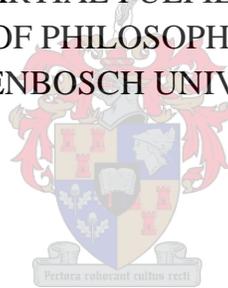


EVALUATION OF THE INVOLVEMENT OF HIV POSITIVE PATIENTS IN THE  
DECISION TO COMMENCE ANTIRETROVIRAL THERAPY AT OSHAKATI  
HOSPITAL, NAMIBIA

FARAI MAVHUNGA

ASSIGNMENT PRESENTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF MASTER OF PHILOSOPHY (HIV/AIDS MANAGEMENT) AT  
STELLENBOSCH UNIVERSITY



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## **DECLARATION**

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

25 November 2009

## **ABSTRACT**

The increase in treatment options for HIV positive people has contributed to an increase in the number of people willing to be tested for HIV since there are now tangible benefits associated with a confirmed HIV positive diagnosis. In Southern Africa the trend towards increased numbers of people who know their HIV status has been more noticeable in women than in men (Muula, et al., 2007), possibly due to the greater health seeking behaviour of women compared to men as well as the access that women have to HIV testing during pregnancy as part of countries' efforts towards preventing mother-to-child transmission of HIV. In Namibia there has been a massive increase in the number of patients commenced on antiretroviral therapy (ART) (MOHSS, 2007) .

It is important to ensure that increases in the number of patients being started on treatment are accompanied by a proportional improvement in the quality of care being provided to the patients. One important concept that has been promoted in recent years is the Greater Involvement of People Living with HIV/AIDS (GIPA). This concept promotes the inclusion of HIV infected individuals in the decision making process when making decisions regarding the welfare of People Living With HIV (PLHIV). One important caveat specific to ART is the high levels of adherence required for sustained effectiveness of the medicines. Involvement of patients in the design of their treatment has been shown to be a facilitator of adherence to treatment.

This study design was a cross-sectional survey whereby a sample of individuals who are registered at Oshakati Communicable Disease Clinic and were receiving ART were interviewed to determine who they perceived to have been the principal decision maker for them to be commenced on ART. The responses were categorized according to the responses from the patients and the frequencies calculated to find the percentage of the patients on ART who considered themselves to have been involved in the decision making process. Having the majority of the patients perceiving themselves as having not been involved in the decision making process was thought to have an important bearing on the counselling which was done prior to starting treatment. This can therefore inform initiatives to improve case management and the involvement of patients in designing their treatment regimens and in making important decisions about their treatment. This ultimately helps to improve the adherence of these patients to their treatment, thereby improving the treatment outcomes and reducing the rate of development of resistance to the antiretroviral medicines (ARVs).

## **OPSOMMING**

### **Agtergrond**

Die verhoging in die behandeling opsies vir MIV positiewe mense het bygedra tot n verhoogde syfers van die mense gewillig om getoets te word vir MIV, omdat daar voordele is geassosieer met die bevestigde MIV positief diagnose. In Suider Afrika die patron teen die verhoogde syfers of mense wat hulle MIV status ken is meer gekenmerk in vroumense as mans, dit is moontlik weens dat die vroumense hul gedrag teenoor gesondheid raadpleging goed is in vergeliking met die mans, en die vroumense het toegang aan MIV toets gedurende die swangerskap periode as deel van die land se poging vir die voorkoming van moeder tot kind transmissie of MIV. In Namibie is daar n geweldige verhoogde syfers in pasiente wat met die MIV behandel/therapie begin (ART) het. Die verhoogde syfers of pasiente wat op behandel begin is moet vergesel word met n propoosie van verbetering in kwaliteit sorg voorsien aan pasiente. Een van die belangrikste konsepte wat gedurende afgelope jare bevorder is die Betrokkenheid van Mense Leef met MIV wat aanmoedig dat die individuele mense wat met MIV Leef ingesluit word in besluitnemings. Betrokkenheid van pasiente in die gebruik van hulle behandeling is n bewys van hulle toewyding tot hulle behandeling.

### **Studie Metode**

Die studie uitleg was n cross-sectional ondersoek waar geregistrede individuele by Oshakati Communicable Disease Clinic, wie MIV behandeling ontvang was ondervra om vas te stel wie was hulle hoof besuitnemer vir hulle om met hierdie MIV behandeling te begin. Die terugvoering is gekategoriseer volgens die bevindings van die pasiente oor hulle betrokkenheid en die besluitneming van hulle behandeling.

### **Uitslae**

Die meerderheid van die pasiente (83%) het terugvoering gegee dat hulle tot n sekere mate in die besluitneming omtrent hulle behandeling betrokke was dit geld vir mans en vroumense.

### **Afsluiting**

Die meerderheid van die pasiente neem aan dat hulle betrokke is in die proses van die besluitneming, wat n positiewe invloed op die toewyding tot hulle medikasie het; en stel voor dat daar wel berading vir pasiente gegee word voor hulle met behandeling begin.

## **ACKNOWLEDGEMENT**

First and foremost I would like to acknowledge the leadership and guidance provided my study leader, Dr Thozamile Qubuda in assisting me in guiding me through the process of developing this thesis. This would not have been possible without his guidance. I also wish to express my heartfelt gratitude to the staff at Oshakati State Hospital Communicable Disease Clinic, without whose support this thesis would not have been a success.

Finally, I would like to thanks all the patients who participated in this study; your courage and strength in the battle against HIV is a source of inspiration for us all.

## **LIST OF ABBREVIATIONS AND ACRONYMS**

AIDS	Acquired Immune-deficiency Syndrome
ART	Anti-retroviral therapy
ARV	Anti-retroviral medicine
GIPA	Greater involvement of people living with HIV/AIDS
HAART	Highly Active Antiretroviral Therapy. This is usually combination treatment comprising of at least three different antiretroviral medicines
HIV	Human immune-deficiency virus
MOHSS	Ministry of Health and Social Services (Namibia)
PLHIV	People living with HIV
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing (for HIV)
WHO	World Health Organisation

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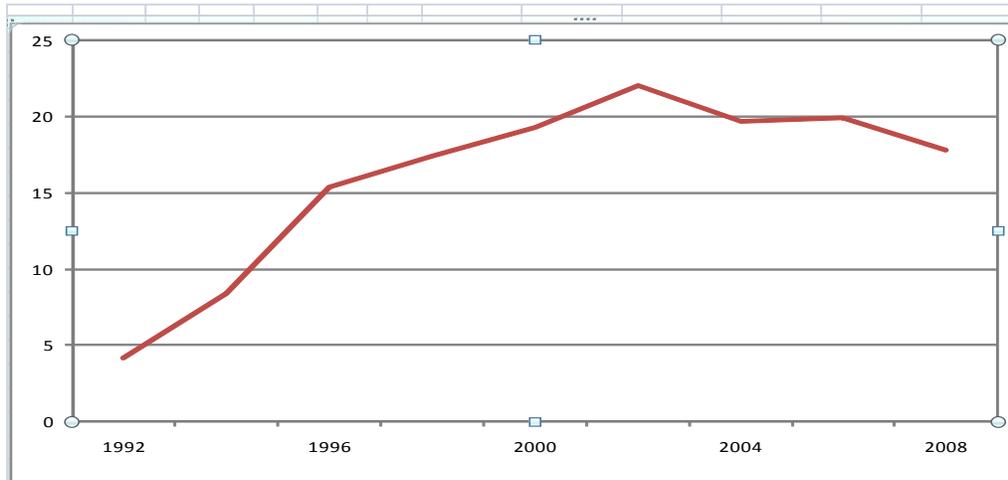
## **1. INTRODUCTION**

### **1.1. Epidemiology of HIV in Namibia**

Just like the rest of Southern Africa, Namibia has a generalized HIV epidemic. The first case of HIV infection was reported in Namibia in 1986 (MOHSS, 2008). The country is among the worst affected in the world with an antenatal seroprevalence rate of 17.8% in 2008 with no notable difference between rural and urban areas (MOHSS, 2008). This represents a slight but notable decline from the 2002 peak of 22%. The antenatal sero-prevalence survey is currently the major source of prevalence data in the country, in the absence of population prevalence surveys. The number of people who were living with HIV in 2008 was estimated to be 204,000 while by 2012/13 this value was predicted to be about 247,000 people. “Despite stabilizing HIV prevalence, the number of people living with HIV will continue to increase as the total population size in that age range grows” (MOHSS, 2008). Unlike in the western world where the epidemic predominantly affects males, about 58% of those living with HIV in Namibia in 2007/08 are women, with women also being infected at a slightly younger age than men (MOHSS).

Public health care facilities began providing antiretroviral therapy (ART) in 2003 and voluntary counselling and testing (VCT) services in 2004, and since then there has been remarkable expansion in the coverage of these interventions (MOHSS). The advent of ART has seen more and more people volunteering to be tested for HIV since there are now tangible benefits associated with knowledge of one’s HIV status. Despite this increase in the number of patients being tested however, HIV testing rates among males remain significantly lower than those of females. This has been partly attributed to the lower health care seeking behaviour in males compared to that in females, as it has been found that “men are less likely to seek health care than women” (UNAIDS, 2000) and for those that do seek health care “older men frequently delay seeking health care for illnesses that could be prevented or cured” (UNAIDS). These general trends of men’s fewer contacts with health care workers are well documented internationally and as much as “eight out of ten men admit to waiting too long before going to see their doctor” (MHFI, 2004). This may be due to various socio-cultural factors and the real threat to their financial stability since men may be afraid of losing their jobs if they are known to be HIV positive (WHO, 2003).

**Figure 1: Trends in antenatal HIV prevalence rates in Namibia; 1992-2008**



When HIV positive patients are enrolled into public care facilities they are usually managed according to standardized protocols. In Namibia follow-up schedules for HIV infected patients at the time of the study were based on their World Health Organisation (WHO) clinical stage as well as the CD4 count, and whether the patient was on ART or not. The clinical stage was used as it gave a qualitative measure of the extent to which the patient's immune system has been damaged by HIV as indicated by the type of opportunistic infections (diseases which afflict patients with impaired immune systems) that the patient presents with, while the CD4 count gave a quantitative measure of this immune destruction since the CD4 cells (a subset of the white blood cells responsible for controlling the body's defense against infection) are the primary target of destruction by HIV.

The country's 2007 version of the *National Guidelines for Antiretroviral Therapy* has the following as the eligibility criteria for commencing HIV positive adult and adolescents on ART:

- WHO Clinical stage 3 and 4 disease, irrespective of CD4 cell count, or
- CD4 count less than 200 cells/mm<sup>3</sup> (less than 250 cells/mm<sup>3</sup> in pregnant women) irrespective of WHO clinical stage, and
- Met social eligibility criteria. The social criteria included are that the patient must:
  - Have lived at a fixed address for the previous 3 months,
  - Have ready access to a designated treatment centre for follow-up,
  - Not drink alcohol,

- Have no untreated underlying psychiatric disorders,
- Be committed to:
  - Lifelong treatment with ART
  - Practising safe sex, and
  - Allowing home visits if indicated (MOHSS, 2007)

As ART continued to be rolled out, many programmes were now battling to improve the treatment outcomes among patients commenced on treatment. One of the key requirements for the success of currently available ART is a high degree of adherence to the treatment. Very high levels of adherence are required to ensure durable suppression of the virus in the blood which will in turn maximize the chances of treatment success and prevent the development of resistance of the HIV to the antiretroviral drugs. Successful treatment also meant that the patient would remain free of the many opportunistic infections that frequently afflict HIV infected individuals. It should be noted however that as ART continues to be rolled out and more and more patients are commenced on treatment “the number of people dying of AIDS related causes will continue to grow... due to the increasing numbers of people on treatment who might default or have adverse reactions as well as the increasing ages of those on treatment” (MOHSS, 2008).

Adherence levels for patients on chronic medication are usually suboptimal. Among patients on treatment for diabetes for example, “non-adherence to treatment is more the norm than the exception” (Rowley, 1999). While there are many factors which may be responsible for this, the health care system is considered to have an input into the levels of adherence to therapy amongst patients on HAART. Health care provider related factors such as accessibility, cost, drug stock out, lack of expertise and lack of sensitivity to the needs of PLHIV can all potentially have an impact on adherence. One factor that is commonly cited as a potential cause of adherence problems is a treatment plan that fails to fit into the lifestyle of the patient. This is often a result of the failure of the health care system to explore the individual patient’s social perspectives and come up with interventions that are tailor-made to the patient’s needs.

Oshakati Communicable Disease Clinic is a hospital based public HIV care clinic in the Oshana Region of northern Namibia. At the time of the study it was the largest HIV clinic in the country with over 12000 registered patients as of July 2008. The clinic offered services to all HIV positive patients whether they currently required HAART or not. Patients who were on treatment were given follow-up schedules based on their duration on treatment and any co-morbidities (other coexisting diseases), while patients who were not yet on treatment and who did not have any other co-existing conditions requiring regular follow-up were given a six-monthly follow up schedule according to the Namibia's *National Guidelines for Antiretroviral Therapy* (MOHSS).

Figure 2: Map of Namibia showing the location of Oshakati (shown by the red asterisk)



## **1.2. Justification for the Study**

The level of patient involvement in the decision making process had not been evaluated for patients in chronic HIV care in Namibia. The massive scale up of anti-retroviral therapy coverage had resulted in a very large number of patients registering for HIV care and being started on ART. Due to pressure in the clinics brought about by these large patient volumes it was possible that there was not enough time in the HIV care clinics to discuss the treatment adequately with each individual patient to ensure that they fully comprehended the requirements of their treatment. Anecdotally this had the potential to have a domino effect as more and more patients were started on treatment since some of the approaches which may have been adopted to cope with the high patient numbers (the so-called ‘short-cuts’) became systematized and adopted as standard practice since they appeared to be “working”. Thus as the country shifted focus from coverage to also include quality of service provided to the patients it was important to involve the patients in the decision making processes regarding how they were managed. To put measures in place to improve patient involvement in the decision making process required a baseline assessment of the current levels of patient involvement in this process. One initial step in this direction was therefore to determine the patients’ current perceived levels of involvement in the decision to start ART.

This study sought to investigate the perceived involvement of patients in the decision to start ART. This was done by interviewing patients who were already on treatment to find out if they considered themselves to have been involved in the decision to start treatment. Patients who were already on treatment were the study population for the study. Low levels of perceived patient involvement in the decision making process was considered a pointer to the need for training of health workers to involve patients in the decision making process. This is because patients’ involvement in major decisions regarding their treatment was thought to have a significant bearing on adherence to treatment.

## **1.3. Background of the problem**

The developments in the field of anti-retroviral therapy have brought significant benefits to patients and their families as well as large corporations. This is because they have transformed HIV/AIDS from an incurable affliction to a manageable chronic illness and has resulted in decreased morbidity and mortality. In Namibia for example, 93% of patients enrolled into the

public ART programme were alive four years after the programme started (MOHSS). With the current treatments, however, the treatment is still life long since there is as yet no proven cure for HIV infection. This lifelong treatment is a major challenge for patients, especially because of the stringent adherence requirements demanded for successful therapy. The *National Guidelines for Antiretroviral Therapy* among other publications say that the patient needs to take at least 95% of the prescribed medicine doses to maintain enough levels of the medicines in the blood to achieve sustained viral suppression, with lower levels of adherence promoting the development of resistance to the treatment (MOHSS). “Knowing that HAART is a lifelong commitment, it is the duty of all stakeholders- including family, friends, employers and other partners- to render support to HIV/AIDS patients to comply with treatment. Failure to do so will result in the development of ARV resistant HIV strains with dire consequences...” (MOHSS). Development of resistance to ARVs is major a public health concern because there is a possibility of drug resistant viruses spreading to other people in the community, especially if HIV prevention messages and interventions are not integrated into the care and treatment protocols. Adherence to ART is made more difficult by the fact that the patients on ART have to continue seeking medical attention long after their symptoms have improved following successful recovery of the immune system.

While the national guidelines are clear on which patients were considered eligible to start treatment, implementation of these guidelines and the role the patient should play in the decision to start treatment were not as clearly defined. For this reason there was likely to be great variability in the extent to which patients are involved in the process based on the approaches of individual clinicians. This lack of uniformity could create potential challenges for patients when they moved from one clinic to another as they would have different expectations of the health care system. It is therefore important to ensure that the entire national programme is striving towards a high degree of patient involvement in at least the major decisions regarding their treatment

The 2007 Namibian guidelines recommended repeating the CD4 count test for patients who were not yet on treatment every six months, and this also tended to be the follow-up interval for these patients since it was deemed unnecessary for them to come before their blood work-up was due.

This did not seem to take into account the additional psychosocial as well as other individual needs of PLHIV as acknowledged by the Namibian technical guidelines; “Follow-up counselling of the patient and review of his/her environment to ensure continued psychosocial support and to enhance adherence to treatment” is a prerequisite for provision of ART (MOHSS). These needs are not uniform among the patients and require a careful empathetic assessment and discussions with the patient to decipher the different needs of each patient. This usually requires more than one clinic visit, and the dynamism of the different stages of psychological evolution following an HIV positive diagnosis also need to be taken onto account.

“Despite all efforts that have gone into prevention and care, active participation of men in all of these (HIV treatment and prevention) programmes is lagging behind” with 64% of the patients on ART in Namibia being women (MOHSS). This observation underscores the problems associated with the generally acknowledged lower health seeking behavior in men in sub-Saharan Africa when compared to their female counterparts. Association between gender and the level of involvement in treatment decisions regarding ART has not been systematically studied in Namibia. The current practice in clinics does not specifically differentiate between genders in the approach to preparing the patient for treatment.

#### **1.4. Statement of the problem**

The 2007 technical guidelines for following up HIV infected patients and initiating them on ART are mainly based on medical criteria. Social criteria were included in the guidelines for Namibia as highlighted above so as to try and eliminate potential inhibitors of adherence to treatment. However the implementation of these guidelines and the involvement of the patients in the decision making process were not being routinely assessed using the existing monitoring and evaluation tools. It was therefore necessary to conduct this study so as to try and determine the extent to which the patients currently on treatment were involved in the decision to start them on treatment. This could then be used as a proxy to measure the involvement of the patient in the overall decision making process.

There are also fundamental differences in health seeking behavior between men and women and this can have a significant bearing on the desired frequency of contact with health care workers. The fact that traditionally men are the decision makers in most sub-Saharan African communities

(Muula, et al., 2007) may potentially influence the decision making process regarding ART, with female patients being inclined to allow the (often male) doctors to make decisions about their treatment. The analysis will include comparing the decision making process by gender and this will then help in the development of gender specific interventions if there is a significant difference between males and females. These issues needed to be evaluated and have their significance validated, and this study sought to provide information in this regard.

### **1.5. Significance of the study**

The acceptability and desirability of the services that are offered to HIV infected patients were not being routinely evaluated in clinical practice in the country. Outcome measures such as the number of deaths averted and the reduction in morbidity are often cited as the major achievements of ART. There is however need to create more patient oriented services, with the views and preferences of patients being taken into account. The study aimed at trying to outline and highlight the level of variability in patient experiences as far as the role which they played in the decision to start treatment was concerned.

### **1.6. Scope of the study**

The study sought to assess patients who were on ART, and it only evaluated those patients enrolled in care. It focused only on the adult patients (18-70 years of age) who were already on treatment (ART) and who were otherwise capable of making their own decisions. The study was confined to one clinic only and assessed the patients already enrolled into care. As such the results of the study are only applicable to that clinic and are not generalisable to other clinics in the country.

### **1.7. Purpose of the study**

The study intended to investigate the patients' experiences as far as the decision to start them on antiretroviral therapy was concerned. It mainly sought to determine who, from their point of view, was responsible for making the decision to start them on treatment. The study also sought to investigate whether there were significant differences in the patients' experiences during initiation of treatment. Significant variability among the patients could suggest a difference among the various clinicians who came into contact with the patients, whereas minimal variability could be a reflection of the organizational issues relating to patient management. This would be very important when reviewing patient management approaches since the patient's

involvement in their own care has been shown to have an impact on the patient's adherence to treatment. Thus a finding of 90% of the patients not being involved in the decision to start them on treatment could necessitate that the protocols and standard operating procedures be revised to enhance more patient involvement in the decision making process; whereas a finding of 40% of patients being involved in the decision for them to start on treatment could suggest a potential problem of implementation of the protocols on the part of individual clinicians.

## **2. RESEARCH PROBLEM, OPERATIONALISATION & HYPOTHESIS**

### **2.1. Research Question**

The research problem which was studied and analysed was:

**Who do HIV positive adults on ART at Oshakati Hospital Communicable Disease Clinic perceive as the person who made the decision for them to start antiretroviral therapy?**

“HIV positive” in this study referred to those patients who had been tested and found to be HIV infected through either rapid HIV tests or through laboratory blood testing and had enrolled into chronic HIV care, while “adults” were those patients registered in the clinic who were aged eighteen years and above at the time that ART was initiated. “ART” refers to Antiretroviral Therapy, which is also sometimes simply referred to as combination antiretroviral therapy (cART) or highly active antiretroviral therapy (HAART).

### **2.2. Hypotheses**

The scientific hypothesis was that the 75% of adult patients who are on HAART at Oshakati Hospital were not involved in the decision to start them on HAART, while the null hypothesis contended that the majority of the adult patients on HAART were involved in the decision to commence them on treatment.

### **2.3. Research Objectives**

The objectives of the research were:

- To find out the proportion of patients who were part of the decision making process when the decision for them to start them on treatment was made.
- To evaluate if this proportion warrants an adjustments to the existing protocols to improve patient involvement in the decision to start treatment
- To identify areas for future research in the field of patient-provider relationships in light of the ever changing scope of chronic HIV care.

## **2.4. Research Design**

The research design which was used for this study was a cross sectional survey. This is a non-experimental research technique which is often used to collect data from a representative sample of the study population. The interview technique was used to obtain data on the patients' experience concerning the decision that was made for them to be started on anti-retroviral therapy. The main challenge in this study design was to select a population that is representative enough of the study population.

## **2.5. Population**

The research was carried out at Oshakati State Hospital Communicable Disease Clinic, which is the clinic that provides care to HIV positive patients in and around Oshakati. The clinic caters for patients who are eligible to be initiated on ART as well as those who are not yet eligible. The population under study was however confined to stable adult patients who were HIV positive and who had been started on ART according to the Namibian guidelines for ART eligibility. These were patients in whom the decision to initiate ART had already been made and are already taking their antiretroviral medicines.

## **2.6. Sampling and Sample Size**

Systematic random sampling was used and patients already on treatment during the month of the study were selected. Children and patients deemed incapacitated to make their own decisions due to mental illness or severe disease were excluded from the study population. To safeguard against the potential pitfall of approaching patients who understood the language that the interviewer was comfortable since these would probably be interviewed faster, or to select patients of particular age groups due to the interviewer preferences, every second eligible patient was enrolled into the study. The sample size was calculated on the basis of an estimated population size of 6500 adult patients currently actively being followed up at the clinic, with a 90% confidence level and a 5% confidence interval. A sample size calculator downloaded from [www.macorr.com](http://www.macorr.com) was used for the sample size calculation and the sample size was determined to be 261. A 95% confidence level would have been preferred but this was not possible due to time limitations since this would have increased the sample size to 363.

## **2.7. Data collection**

The selected patients were interviewed following a predesigned questionnaire (Annex 1) using the face to face method of data collection. The responses were then categorized and from these interviews the proportion of patients who were involved in the decision making process was calculated. There were three categories of responses: decision made by health worker, decision made by the health worker and patient (joint decision) or decision made by patient alone. The questionnaire was administered in the local Oshiwambo language which is the language spoken by the majority of patients in this clinic.

## **2.8. Variables**

The variable that was measured in this study was the person who made the decision to commence anti-retroviral therapy. The frequency of each of the responses was quantified as a proportion of the total number of patients interviewed. While the true range of variation is infinite (since there are varying levels of involvement in the decision making process), the responses were categorized into three possible responses as discussed above; thereby making this a discreet variable.

## **2.9. Pilot study**

This questionnaire was field-tested on 20 patients and was then refined based on the issues identified during the pilot study. Other operational and logistical issues were also fine-tuned during this pilot phase.

## **2.10. Analysis**

The responses were categorized into the three possible categories and the frequency of each response was determined. This was then expressed as a percentage of the total number of patients interviewed; the responses were analysed by comparing the different frequencies of the responses. Data was double entered in Epidata 3.1 (210108) and analyzed using Epidata analysis V2.0.3.129.

## **2.11. Ethical Aspects**

The patients were approached to participate in the interview during routine consultations when they presented for care in the clinic. The purpose of the interview was explained to the patients and the patients were asked to give verbal consent of their participation in the study. The

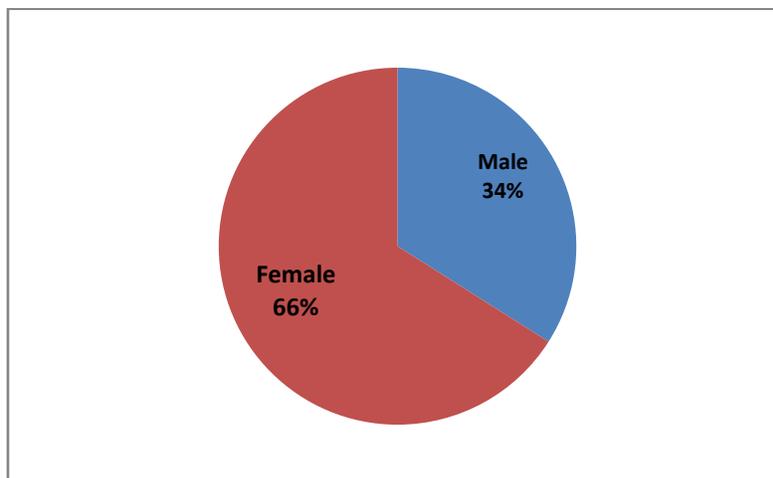
questionnaire was administered on those patients who consented to taking part in the study. No identifying details were obtained from the patients. The research was conducted as part of ongoing operational research for quality improvement at Oshakati Hospital and was thus exempt from the requirement of the full approval by the Research Committee in the Ministry of Health and Social Services.

### 3. RESULTS

#### 3.1. Demographic data

A total of 266 patients were interviewed for the study. 7 of these patients were excluded from the analysis due to missing information. The 259 patients whose responses were analysed comprised of 171 females and 88 males. This represents a female to male ratio of almost 1.9:1 which is probably a reflection of the patient population in this clinic. However this could also be due to the timing of the data collection since many of the men are seasonal workers who routinely migrate from Oshakati to go and work in the Southern part of the country. Furthermore this could also be a result of the lower health seeking behavior in males resulting in fewer of them being tested for HIV and put on treatment timely (discussed below). The mean age of the respondents was 40 years.

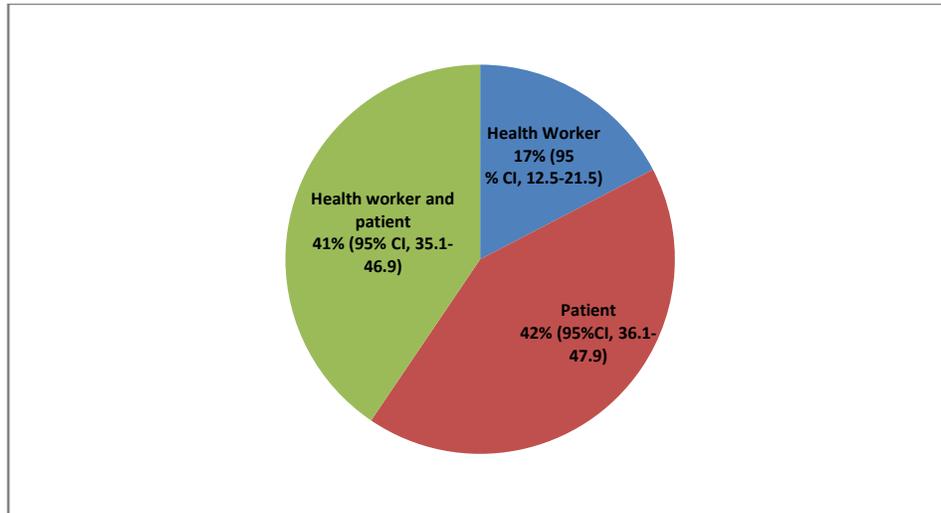
**Figure 3: Gender distribution of the study sample**



#### 3.2. Proportion of patients involved in the decision making process

It was hypothesized that 75% of patients were not part of the decision making process as far as the initiation of their anti-retroviral treatment was concerned. On the contrary however, as figure 4 below shows; only 17% (95% CI, 12.5-21.5) of the patients responded that the decision for them to commence on ART had been taken exclusively by the health worker.

Figure 4: Chart showing the perceived decision maker to start HAART for both male and female patients



The unexpected (yet desirable) outcome was that a significantly greater proportion of patients said they were part of the decision making process. 42% (95%CI, 36.1-47.9) said they decided on their own while 41% (95% CI, 35.1-46.9) said they made the decision together with a health worker. This means that overall, 83% (95% CI, 78.5-87.5) of the patients responded that they were involved to varying degrees in the decision to commence treatment. Using the Z-test for two proportions (<http://www.dimensionresearch.com/resources/calculators/ztest.html>) it was determined that there is a statistically significant difference between the hypothesized percentage of 75% and the actual finding that only 17% of the patients responded that they were not part of the decision to start treatment (Z-value=13.156 at 95% Confidence Interval). Thus the finding provides evidence for rejecting the scientific hypothesis that the majority of patients are not part of the decision to start ART.

The above findings suggests that the GIPA principle is being implemented in Oshakati Communicable Disease Clinic. It should be noted that this can also be a result of social desirability bias since the questionnaires were administered by health care workers who work in the clinic and in a health care setting. Due to the stigma and difficulty associated with finding and interviewing PLHIV in the community, the health care setting was however the most feasible place to conduct these interviews.

The advantages of having patient involvement in decisions concerning their treatment have been highlighted above. The ideal would therefore be to have all patients at least being involved to some extent in the decision concerning their treatment. It was noted by Beach C. M et al that “Compared to patients who prefer to share decisions with their HIV provider, patients who prefer that their provider make all/most decisions were significantly less likely to adhere to HAART...” (Beach, Duggan, & Moore, 2007). This emphasizes the need for collective decision making between the patient and the health care provider.

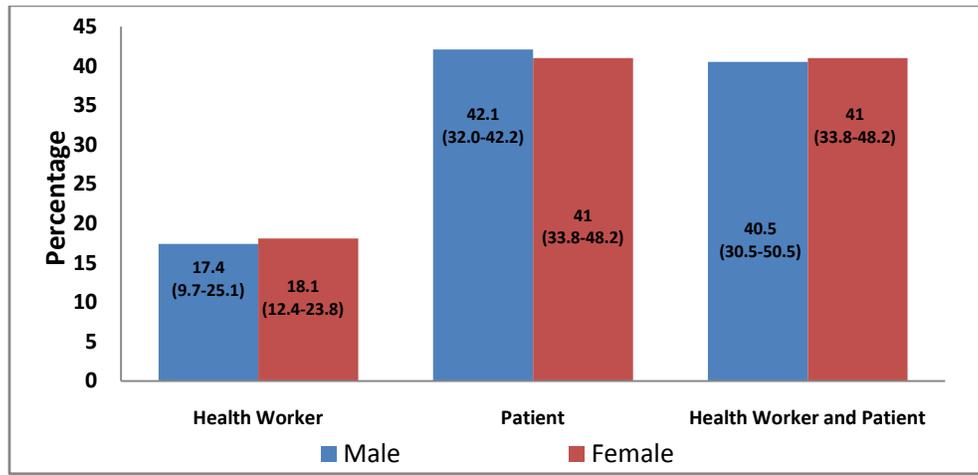
### 3.3. Gender and the decision to start treatment

Figure 5: Table showing proportions of by patients’ perceived decision makers to start ART by gender

Reported decision maker	Proportions by gender (%)		z-value (95% CI)
	Male	Female	
Health Worker	17.4	18.1	0.028
Patient	42.1	41.0	0.022
Patient and Health Worker	40.5	41.0	-0.133

As shown in the table above and Figure 6 below there was remarkably little difference between males and females as far as the perceived decision maker for them to commence on ART was concerned. Although there was a significant difference in population size between males and females; this finding suggests that there is no major difference between males and females in their involvement in decisions regarding commencement of ART.

Figure 6: Chart showing the proportion of patients' perceived decision maker (95% C I in brackets)<sup>1</sup>



<sup>1</sup> The confidence intervals were determined on the assumption that the gender proportion of the study sample was representative of the gender proportion of the study population.

## 4. LITERATURE REVIEW

### 4.1. Introduction

It is a well established fact that adherence to treatment is the cornerstone to optimal results with the currently available range of antiretroviral therapy (Johnson, et al., 2006). Conversely suboptimal adherence is the commonest reason for failure of anti-retroviral therapy and development of resistance to antiretroviral medicines. Operational research for antiretroviral therapy has therefore focused on trying to identify modifiable factors that can inhibit or facilitate adherence.

### 4.2. Determinants of adherence to treatment

According to (Konkle-Parker, Erlen, & Dubbert, 2008) there has been a lot of research into barriers to and facilitators for medication adherence for HIV infected individuals on antiretroviral therapy (ART). Barriers are usually classified into four main categories:

- *Patient related factors*

These are factors that depend on the patient and include factors such as literacy level, alcohol and substance abuse, health beliefs and depression and other psychiatric disorders. As can be noted many of these factors can be addressed by tailoring interventions to individual patients and making sure that the patient understands what they are supposed to do and that all co-existing conditions are treated accordingly. Schneider *et al* also noted in a 2004 study that it is critical to determine and incorporate patients' belief systems about ART into adherence counselling sessions and to also screen for and treat psychiatric illnesses (Schneider, H, Greenfield, Li, & Wilson, 2004). This can be only if the individual patient's circumstances and belief systems are meticulously explored after establishing a trusting relationship with the patient. This reiterates the need for the active engagement of the patient in the entire treatment and care process.

- *Medication related factors*

These are factors related to the medicine itself and include side effects of the medicine, treatment complexity, number of pills as well as the dosage requirements for each medicine. The impact of medication related factors can be minimised if these are explained to the patient in advance and if the side effects are adequately treated.

- *Environmental factors*

Environmental factors include beliefs of significant others, transportation and finances. Again these can only be understood and considered if the patient is assessed holistically and comprehensive intervention packages are implemented.

- *Provider related factors*

Provider related factors include such factors as communication and language, health worker attitude, clinic operational hours and accessibility of the health centres as well as the ability of the patient to participate in the decision making process. There are numerous studies that have been conducted directed at adherence issues for patients on antiretroviral therapy. There are however very few studies if any that have investigated the issue of relations between and health care providers and adherence to treatment (Johnson, et al.). In a study published in 2006, Johnson et al aimed “to explore a model of medication adherence in which the relationship between positive provider interactions and adherence is mediated by adherence self efficacy” using computerized self administered and interviewer administered self reported measures of medication adherence. They found that positive provider interactions may foster greater adherence self-efficacy among patients, which is associated with better adherence to medication. Patient-focused interventions that enhance self-efficacy may improve provider-patient interaction and lead to greater self-efficacy for medication adherence” (Johnson, et al.). Indeed the finding in this study suggest that there is significant patient involvement in major treatment decisions which can have a positive bearing on the patients’ adherence to treatment.

Jonson M.O et al therefore concluded that

In a wide range of illness contexts, dimensions of patient satisfaction with providers' communication, engagement, and general interaction skills are linked to adherence to care. In HIV treatment, treatment plan adherence has been associated with patients' perceived level of engagement and satisfaction with their providers... For example, greater patient-physician agreement about top priority treatment strategies has been shown to predict greater self-efficacy for diabetes self-management (Johnson, et al.).

It is for this reason that they postulated that training of health workers to increase collaborative negotiation with the patient in setting treatment goals and implementation of strategies to maximize the treatment outcomes is also likely to improve adherence self-efficacy and consequently improve the adherence itself. Patient-health care provider communication can also

improve adherence by allaying fears by patients about their condition, thereby reducing the stress associated with the disease (Johnson, et al.).

In a study published in 2004, Schneider *et al* demonstrated that the nature of the doctor-patient relationship was associated with treatment adherence in PLHIV, suggesting that improving doctor-patient relationship quality can positively influence adherence to ART (Schneider, H, Greenfield, Li, & Wilson, 2004).

“The belief that good physician-patient relationships are associated with better adherence to antiretroviral regimens for HIV infection is widespread, and supported by several qualitative studies.... Because accumulating evidence indicates that physicians’ behaviors can be improved through training, targeting those specific aspects of the physician-patient relationship linked with greater adherence can serve to focus targeted, effective interventions.... Because of this, it is particularly important that providers understand every potentially modifiable risk factor for poor adherence” (Schneider, H, Greenfield, Li, & Wilson).

The findings on the relationship between provider-patient relationships and adherence are however not uniform. In their study Konkle-Parker *et al* found no problems regarding the patient-provider relationship as a cause of poor adherence to treatment. They were however quick to note that as with the Oshakati study, the participants in this particular study were all from one clinic where recruitment for the focus groups occurred, and that the principal investigator was also from the same clinic. This might therefore have minimized willingness by the participants to mention negative feelings due to social desirability. The study however noted that support provided to patients by providers was a facilitator of adherence (Konkle-Parker, Erlen, & Dubbert, 2008).

### **4.3. Gender and treatment adherence**

The gender dynamics associated with medication adherence need to be understood and accepted, and taken into consideration when designing interventions targeting patients of different genders. The differences in health seeking behavior between males and females in different communities need to be acknowledged. Traditionally men tend to take longer to visit a health

facility when ill than females. A UNFPA paper noted this issue and advised that organisations and individuals “working with young men should be aware that they (young men) are not likely to seek health services, may see reproductive health as a women’s concern, and are frequently misinformed” (UNFPA, Undated). Again it is important to take these factors into account when designing programmes addressing men. The current Namibian programme for the provision of ART does not distinctly specify these gender differences in the approach to patients despite it being generally agreed that men are taking longer to come to the HIV care clinics and that they are starting treatment when their CD4 count levels are lower compared to their female counterparts.

Unfortunately many of the studies that have been carried out in this regard have been conducted in populations where the dynamics of the epidemic are very different for the sub-Saharan Africa situation. In Germany for example only 17% of the 59,000 PLHIV are female compared to sub-Saharan Africa where the epidemic shows varying degrees of female predominance, and thus most of the clinical studies as well as cohort analyses have been conducted principally on HIV infected men. Harbel A. E et al noted in their study that there appears to be gender differences in the virological treatment outcomes between males and females. It is therefore important to consider and acknowledge these differences not only in behavior but in treatment outcomes as well (Haberl, S, Hanhoff, & Holm, 2008). This might even suggest that there are intrinsic differences between males and females which might require different levels of adherence to achieve the same levels of treatment success. These findings need to be validated in populations like in Namibia where the HIV infection tends to be more heterogeneous, with more females than males being HIV infected.

While these gender differences have been acknowledged and reported in a number of treatment programmes, Applebaun J. A *et al* found no significant difference between the genders as far as the adherence levels were concerned. They however acknowledged that there is growing evidence of a discrepancy in adherence to ART between males and females possibly as a result of the different barriers to treatment faced by the different genders. In their study population they found that women living with HIV appeared to be particularly vulnerable to depressive

symptomatology which can potentially have a negative impact on adherence (Applebaum, Richardson, Brady, Brief, & Keane, 2009).

Karina M. Berg *et al* also noted that a consistent relationship between gender and adherence has not been found, with several studies failing to show a significant association. They however noted that at the time they conducted their literature review there had been four published studies and five preliminary studies showing that women are less adherent than men. They also highlighted that the studies that showed no association between gender and adherence were limited either by small numbers of women or by the use of self-report as a measure of adherence; self-reporting has been shown to overestimate adherence. Their assessment of social and behavioural factors in their cohort of current and former opioid users showed that different social and behavioral factors are associated with adherence in men and women. “Among both men and women, worse adherence was associated with lack of long-term housing, not belonging to an HIV support group, crack/cocaine use, and medication side effects. Among women only, alcohol use was associated with worse adherence” (Berg, Demas, Howard, Schoenbaum, Gourevitch, & Arnsten, 2004). This was however in a specific population of former and current opioid users and can therefore not be taken to be representative of the general population.

A different study sought to establish the intrinsic differences between men and women in their comprehension skills and assessed its potential impact on adherence. Waldrop-Valverde et al found that “women were less able than men to follow medication instructions and answer questions about (a) mock regimen” (Drenna Waldrop-Valverde). According to the authors of the study these findings highlight the differences in the skills used in managing medication regimens between men and women, and “suggest avenues to target for identification and intervention in medication management among women and men with HIV” (Drenna Waldrop-Valverde). The different health seeking behaviours of men and women was highlighted by Muula S. et al in 2007 when they noted that

(w)hile female to male HIV infection prevalence ratios in the southern African countries ranged from 1.2:1 to 1.6:1, female to male ratios on HAART ranged from 0.8: 1 to 2.3: 1 with the majority of the reports having female: male ratio in treatment exceeding 1.6.

Overall, there were more females on HAART than there were males and this was not solely explained by the higher HIV prevalence among females compared to males

As with the Oshakati study, they found that indeed there were proportionally more females on HIV antiretroviral treatment than men in Southern Africa even after accounting for the higher HIV infection prevalence in women. Even in the United States it has also been reported that women access HIV care earlier than men, with others reporting opposite findings (Muula, et al., 2007). This accessibility seems to be reflected in the Namibian situation as well. This is thought to be due to the increased access facilitated by the testing of pregnant women for HIV during antenatal care as part of efforts aimed at prevention mother-to-child transmission of HIV. These differences suggest that interventions for treatment adherence cannot be uniform and are probably gender sensitive. It is therefore crucial to actively engage the patient in the treatment process and to make sure that the patient takes an active (if not leading) role in determining the direction of the ART. It is through such engagement that the patient's self efficacy is enhanced and the adherence to treatment is improved.

#### **4.4. The GIPA Principle**

The foregoing discussion has mainly focused on the provider-patient relationship as being able to facilitate or impair patients' adherence to treatment. One important factor is how well health care workers are responsive to the needs of the patients. This is important especially with medication adherence due to the limited measures that exist as far as trying to determine the true adherence to treatment is concerned. It is known that "clinicians tend to overestimate medication adherence, inadequately detect poor adherence, and may therefore miss important opportunities to intervene to improve antiretroviral adherence" (Miller, et al., 2002). Given this proven inability to predict or detect poor adherence it is imperative that health workers do what they can to try and facilitate adherence by maximising the facilitators and minimising the inhibitors of treatment of adherence. Responsiveness to patients' needs and including patients in the decision making process is one way of doing this. Taking into account the individuality of patients is another way of making sure patients adherence is facilitated.

The Greater Involvement of People Living with HIV/AIDS (GIPA) has been advocated as the best way forward in designing programmes and interventions for PLHIV. According to Morolake *et al* GIPA "represents a mobilising and an organising principle for the involvement of

PLHIV in program and policy responses” (Morolake, Stephens, & Welbourn, 2009). They note however that governments and health systems have not yet fully harnessed the potential and resources of PLHIV in their efforts to fight the epidemic. (Morolake, Stephens, & Welbourn). They also noted that by its failure to take into account the specific and individual needs of PLHIV and through the negative experiences that PLHIV have had, the health care system has failed the majority of PLHIV and that health systems needed to be more responsive and had to adopt an “integrated approach ...based on a human rights framework, grounded in community realities and delivered in partnership and solidarity with people living with HIV...” (Morolake, Stephens, & Welbourn). They further advocated for the development of a “proper *people-centred* not system-centred thinking and to create holistic projects which reflect real lives” (Morolake, Stephens, & Welbourn).

Beach M. C *et al* also supported patient involvement in decision making in a study published in 2007. Their literature review showed that patients who are more involved in their own medical care tended to have better treatment outcomes than those who left the decision making process entirely to their health care providers. They also noted that “23% of patients preferred that their doctor make all or most decisions, 63% preferred to share decisions with their doctor, and 13% preferred to make all final decisions alone”. However they also found in their study that those patients who preferred to make all the decisions on their own were less likely to adhere to their ART than those who preferred to make these decisions with the health care provider (Beach, Duggan, & Moore, 2007).

“Studies have found that patients who report greater involvement in medical care are more satisfied with their physicians, report more understanding, reassurance, and perceived control over their illness and have improvements in medical conditions<sup>1</sup>. Furthermore, interventions to increase patient involvement have had beneficial effects on satisfaction and functional status, blood glucose (in diabetic patients), quality of life, and the frequency and length of hospitalizations ...” (Beach, Duggan, & Moore).

Patient involvement in care has not been as well studied among PLHIV but it needs to be borne in mind that HIV infection has received a lot of publicity. There are therefore bound to be a lot of misconceptions and myths brought about by this plethora of information and misinformation. Furthermore HIV treatment has a lot of options, hence the need to carefully engage the patient in

the selection of the treatment regimens. Because ART regimens require that the patient be adherent to avoid the development of resistance to the medication and the consequent disease progression, it is imperative for the patients themselves be fully committed to the treatment regimens (Beach, Duggan, & Moore).

According to Martin R. L. *et al* “patient satisfaction and patient adherence are enhanced by patients’ involvement and participation in their care” (Martin, Williams, Haskard, & DiMatteo, 2005). They reiterated the finding that those patients with depression who actively participates in discussions of behavioral strategies as part of their treatment with their doctor are more likely to adhere to their antidepressant treatment and that “even when dealing with a serious illness such as cancer, most patients have been found to desire all possible information regarding their condition and treatment” (Martin, Williams, Haskard, & DiMatteo). For these reasons they concluded that “Participation, engagement, collaboration, negotiation, and sometimes compromise enhance opportunities for optimal therapy in which patients take responsibility for their part of the adherence equation” (Martin, Williams, Haskard, & DiMatteo).

#### **4.5. Summary**

Numerous studies have demonstrated that treatment outcomes for ART are strongly determined by the patient’s adherence to treatment. This in turn is influenced by a number of factors which may be patient factors, medicine related factors, environmental factors and health worker related factors. Provider-patients relationships play a significant role in patients’ adherence to treatment and most studies and authors advocate the active involvement of the patient in the decision making process and the designing of patients in their treatment. This is the main thrust of the GIPA principle. The extent of provider-patient concordance in the decision making process had not been well documented in Namibia, and it was not clear how well patients are involved in the decision making process as far as ART related decisions are concerned.

#### **4.6. Conclusion**

Based on the above information it was therefore necessary to establish the current levels of patient involvement in decision making process for ART in Namibia. This study therefore sought to find out what proportion of patients on ART perceived that they were part of the decision

making process when they started ART. It was found that a significant proportion of patients (83%) said that they were involved in the decision to commence treatment; and that there was no significant difference between males and females in their involvement in the decision to commence treatment. Whether the patients were actually involved in the decision making process or not could not be concluded from this study. This means that there is currently no evidence to suggest the need to modify the existing treatment protocols in Namibia. However, more research needs to be conducted in different settings to determine if the Oshakati findings are reflected nationally. Furthermore it would be useful to also conduct the study whereby the respondents are matched for gender for comparability purposes.

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## ANNEXES

### Annex 1: Questionnaire

Unique ID. (Interviewers initials and sequential number: e.g. FM1, FM2, FM3, FM4 for 1,2,3,4 etc

Sex M F

DOB

Age (in years)

By whom could you say; made the decision to start treatment? I will give you three answers and you choose the one that approximately describe your situation.

1. The decision to initiate treatment was made by the health worker
2. The decision to initiate treatment was made by the myself alone
3. The decision to initiate treatment was made by myself and the health worker

### Annex 2: Electronic data capturing tool: Code book

Field name	Field Label	Field type	Field length	Field Values	Value labels
UID	Unique Patient ID	Text		As recorded	
SEX	Sex of the patient	Number	1	1	Male
				2	Female
				9	No sex indicated
DOB	Birth date of patient	Date	10	01/01/1920-31/12/2007	Exact date of birth
				01/01/1800	No date of birth recorded
Age	Age as recorded	Number	3	0-120	The age as recorded
				999	No age recorded
Decision maker	Who made decision	Number	1	1	Doctor/nurse
				2	Patient
				3	Patient and Health worker (s)
				69	Not indicated