then when a person walks over that particular medicine he/she becomes sick. Some say they have got 'isidliso' (something you have eaten) they have been bewitched through food that is why some of them are saying that HIV is transmitted through food. One male respondent said that HIV is 'ikhubalo' (something that causes an injury). He says that is some traditional medicine that is

being put on the female's private part by a male so that if she has sexual intercourse with other men they will die or become sick. Only one of the male participants believe that if a man is circumcised HIV transmission is not possible to both partner and therefore the use of condom is not necessary when a man is circumcised.

## **5.6 MANAGEMENT AND TREATMENT**

When asked about use of other medicines some respondent use ART and traditional medicine concurrently. Some say the use immune boosters they buy from pharmacies and agents. They gave names of other used medicines as Vukuhlale, Uzifozonke, Isiwasho , Forever, Traditional Medicine, CD4 max and 38% of respondents admits to missing of treatment doses and gave different reasons such as forgetfulness, work, alcohol intake, use of other medications, being away from home and others are just tired of taking medication. When asked about the thought of stopping medication 18% of the think of stopping but they say they are scared that if they stop they will die.

## **5.7 RECOMMENDATIONS**

The study revealed that there is still lack of information on HIV/AIDS with regard to what HIV/AIDS is and the cause hence there is a lot of misconceptions. The staff should be more empowered on how to convey the message in a simple language that can be easily understood by patients especially the health promotion practitioners. Strengthening of health promotion and health education to patients in facilities is necessary as well as the development of posters and information leaflets in different languages on the topic.

The study showed that HIV/AIDS patients resort to other means in order to cure HIV/AIDS such as traditional medicine, spiritual water, tea, fat, etc., Health System Strengthening (HSS) is necessary and in the management of HIV/AIDS all other stakeholders should be taken on board. Traditional Health Practitioners, Traditional leaders, Faith Based Organizations, Community Based Organizations and all other stakeholder must be involved in HSS.

It is suggested that further research should be conducted on the topic because the results of the study showed that there are cultural factors that influence the management of HIV/AIDS in patients on ART and to identify more factors that may not have been revealed in this study.

## **5.8 CONCLUSION**

This study has shown that cultural factor influence the management of HIV and it is clear that putting all technical health systems into place without imparting enough information and knowledge to care consumers can yield negative results. It is revealed in the study that most HIV/AIDS patients in the population that was studied do not know what HIV/AIDS is and that can apply to the population at large and hence the misconception and confusion which make them resort to other means of management such as traditional medicine and forth. Therefore the study says the management of HIV/ AIDS starts with information giving at all angles. Advocacy, Communication and Social Mobilization (ACSM) strategies should be intensified to counter myths and misconceptions about the disease.

## BIBLIOGRAPHY

American Journal of Transplantation (2009). 9 (Suppl 3): S38–S40

Biadgilign,S., Deribew,A., Amberbir, A. & Deribe, K. (2009). Barriers and facilitators of antiretroviral medication adherence among HIV infected paediatric patients in Ethiopia.Vol.6. No 4.

Dahab, M., Charalambous, S., Hamilton, R., Fielding, K., Kielmann, K., Churchyard,G.J. & Grant, A. D.(2008). "That is why I stopped the ART": Patients' & providers' perspectives on barriers to and enablers of HIV treatment adherence in a South African workplace programme <https://www.google.co.za>

Health Sciences. (2012). The influence of traditional medicine and religion on discontinuation of ART in an urban informal settlement in Nairobi, Kenya peer-00677866, version 1 - 10 Mar 2012. <http://mc.manuscriptcentral.com/ac-phm-vcy>

Kellerman, R. & Thomas, L. (2013). A District Public Health Unit: experiences and lessons learnt from Ekurhuleni. [http://www.phasa.org.za/wp-content/uploads/2013/08/Kellerman\\_a-district-public-health-unit.pdf](http://www.phasa.org.za/wp-content/uploads/2013/08/Kellerman_a-district-public-health-unit.pdf)

Koenig, S., Ivers, L.C., Pace,S., Destine, R., Leandre, F., Gdandpierre,J. ,Mukherjee, J., Farmer, P.E., & Pape, J.W.(2010). Successes and challenges of HIV treatment programs in Haiti: aftermath of the earthquake. NIH-PA Author Manuscript

Kothari, C.R. (2004). Research Methodology: Methods and Techniques. New Age International Limited Publishers. New Delhi

Machtinger, E. L., Bangsberg,D. R. (2005). Adherence to HIV Antiretroviral Therapy. University of Carlifonia San Francisco

Maluleke, R.X. (2005). Environmental Management at Ekurhuleni Metropolitan Municipality. Department of Public Management. Faculty of Social Development Studies. Tshwane University of Technology.

Maokisa, T., C. (2011). Factors Contributing to Poor Antiretroviral Therapy adherence among Patients at Jwaneng Mine Hospital Masa Clinic in Botswana.

Motja, L. (2013). Cultural Factors Influencing the Management of HIV/AIDS in Patients on Anti-Retroviral Therapy in Ekurhuleni North Gauteng. Research Proposal. Stellenbosch University.

Mumbuna, Y. (2011). A Study to Establish Factors that Lead to Non-adherence to Antiretroviral Treatment for Orphans Living with HIV in Okahanja Constituency. Stellenbosch University

National Department of Health (2011). The 2010 National Antenatal Sentinel HIV & Syphilis Prevalence Survey in South Africa. Pretoria

Nyambura, A. W. (2009). Factors that influence non-adherence to antiretroviral therapy among HIV and AIDS patients in Central Province, Kenya.

Okonkwoh, C. (2011). Factors Affecting Antiretroviral Treatment Adherence amongst Young Adults Living with HIV/AIDS in, Yaba, Lagos, Nigeria: A qualitative study.

Peltzer, K., Friend-du Preez, N., Ramlagan, S. & Fomundam, H. (2012). Use of traditional complementary and alternative medicine for HIV patients in KwaZulu-Natal, South Africa. <http://www.biomedcentral.com/1471-2458/8/255>

Sasaki, Y., Kakimoto, K., Dube, C., Sikazwe, I., Moyo, C., Syakantu, G., Komada, K., Miyano, S., Ishikawa, N., Kita, K. & Kai, I. (2012). Adherence to antiretroviral therapy (ART) during the early months of treatment in rural Zambia: influence of demographic characteristics and social surroundings of patients Sasaki et al. *Annals of Clinical Microbiology and Antimicrobials* 2012, 11:34. <http://www.annclinmicrob.com/content/11/1/34>

STATISTICS SOUTH AFRICA (2013). Mid-year population estimates

Susser, I. (2009). AIDS, sex and culture: Global Politics and Survival in Southern Africa.

The Concise Oxford Dictionary. (1983). 7<sup>th</sup> Edition

UNAIDS. (2012). Global Report

UNAIDS. (2013). Global Report

Van Dyk, A. (2012). Fifth edition. HIV AND AIDS Education, Care and Counselling. A multidisciplinary approach.

Wasti, S. P., Simkhada, P., Randall, J., Freeman, J.V., & van Teijlingen, E. (2012). Factors Influencing Adherence to Antiretroviral Treatment in Nepal: A Mixed-Methods Study. PLoS ONE 7(5): e35547. doi:10.1371/journal.pone.0035547

Wooding, K., D. (2007). Adherence or non-adherence? Good practice in administering antiretroviral to children with HIV/AIDS in rural resource-poor settings. The case of Kiwoko Hospital.

Zelege, A. B. (2012). Factors that influence adherence to Antiretroviral Therapy among Adult at Nekemte Referral Hospital in Ethiopia. University of South Africa.

## APPENDICES

### APPENDIX 1: PERMISSION LETTER



## RESEARCH CLEARANCE CERTIFICATE

**Research Project Title:** Cultural factors influencing the management of HIV/AIDS in patients on anti-retroviral therapy in Ekurhuleni North Gauteng

**Research Project Number:** 02/12/2013-2

**Name of Researcher(s):** Lulama Motja, Student number: 17369592

**Division/Institution/Company:** MPhil HIV/AIDS Management, University of Stellenbosch

DECISION TAKEN BY THE EKURHULENI HEALTH DISTRICT ETHICS PANEL (EHDEP)

- THIS DOCUMENT CERTIFIES THAT THE ABOVE RESEARCH PROJECT HAS BEEN FULLY APPROVED BY THE EHDEP. THE RESEARCHER(S) MAY THEREFORE COMMENCE WITH THE INTENDED RESEARCH PROJECT.
- NOTE THAT THE RESEARCHER WILL BE EXPECTED TO PRESENT THE RESEARCH FINDINGS OF THE PROPOSED RESEARCH PROJECT AT THE ANNUAL EKURHULENI RESEARCH CONFERENCE.
- THE ETHICS PANEL WISHES THE RESEARCHER(S) THE BEST OF SUCCESS.

*DR JOSEPH SEPUYA*  
DEPUTY CHAIRPERSON: EKURHULENI METROPOLITAN MUNICIPALITY  
Dated: 8/12/2013

*Dr. R. Kelleerman*  
CHAIRPERSON: GAUTENG DEPARTMENT OF HEALTH (EKURHULENI REGION)  
Dated: 8/12/2013

## APPENDIX 2: CONSENT FORM



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY  
jou kennisvenoot • your knowledge partner

### STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

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#### CULTURAL FACTORS INFLUENCING THE MANAGEMENT OF HIV/AIDS IN PATIENTS ON ANTI-RETROVIRAL PATIENTS IN EKURHULENI NORTH GAUTENG

You are asked to participate in a research study conducted by Mrs Lulama Motja, from the Africa Centre for HIV/AIDS Management at Stellenbosch University. The results of the research study will contribute toward the researcher's Master's level thesis as part of a requirement for the completion of the MPhil in HIV/AIDS Management programme. You were selected as a possible participant in this study because you are a patient in a facility where the research will take place.

#### **1. PURPOSE OF THE STUDY**

The purpose of this study is to identify cultural factors influencing the management of HIV/AIDS patients in order to raise awareness and improve management of patients within the community of Ekurhuleni North in Gauteng

#### **2. PROCEDURES**

If you volunteer to participate in this study, we would ask you to do the following things:

You will be asked to participate in an individual interview with the researcher. This interview will take place at the clinic during a suitable time or at a venue and time which is convenient for the participants. The interview should not last more than 60 minutes and will also be tape recorded for the purpose of accurate data collection. Confidentiality, anonymity and privacy of data will be maintained at all times.

#### **3. POTENTIAL RISKS AND DISCOMFORTS**

Although there is no foreseeable risk, participants may experience some discomfort in expressing their opinions regarding HIV/AIDS and sexuality as well as their cultural practices. Participants will be assured of the confidentiality, anonymity, and privacy of the data and that answers to questions are voluntary. The researcher will be present during the answering of the questionnaires to clear up any



misunderstandings that might arise or to put the patient at ease should he/she feel a degree of discomfort. If the need for counseling should arise, I can be contacted for counseling option referrals.

#### **4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

The management of HIV/AIDS patients that are on ART will improve and good adherence will be achieved and patients will live a healthy normal life.

#### **5. PAYMENT FOR PARTICIPATION**

No remuneration will unfortunately be offered for your participation in this research study.

#### **6. CONFIDENTIALITY**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of no names or personal identifiers will be recorded in any of the data collection tools. In reporting the results, care will be taken not to report results in a way that would enable any participants to be identified and/or stigmatized in their views. Data will be stored in a safe place at all times. The researcher and her supervisor will be the only persons having access to the data. All data collected will be destroyed after successful completion of the thesis, for the purpose of which it was collected. The anticipated period is after one (1) year. As mentioned previously, all interviews will be tape recorded and the interviews will be transcribed verbatim, without making any reference to your name or personal identifiers. Confidentiality and anonymity will be maintained throughout.

The purpose of the study is for the completion of an MPhil degree in HIV and AIDS Management and due to the requirement of the publishing of a thesis, the data collected, analysed and interpreted in this study will be reported on. In the writing of the thesis, confidentiality, anonymity, and privacy of participants will be maintained at all times.

#### **7. PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

#### **8. IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact the researcher Mrs Lulama Motja at 072 404 7850 or 082 757 6229 and email: [lulamamotja@gmail.com](mailto:lulamamotja@gmail.com) or the supervisor Dr Thozamile Qubuda at (021)808-3999 and email: [tqubuda@sun.ac.za](mailto:tqubuda@sun.ac.za)

## 9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

### SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to [*me/the subject/the participant*] by..... in [*Afrikaans/English/Xhosa/other*] and [*I am/the subject is/the participant is*] in command of this language or it was satisfactorily translated to [*me/him/her*]. [*I/the participant/the subject*] was given the opportunity to ask questions and these questions were answered to [*my/his/her*] satisfaction.

[*I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.*] I have been given a copy of this form.

\_\_\_\_\_  
**Name of Subject/Participant**

\_\_\_\_\_  
**Name of Legal Representative (if applicable)**

\_\_\_\_\_  
**Signature of Subject/Participant or Legal Representative**

\_\_\_\_\_  
**Date**

### SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to \_\_\_\_\_ [*name of the subject/participant*] and/or [his/her] representative \_\_\_\_\_ [*name of the representative*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/\*English/\*Xhosa/\*Other*] and [*no translator was used/this conversation was translated into \_\_\_\_\_ by \_\_\_\_\_*].

\_\_\_\_\_  
Signature of Investigator

## **APPENDIX 3: QUESTIONNAIRE**

### **INTERVIEW QUESTIONNAIRE**

#### **PATIENT**

Name of facility:

Name interviewer:

Interview number:

Date:

CULTURAL FACTORS INFLUENCING THE MANAGEMENT OF HIV/AIDS IN PATIENTS ON ANTI-RETROVIRAL THERAPY IN EKURHULENI NORTH GAUTENG is a research study conducted by Mrs Lulama Motja, from the Africa Centre for HIV/AIDS Management at Stellenbosch University. The results of the research study will contribute toward the researcher's Master's level thesis as part of a requirement for the completion of the MPhil in HIV/AIDS Management programme.

#### **1. Demographic information**

Sex	
Age	
Religion	
Ethnic group	

Who do you live with	
Type of dwelling	
Number of dependants	
Occupation	
Education level	

## 2. Pre-diagnosis

I would like to understand what people actually know about the illness. Can you tell me what you know about HIV/AIDS and you have heard in the community

What is HIV/AIDS?	
What causes HIV/AIDS	
How is it transmitted?	
How is it prevented?	
How is HIV/AIDS treated?	
Is it curable?	

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**3. Post - HIV infection**

When were you diagnosed with HIV?	
When did you start treatment for HIV (ARVs)?	
How do you feel about your health since you started treatment?	
Is there anything else which can make the disease symptoms better?	

**4. Cultural factors**

**From your experience how do you think cultural factors influence adherence? Please explain.**

Traditional and religious rituals	
Traditional medicine	
Gender inequality	
Cultural beliefs and rituals	

Witchcraft	
Other	

**5. Management and treatment**

Is there any other medication you are taking?	
When did you last take your medication?	
Did you may be miss any doses?	
If you sometimes miss a dose, please can you tell me what causes this to happen?	
Have you ever thought about stopping HIV/AIDS medicines (ARVs)? If yes, what are the reasons?	

**If there is anything else you would like to say or ask please feel free to do so.**

**Thank you very much for your participation in this interview.**