

**THE PERCEPTION AND EXPERIENCE OF STIGMA AND DISCRIMINATION
AMONG HIV-POSITIVE PEOPLE AT OSHAKATI ARV CLINIC IN OSHANA
REGION, NAMIBIA**

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Assignment presented in partial fulfillment of the requirements for the degree of Master of
Philosophy (HIV and AIDS Management) at Stellenbosch University



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March 2011

Declaration

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Loide Nghifikwa

March 2011

Acknowledgement

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

I dedicate this to my late father Lamek Ndinoshisho Ambuga and my beloved mother Aina Nekango Tomas who brought me into this world. I wish to thank my lovely husband Mr Julius Natangwe Nghifikwa for being patient and understanding. He provided the support and encouragement that enabled me to finish the study. Special thanks go to my two boys James and Junias Nghifikwa and my four girls Paula, Joan, Helena and Selma for taking over the domestic duties and responsibilities on my behalf when I was busy with my study.

I wish to acknowledge the long standing support and encouragement of Dr Ongunmokun of the University of Namibia that provided me the enthusiasm to complete this study.

I would also like to thank Dr Ebong Akpabio for his valuable support, and technical assistance. My sincere thanks to my supervisor Dr Thozamile Qubuda for his valuable support, guidance and encouragement throughout the whole course.

I wish to express deep appreciation to the Nurses and patients at Oshakati Hospital ART clinic for their willingness to assist and participate in the study.

Finally, I would like to express my gratitude to my friends and colleagues who provided me with words of encouragement when I felt tired and not willing to continue. Your encouragement really provided the fuel that powered me to complete this study.

Key words

Stigma

Discrimination

HIV/AIDS

Health care workers

Health care facilities

PLHAs (People Living with HIV/AIDS)

ART (Antiretroviral therapy)

Qualitative research

MOHSS (Ministry of Health and Social Services)

Abstract

The researcher conducted an explorative, qualitative study to identify the perceptions and experiences of stigma and discrimination among people living with HIV and AIDS in order to establish strategies within ARV Clinic to deal with the situation and eliminate this as a barrier to access the services. The study population included 5 men and 5 women who access health services at Oshakati ARV Clinic and have been on ARVs for more than one year, aged 20-60 years old. The study participants were selected using a purposive sampling approach and interviewed in the ARV clinic.

The study found that participants have experienced enacted and internal stigma and discrimination related to their HIV status within their community and families. They however did not perceive or report any experiences of stigma and discrimination in the ARV clinic. Possibility exists that the participants might not be well empowered to detect acts of stigma and discrimination in the health care environment.

Opsomming

Die navorser het 'n verkennende, kwalitatiewe studie uitgevoer om die waarnemings en ervarings van stigma en diskriminasie tussen mense wat met MIV en VIGS leef, vas te stel met die doel om strategieë te bepaal binne die ARV kliniek om die situasie te hanteer en die hindernes om dienste te bekom te verwyder. Die studiepopulasie het bestaan uit 5 mans en 5 vroue wat die gesondheidsdienste van die Oshakati ARV kliniek gebruik en wat ARV'S vir meer as een jaar gebruik en tussen die ouderdomme van 20-60 jaar is. Die deelnemers is gekies met 'n doelgerigte steekproeftrekking-benadering en onderhoude is gevoer in die ARV-kliniek.

Die studie het bevind dat die deelnemers interne stigma en diskriminasie wat verband hou met hul MIV-status binne hul gemeenskap en families ondervind het. Hulle het egter nie aangedui dat hulle stigma en diskriminasie ervaar het by die ARV-kliniek nie. Die moontlikheid bestaan dat die deelnemers nie goed bemagtig is om dade van stigma en diskriminasie in gesondheidsdienste te kan identifiseer nie.

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Chapter 1: Introduction and background

1.1 Introduction

This chapter involves the orientation to the study with the description of the research problem, purpose and significance of the study, research methodology, ethical consideration and limitation of the study. Also an outline of the study is given.

1.2 Formulation of the Problem

Background to the problem

Human Immunodeficiency Virus infection and Acquired Immunodeficiency Syndrome (HIV/AIDS) continue to be a major global health priority. Although important progress has been achieved in preventing new HIV infections and lowering the annual number of AIDS-related deaths, the number of people living with HIV continues to increase. AIDS-related illnesses remain one of the leading causes of deaths globally and are projected to continue as a significant global cause of premature mortality in the coming decades WHO (2008). Although AIDS is no longer a new syndrome, global solidarity in the AIDS response will remain a necessity.

Sub-Saharan Africa is more heavily affected by HIV and AIDS than any other region in the world. An estimated 22.5 million people are living with HIV in the region, which are around two thirds of the global total. In 2009 around 1.3 million people died from AIDS in sub-Saharan Africa and 1.8 million people became infected with HIV. Since the beginning of the epidemic 14.8 million children have lost one or both parents to HIV and AIDS (UNAIDS 2009).

Namibia HIV and AIDS epidemic has stabilized over the last few years. Namibia has been monitoring the prevalence of the epidemic every second year through anonymous unlinked sentinel surveillance of pregnant women attending ante-natal care clinics since 1992. The results of the National HIV Sentinel Survey 2010 indicates a slight increase in the prevalence of HIV infections in the country Overall the HIV prevalence of 2010 among pregnant women attending ante-natal care services in the country was 18.8% in comparison to the 17.8% of 2008. While the prevalence rate peaked in 2002 at 22%, the country is now experiencing an

apparent stabilization since 2004 until 2010. The 2010 survey shows an increase of 1% over the 2008 result with no significant difference between the urban (18.5%) and the rural areas (19.1%) The report of the sentinel survey of 2010 is an indication that the epidemic is still much in the country (MOHSS 2010).

According to the President Hifikepunye Pohamba on the launching of the National Strategic Framework for HIV/AIDS and the Second Medium Term Plan for TB Control and Leprosy during 2010 World AIDS Day Commemoration there are more Namibians who have been infected with HIV (Smith, 2010). Therefore effort needs to be made to utilize every skill that the nation possesses to fight against AIDS pandemic.

The theme for the 2010 World AIDS Day was “Addressing stigma and discrimination to prevent new infections”. Stigma and discrimination have been recognized as the greatest barriers to curb the spread of the pandemic.

Research problem

Namibia has a generalized, mature epidemic with HIV primarily transmitted through heterosexual means. The first case of HIV was reported in 1986. It is estimated that HIV prevalence of the general population aged 15 to 49 years in Namibia was 13.3% in 2008/09 (MOHSS, 2009), resulting in around 6,130 AIDS-related deaths in 2008/09 which amounts to approximately 23% of all deaths in Namibia. In the financial years 2008/09, approximately 5,830 people were infected with HIV, with 16 new infections occurring each day (MOHSS, 2009). This steady stream of new infections over a long period of time has resulted in an estimated 174,000 adults and children living with HIV and AIDS in Namibia by the end of 2009. Approximately 250,000 children aged 18 years and younger are orphan or vulnerable (NCP 2006).

The government of Namibia responded by developing strategies/priorities and mechanisms deemed necessary to each stage of the epidemic and tasked various sectors to contribute in combating the epidemic. Namibia adopted a National Strategic Framework for HIV and AIDS 2010/11-2015/16. The National Strategic Framework for HIV and AIDS is a policy and leadership framework to guide all sectors in Namibia as to which HIV and AIDS program that need to implement, for which target population, in order to achieve which results. The National strategic framework is a successor to the Medium Term Plan III which came to an

end in March 2010(Republic of Namibia, 2010 b). The priority of National strategic framework is to prevent the occurrence of new HIV infections in prevention strategy will capitalize and sustain the current trends in the reduction of HIV prevalence among several age groups in particular young age 10-14 and 15-24 years. Intervention targeting behavior, biomedical and structural drivers of epidemic will be intensified and implemented through a combination strategy. The priority will be focused on the drivers of epidemic. These drivers include multiple and concurrent partnership, inconsistent use of condoms, low male circumcision, low level of HIV testing, alcohol abuse, intergenerational sex and transactional sex (Republic of Namibia, 2010,b).

Lack of confidentiality has been repeatedly mentioned as a particular problem in health care settings. Many people living with HIV/AIDS do not get to choose how, when and to whom to disclose their HIV status.

Counseling is done to patients at antiretroviral clinics and also at other health facilities, but still people are talking in the community that nurses are not listening to the patients and they seem not prepared and not well informed. At the clinics and sometimes at health facilities patients are not willing to disclose their HIV status to their partners or friend and also to the family members. Some of these patients can decide not to have treatment supporter because they believe that they are not supporting them. From the look of things it is not clear whether people living with HIV/AIDS get enough information. The media talk about it that HIV-positive people are not willing to share or disclose their status and there is fear to disclose to the family. Fear of stigma and discrimination may be the underlying factor. It is against this background that it is important to know how HIV positive people perceive stigma and discrimination. This will enable understanding and facilitate ways to address their fear of disclosure and access to treatment.

Aim

The study aimed to identify the perceptions and experiences of people living with HIV/AIDS on stigma and discrimination in order to establish strategies within antiretroviral clinic to deal with the situation and eliminate this as a barrier to access of services.

Objectives

In regard to the perceptions and experiences of stigma and discrimination of people living with HIV/AIDS at Oshakati Hospital ARV clinic the study's objectives were:

To identify the perceptions and experiences of stigma and discrimination of people living with HIV/AIDS and receiving ARVs at Oshakati ART clinic.

To describe the perception and experience of stigma and discrimination in the community among patients attending ART clinic at Oshakati Hospital.

To identify and recommend possible ways to reduce stigma and discrimination in Oshakati.

Significance of the Study

The study will bring to light any existing perceptions and experiences of people living with HIV and AIDS with regards to stigma and discrimination in a health care setting and in the community.

The study will benefit the patients and clients because if the solution to stigma and discrimination against people living with HIV/AIDS can be found, then people living with HIV/AIDS will not feel compelled to spread the virus and they may be willing to seek treatment and live positively. They will not be hesitant to disclose their HIV status. Patients and clients will be able to tell their partners and family members about their HIV status, there will be no fear of being harassed or discriminated against. The patients and clients will have opportunities to timely look for medical and social support. To the health workers, they will have better knowledge on how HIV/AIDS is transmitted, develop positive attitude towards people living with HIV/AIDS and will not be overloaded with work as result of decrease in numbers of HIV/AIDS patients and will be motivated to provide adequate care to patients in public hospitals and clinics. To the society at large this will enhance HIV/AIDS prevention as well as proper care and support to people living with HIV/AIDS. By reducing stigma and discrimination it will enable people to protect themselves and others and to cope with HIV infection.

Outline of the Study

Chapter 1: Introduction of the study, formulation of the problem.

Chapter 2: Review of literature

Chapter 3: Aims and objectives of the study, significance of the study and outline of the study.

Chapter 4: The research methodology – designs of the study, study setting, sampling, data collection procedure and data analysis, ethical consideration and limitation of the study.

Chapter 5: Presentation of the findings

Chapter 2: Literature Review

2.1 Introduction

This chapter will deal with literature review related to the study. Relevant literature reviewed is based on presentation and findings of other researches of the same topics. The following literature review will focus specially on studies and literature relating to the issues of stigma and discrimination, the health care provider HIV and AIDS related stigma and discrimination. The review would however be incomplete without an initial discussion on the general aspects relating to HIV and AIDS internationally as well as nationally.

2.2. History of understanding of HIV transmission

Over the past 25 years, there has been an evolution in the understanding of HIV (the virus), of the AIDS epidemic, and of the factors involved in HIV transmission, prevention and care. When AIDS was first detected, it was closely associated with certain sub-population. Epidemiologists identified and labeled them as “risk group”. The enduring responses to this labeling have been systematized stigmatization and distancing. People, who do not identify with these sub-populations or were deemed to be part of them, were ostracized and branded as perpetrators of infection. At the time, the source of an immune system breakdown was unknown and response was based primarily on fear and conjecture. Through the 1980 and into 1990, the new concept of risk factors came into play and led into reconceptualization of HIV regarding “risk situation” (Delor &Hubert, 2000)

2.3. Understanding Stigma and Discrimination

Defining stigma

Stigma refers to the realm of attitudes and perceptions, discrimination related to action and behavior. The word stigma has Greek origin referring to the marks of physical deformities of foreigners or person deemed inferior. Christians gave this word a twist by using it to refer to physical indications of the divine spirit. In modern times, stigma has been defined as “an undesirable or discrediting attribute that an individual possesses, thus reducing that individual’s status in the eyes of society. It is a labeling of an individual or group as different or deviant (Goffman, 1963)

HIV related stigma is multi-layered, tending to build upon and reinforce negative connotation through the association for HIV and AIDS with already marginalized behaviors, such as sex work, drugs use and homosexual and transgender sexual practices. It also reinforces fears of outsiders and otherwise vulnerable groups, such as prisoners and migrants. Individuals living with HIV are often believed to deserve their HIV positive status as a result of having done something wrong. Blame is attributed to particular individuals and groups that are different. Others can absolve themselves from acknowledging their own risk, confronting the problem and caring for those affected. Stigma is deeply rooted, operating within the value of everyday life. Although images associated with AIDS vary, they are patterned so as to ensure that AIDS - related stigma plays into, and reinforces social inequalities. These inequalities particularly include those linked to gender, race and ethnicity and sexuality (Parker and Aggleton, 2002).

Defining discrimination

When stigma is acted upon, the result is discrimination. Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized. Discrimination as defined by (UNAIDS, 2000) in the *Protocol for Identification of Discrimination against people with HIV*, refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only of an inherent personal characteristic or perceived belonging to a particular group; in the case of HIV and AIDS, a person's confirmed or suspected HIV positive status irrespective of whether or not there is any justification for these measures.

2.4 Interrelatedness of stigma and discrimination

Even through the word stigma and discrimination are often used interchangeably, their meanings do differ. Discrimination focus on behavior: the unjustifiably different treatment given to different people or groups (Manser &Thompson, 1999). "Stigma is defined as an attribute or quality which "significantly discredits" an individual in the eyes of others. Importantly, stigma is a process. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy" (UNAIDS, 2002).

Stigma and stigmatization are mostly easily understood as social processes, which play a key role in producing and reproducing relations of power and control in social systems. Stigma is therefore linked to social inequality. Stigma operates in relation to difference. By making social inequalities seem reasonable, it creates and reinforces social exclusion (Policy project, 2003)

Fear and moral judgment are considered to be the root sources of HIV/AIDS stigma. HIV/AIDS is associated with many different fears. People may fear the casual transmission of the virus, fear the loss of productivity of PLHAs, and fear that resources may be wasted on PLHAs, fear living with the disease or fear imminent death. Similarly, moral judgment may cause stigma. PLHAs are often seen as culpable and deserving because the transmission of the virus is linked to stigmatized behavior, which allows people to understand HIV/AIDS in terms of concept of blame. It is important to note that HIV/AIDS because of their associated with HIV/AIDS. Stigma may manifest itself externally or internally and may have different effects. Therefore stigma and discrimination are interrelated, reinforce and legitimize each other.

2.5 Types of stigma

External stigma (enacted stigma) refers to actual experiences of discrimination (UNAIDS, 2000). This may include the experience of domination, oppression, the exercise of power or control, harassment, categorizing, punishment, blame, exclusion, ridicule, or resentment. It may sometime lead to violence against a person living with HIV/AIDS.

Internal stigma (felt or imagined stigma) is the shame associated with HIV/AIDS and PLHAs fear or being discriminated against. Internal stigma is a powerful survival mechanism to protect oneself from enacted or external stigma and often results in the refusal or reluctance to disclose HIV status or the denial of HIV/AIDS and unwillingness to seek help.

AIDS related discrimination may occur at various levels. Discrimination can occur in the family and community setting, which has been described by some writers as enacted stigma. This is what individuals do either deliberately or by omission so as to harm others and deny to them services or entitlements (UNAIDS, 2000).

2.6 Effects of stigma and discrimination.

For most people information on the HIV/AIDS pandemic has been a direct part of their lives to a large extent as students are taught about it at school, and there are endless campaign about it on the radio and Television, dramas and other flora. The Government of Namibia and Nongovernmental organizations have done their part to educate the nation about HIV and AIDS and yet it seems after everything that has been said and done stigma and discrimination still remain a big problems and barriers to winning the war against the epidemic.

AIDS related stigma and discrimination can result in those living with virus being shunned by family, peer, and the wider community , poor treatment in health care and education setting, human right violation, psychological damage and can negatively affect the success of testing and treatment. People are discriminated and stigmatized against even in corporate world nowadays. HIV has become very manageable and people can live with the virus for more than ten years and yet some Insurance companies do not provide life cover to people who are HIV positive. In certain institution HIV testing is a prerequisite for employment and people who test positive are not recruited (Antoinette, 2010).

2.7 Action done to address stigma and discrimination.

Stigma lies at the root of discriminatory actions, leading people to engage in action or omission that harm or deny services or entitlement to others. According Malcolm (1998) discrimination can be described as the enactment of stigma. In turn, discrimination encourages and reinforces stigma. Discrimination is a violation of human rights. The principle of non discrimination based on recognition of the equality of all people, is enshrined in the Universal Declaration of Human rights and other human rights instruments (UNAIDS, 1999). These texts prohibit discrimination based on race, color, sex, language, religion, political or other opinion, property, birth or other health status including HIV/AIDS. Thus discrimination on the basis of actual or presumed HIV positive status is prohibited by existing human rights standards. There are many direct and indirect links between the HIV epidemic and lack of protection of human rights. Violation of rights may worsen the impact of HIV, increase vulnerability, and hinder positive response to the epidemic (UNAIDS, 1999)

In 2008 Ho Chi Minh City conducted a study on stigma and discrimination against people living with HIV/AIDS in Vietnam and it reveals that people in Vietnam who are HIV positive are facing problems because of propaganda associating HIV with social evil of sex workers or drugs (Anah, 2008). There was little understanding of the causes and consequences or effects of stigma and discrimination on People living with HIV. Nearly all participants in this study experienced stigma and discrimination in their lifetime.

According to Herek (1999) HIV/AIDS stigma is a problem in the Unites State and throughout the world, stigma has expressed in a variety of ways, including ostracism, rejection and avoidance of people living with HIV/AIDS, discrimination against people living with HIV/AIDS by their families, health care professional, communities and government, mandatory testing of individual without consent or confidentiality protection etc.

In Australia and New Zealand regular studies are undertaken to evaluate the living conditions, stigma and discrimination experienced by people living with HIV/AIDS .The purpose of the study conducted in Australia and New Zealand on stigma and discrimination of HIV positive people was to examine the extent to which stigma and discrimination occurs and to observe the impact that it has on the quality of life of people living with HIV. This provides opportunity for the voices of people living with HIV/AIDS to be heard, allowing them to contribute to address HIV/AIDS related stigma and discrimination (Roger, 2007).

Once identification of HIV infection has occurred, health –seeking behavior and planning for the future becomes possible. Ideally, HIV positive individuals notify their partners, families, and wider community, adopt safe behaviors to avoid further transmission, and receive care, understanding and support in return. In reality persons infected with HIV/AIDS bear the burden of societal hostility at a time when they are most in need of support (Herek and Glunt, 1988). The result are varied and numerous. HIV infected people do not seek available care option, they are treated disrespectfully or denied services at health care facilities. They receive treatment only at late stages for isolating cases of opportunistic infection rather than being treated holistically with whatever medical and psychosocial care model are locally available. They are unable to plan for the future with the participation of their dependents’ and in interaction with their wider communities (Gilmore and Somerville, 1994; Gruskin, and Tomasevski, 1996; Malcolm, 1988).

In Africa a population based study conducted in Botswana on adults in 2006 to assess knowledge and attitudes toward routine testing and correlations of HIV testing revealed that most of the participants were in favor of routine testing, but need protection from HIV-related discrimination (Weiser, 2006).

Stigma and discrimination continue to affect people living with AIDS to the end of their life, hampering the ability of the community to normalize the disease and integrate it into shared coping strategies as might occur with other terminal illnesses. If care and support mechanisms are not present or people are too afraid to utilize them, communities do not address the issues surrounding HIV nor are they exposed to People living with HIV before the most debilitating phases of their illness. Not only is this detrimental to people living with HIV, but it interrupts the cycle where care can directly influence future prevention (MacNeil and Anderson, 1998). People living with HIV, who are acknowledged, visible and accepted in their communities do much to aid ongoing prevention efforts within the community (MacNeil and Anderson, 1998). Not only does familiarity with people living with HIV personalize the risk for others and stimulate behavior change, good care and support programs demonstrate how casual contact with people living with HIV is safe. Experience from throughout the world indicates that knowing someone with HIV/AIDS can have a strong prevention impact, but when care and support are lacking, people tend not to reveal their HIV status. As a result, opportunities to facilitate prevention are lost. Similarly, care helps people and their family plan for the future, for bereavement and for the economic security and social arrangement for dependents (MacNeil and Anderson, 1998).

Article 10 in the Namibian Constitution spells out equality and freedom from discrimination and it says all person shall be equal before the law and no person may be discriminated against on the ground of sex, race, colour , ethnic origin, religion , creed or social or economic and HIV/AIDS. The Namibian National HIV/AIDS Policy also prohibits discrimination that HIV/AIDS shall not be used as reason for denying an individual access to social services including health care, education and employment. The policy states that people living with HIV/AIDS shall not be discriminated and privacy and confidentiality shall be upheld. Social workplace policies shall be put in place that effectively address discrimination on the basis of HIV/AIDS and take steps to effectively eliminate stigma and discrimination in all their institution and in the implementation of sectoral mandate (Republic of Namibia, 2007).

In Namibia discrimination against people living with HIV/ AIDS still continues despite efforts made by the government to prevent it. People living with HIV/AIDS are considered by some to be sinners or people who are about to die. They find it difficult to disclose their status because they run the risk of losing family support and being regarded as prostitutes (Republic of Namibia, 2009). According to Kennedy (2010), a senior in-house trainer at Positive Vibes, an innovative HIV and AIDS Communication Initiative based in Namibia as reported in the Southern Times, a lot needs to be done to fight stigma and discrimination in Namibia. He pleaded with the National leaders to take a lead against stigma and discrimination as societies will follow if its leaders take the lead. He also said if the leaders who are HIV positive come out of their communities it will help in the fight against stigma and discrimination. Stigma not only makes it difficult for people trying to come to terms with HIV and manage their illness on a personal level, but also interferes with attempts to fight the pandemic. On a national level, the stigma associated with HIV can deter the government from taking fast, effective action against the epidemic, whilst individuals become reluctant to access HIV testing, treatment and care. Stigmatization help make AIDS the silent killer because people fear the social disgrace of speaking about it or taking easily available precaution. Stigma is the chief reasons why AIDS epidemic continued to devastate societies in Namibia.

Chapter 3: Methodology

3.1 Introduction

This chapter introduces the methodology used to carry out the research. Research methodology include study design, data collection and data analysis, validity/rigour of the study, ethical consideration and limitation of the study.

3.2 Research design

An exploratory approach was used to conduct the study. This method is used in attempt to gain insight into a particular area of a problem (Bless and Higson-Smith, 1995). It is considered relevant since the study attempted to get some insight into what HIV positive people perceive as stigma and discrimination and their experiences thereof.

The study is qualitative in nature. Qualitative data are those pieces of information which are non-statistical in nature and which are generally observational data analysed in a non statistical manner (Bailey, 1987). It takes place in the real life of the participants.

According to Creswell (2003), qualitative research collects participants' meanings, focuses on a single concept or phenomenon, studies the context or setting of participants, makes an interpretation of the data and creates an agenda for change or reforms. According to Terre Blanche and Durkheim (1999), when the aim is to study phenomenon as they occur in real world situation without manipulation of variables to determine a cause-effect relationship, then the appropriate approach to use is qualitative research.

The purpose of this research was to gain an understanding of what HIV positive people perceive as stigma and discrimination and their experiences. Consequently direct contact with HIV positive people would be the most feasible option. Such interaction can be better done using a qualitative methodology. Looking at the nature of this study, it can clearly be seen that it would not be suitable to use a quantitative methodology with structured questionnaire which may not capture all information needed to answer this important research question. As a result, the researcher chose qualitative research that could allow an interview schedule to be used as a method of data collection, without restricting participants to responses and allow

probing and follow up on responses. Furthermore by using individual semi-structured interview it will enable the researcher to obtain a great deal of useful information and produce a most useful individual opinion (Katzenellebogen, Joubert and Karim, 1997). Interviews also assist in building rapport and empathy; it allows for flexibility in the direction of the interview and as a result produces richer data (Blanche and Durkheim, 1999). Therefore an interview schedule was designed for this study to test the perceptions and experiences of stigma and discrimination of people living with HIV/AIDS at Oshakati Hospital ARV clinic.

3.3 Study setting

Namibia is located on the southwestern coast of Africa. It borders Angola and Zambia to the North, Botswana to the east, the Atlantic Ocean to the west and South Africa to the south. It is ranked as a lower middle income country (MOHSS, 2003). The estimated population (for 2011) is 2,031,000 (Government of the Republic of Namibia, 2002).

Namibia consists of 13 administrative/political regions. This study was conducted in Oshana region, which has an area of 5290 square kilometers and located at the northwest part of Namibia, in the peri-urban area of Oshakati. Oshana is the smallest region, with 161916 populations, whereby 73957 are men within the age 15-59 years of 56% and 93% of the population is Oshiwambo speaking, black people (Government Republic of Namibia, 2001) Oshakati ART clinic is situated within Oshakati Intermediate Hospital which is a referral hospital for four other regions, which are Omusati, Ohangwena, Oshikoto and Kunene. According to the Namibian sentinel survey 2010, HIV prevalence in Oshakati is among the top highest in the country at 25.1 % among pregnant women attending ante-natal clinics. Oshakati Hospital ARV clinic started in 2004. About 9184 people are receiving ARV treatment at Oshakati Hospital ART clinic, of which 6085 are female and 3099 male patients (Oshakati ART clinic Annual Report of 2010).

3.4 Study population and sample

According to Brink (1999) a population is the entire group of people or object the researcher wishes to study provided that they meet the criteria of the study. Oshakati Hospital ARV clinic has been on existence since in 2004. There are more than patients on ARV. The study

population of this study included HIV positive people who came to ARV clinic at Oshakati Hospital and they have been on ARV for more than one year. The sample comprised 5 males and 5 females who were willing to share their experiences with the researcher. It was a voluntary exercise; all patients at the clinic were informed about the purpose of the study and only those who volunteered participated. The clinic was chosen as it was easy to get the participants and suited the limited resources of the Researcher due to its proximity.

3.5 Sampling design

A non probability, purposive sampling method was used to select the study participants. HIV positive people who are on ARV for more than a year were purposively selected since they have experience of the situation and should be able to give more information concerning stigma and discrimination experience in community and in the health care set up. According to Brink (1999) the method is advantageous as it allows the researcher select the sample based on the study topic.

Criteria for sample included:

- Must be HIV positive
- On ART for more than a year
- Attended to at Oshakati Hospital ART clinic
- Able to physically and mentally participate in an interview
- Gave informed consent

3.6 Data collection

Data Collection Procedure

Data were collected on the 27-28 December 2010 through face to face in-depth interview using an interview guide with semi – structured questions. The interviews were held at Oshakati Hospital ART clinic in one of the consulting room. The venue was more convenient for participants and it was quiet and private. The interview took 45-60 minutes for each study participant. The researcher used the interview schedule to guide the interview process. All interviews were conducted by the Researcher in the local Oshiwambo language and later translated from Oshiwambo to English. Interviewers were asked to sign informed consent

forms which informed them about the aim and the process of the research. The procedures which would be followed during the interview were explained to the participant before the start. It also reinforced the fact that participation in the interviews was voluntary and that the participant could stop the interview at any point and no negative consequences regarding their care in the ARV clinic would occur as a result. None of the selected participants refused to participate or terminated the interview before conclusion. Permission to tape-record the interviews was requested and given and the interviews were tape-recorded in addition to the notes taken by the interviewer.

Data collection Instruments

An open interview guide was developed to allow participants to respond to the study topics. Interview guide allows participants more flexibility to express all what they know, richer information can be provided and more probing can be done to get more deeply what the respondents think (Giddens, 1999)

3.7 Data analysis

According to Patton (1990) qualitative data analysis is the process of systematically organizing the interview transcripts, field notes and other accumulated material until they are understood in such a way they address the research question and present the result and create understanding to others. Marshall and Rossman (1995) describe it a process of bringing order, structure and meaning to the mass of collected data. The researcher will go through different stages of analysis before the report is produced. At first data will be coded to form different categories and subcategories of the main themes from the raw data. Thematic content analysis which involves identifying, themes from the primary patterns in the data will be used to analyse data (Patton, 1990). According to Burnard (1991) the purpose of qualitative analysis is to produce a systematic recording of the themes and issues to be discussed in the interview and to link the themes and interview under exhaustive categories. By adopting Burnard `s model the researcher went through the following stages:

The researcher listened to audio tape after interview, did the transcription through listening repeatedly to the tape; went through the notes and read through the response; and identified the main themes and grouped the themes in hierarchy. The data was therefore manually analyzed by the researcher and no specific qualitative data analysis software was employed.

3.8 Validity / rigour of the study

Validity in qualitative research is concerned with the accuracy and truthfulness of scientific finding (Le Competed et al, (1992) cited in Brink (1999)). If the soundness of the qualitative research is to be measured Gifford (undated) suggests that judgment should be based on credibility, transferability dependability and conformability. The tool used to collect the data was reviewed by experience researchers, this was necessary to ensure that the tool really measured what is intended as per objectives. Ms J. Mutileni a Language Lecturer at the University of Namibia assisted in translation of the tool to the local Oshiwambo language as well as in translating the data collected into English language.

Credibility

Providing a thick description rich in information related to the study enhanced credibility of the study. Suitable participants were identified and their description given before interview. The researcher introduced the aim of the study to the participants and asked permission to participate in the study. This was done to build up a good trustful relationship which could increase the willingness to participate and give information. The interview was tape-recorded and notes taken to ensure that information provided were not missed. The recorded transactions were later transcribed into English language.

Transferability

Transferability refers to the degree to which the result of a study can be generalized to setting or sample other than the one studied (Brink, 1999). The researcher ensured transferability by describing the study setting and participants. This will make it possible for the results to be applied to other similar context. However, as this was an exploratory study, more studies may need to be done to validate the findings from this research in Namibia.

Dependability

Dependability was achieved by maintaining reflexivity. Non – verbal cues of respondents were noted and followed up by the researcher during the interview to enrich the process.

Confirmability

According to Gifford (Undated), confirmability has to do with the collect data whether they are real and not produced by the researcher being biased. The transactions during the interviews were tape-recorded in addition to the notes taken by the researcher.

3.9. Ethical consideration

Permission to conduct the study.

Ethical clearance was received from the University of Stellenbosch Research Ethics Committee. Prior to data collection, the researcher obtained permission to conduct the research from the Permanent Secretary of the Ministry of Health and Social Services in Namibia and from the management of Oshakati Intermediate Referral Hospital where the research was carried out (*See Annexure A B, and C*).

Right to full disclosure

The aim and benefits of the study was explained to participants. Prior to the start of the interview, signed consent was obtained from each participant (*See Annexure D*).

Freedom from exploitation

Participants were informed that participant could also withdraw from the study any time. The estimated time that was required for the interviews was also mentioned to each participant. The expected benefits of the outcome of the study were discussed with the participants.

Right to confidentiality

Any information that obtained in connection with the study remains confidential and will be disclosed only with participants' permission or as required by law. No names or other personal details appeared on the questionnaire. The collected data is kept in the computer and in memory stick with password known only by the researcher. The researcher and the principal investigator have access to the data. The finding of the research study will be presented in a report without identifying participants' names and with permission granted by the Ministry of Health and Social Services. Data which was audio-taped during the interviews will be erased at the completion of the research process.

3.10. Limitations of the study

Data collection was limited to 27-28 December 2010 and it is a limitation because it was during the holiday period and those who were interviewed were those who came to the clinic during that period. Data were collected only at the Oshakati Hospital ARV clinic which does not represent the entire population of Oshakati. The other limitation is that since the interviews took place within the ARV clinic participants may not want to say anything against the clinic staff and may have some fear to tell the truth.

Lack of funds and time hampered the extent of the study in terms of the number of study sites and number of study participants. The interview was done in local language and the researcher with assistance translated the participants' responses into English. It is a limitation because some words may change or words may not have a direct English translation.

Chapter 4: Presentation of findings

4.1. Introduction

The purpose of this chapter is to present the results obtained from the interview held with the study participants. A description of the demographic approach to the analysis of the data will be given. The identified themes which emerged from the analysis will be focused on. The quotes used are presented verbatim to support the findings of the research. Finally, a brief summary of the main findings will be given.

4.2 Socio-demographic information

Five males and five female clients were interviewed. All are HIV positive and have been on ART for more than a year and used to be attended to at Oshakati ARV clinic. All were able to participate in the interviews and gave informed consent. Their ages ranged from 22-60 years. They further indicated that they have live in Oshana Region for the last one year. Six participants were unemployed while four were employed. Three are married and seven are single.

4.3 Results

An interpretative phenomenological analysis was concluded using transcripts of 10 participants. The analysis focused on how participants in the study make sense of their personal and social world as their perception and experiences of stigma and discrimination in the ARV clinic and in the community may occur. The focus is placed on the meaning that experiences, events or state holds for participants. The participant's personal perception or account is the focus rather than attempt to produce an objective statement (Smith and Osborn, 2004). This particular type of analysis has been chosen since the research came to understand how PLHAs experience the healthcare setting by looking at their experience in this setting. The analysis provided access to the experiences of PLHAs within health care clinic. The study provided access to other experience which were stigmatizing for the participants. Two themes emerged from the data analysis and twelve sub-themes. The themes cover internal stigma and external stigma of the experienced by participants in the community and in health care setting, as well as suggestions for elimination of stigma and discrimination.

External (enacted) stigma

External stigma refers to the actual experience of discrimination. Included are avoidance, rejection, moral judgment, and stigma by association, unwillingness to invest in PLHAs, discrimination and abuse.

Avoidance included the following: not sharing objects, social distancing, physical distancing, distancing from family and friends of PLHAs. All the participants indicated that they have experienced some forms of avoidance by family and community. One participant indicated that he experienced negative response in the community as “*some people are laughing at us and talking bad things at us*”

Rejection include the following: being abandoned by significant others having to leave social, organization setting after disclosure, pressurized to leave place of residence, not welcoming PLHAs into the home. One participant experienced rejection by health care provider:

“Some health care providers behave in a rude way to us.”

“*Some PLHA are not accepted in the community*”, noted another participant who might have experienced or perceived rejection by the community members.

Moral judgment include the following: blaming where PLHAs are perceived as innocent or guilty based on their behavior and perceived responsibility, judging PLHAs base of religious beliefs or values as immoral. One of the participants experienced moral judgment: “*PLHA are regarded as don’t care because of being HIV positive*”

Stigma by association include: people who are stigmatized based on association related to HIV and AIDS.

One participant referred to herself as being recipient of this type of stigma:

“One day a neighbor came to me and say, oh why are you killing yourself, you don’t look healthy” reported the participant.

Abuse includes verbal abuse such as name calling, insults and threats and physical abuse.

Four participants indicated that they experience verbal abuse in different forms in the community.

“Some people are shouting at me like ah this one is already dead”.

“Some people are laughing and say bad things to us”

A brother of mine who shouted at me by saying “Hey you, who have AIDS”,

Internal stigma

Experience referred to the shame associated with HIV and AIDS and the fear of being discriminated against indication of this type of stigma included negative perception of self, social withdrawal and fear of disclosure, overcome compensation.

Negative perception of self refers to a low self as a result of being HIV positive.

Participant reported experience low self esteem and guilt feelings.

“I almost committed suicide by attempting to take tablets”.

“I am feeling bad because I am no longer healthy like before.”

These participants have low self esteem because they have some fear they can feel sick anytime.

“*Nurses feel empathy*” it means already the participants display issue of low self esteem.

“*Where this virus did come from*” This participant has self doubt.

Negative perception of self and guilt feelings was also revealed in the transactions from the participants “*I am still angry up to now*”

“It is part of life it can happen to you.”

Social withdrawal includes little interaction with people as a result of the HIV positive status. PLHAs choosing not to have intimate relationship and less interaction with HIV negative individual. PLHAs feel they are not accepted in the community: “*Still PLHAs are not accepted in the community*”s one participant stated portends the tendency of HIV positive people not to associate with others in the community because of perceived or internal stigma.

Fear of disclosure includes disclosure to sexual partner.

“*Even now people are afraid to come for HIV test*” as one participant noted indicates fear of disclosure may be common among the participants.

Over compensation: This means to contribute more which may include working harder or making more of an effort than people who are not living with HIV/AIDS. “*I used to pray to God to help*” reported one participant. Most of the participants did not seem to experience enacted stigma from the health workers. The participants reported that they think no other factors such as gender or age or ethnicity are considered by the healthcare workers when they

are treating them. Participant further explained that the positive things and initiatives done in the community to support PLHAs in the community for example income generating projects, awareness information about HIV/AIDS, free treatment in health facilities and provision of ARVs have gone a long way to assist them and improve their feelings and outlook in life.

Suggestions by participants to address stigma and discrimination

The participants suggested what to be done in order to remove stigma in the community. Examples are:

- Awareness campaign against stigma and discrimination in the community should be on going
- People should be educated to accept PLHAs as normal human being without discrimination
- There should be an office to report cases of stigma and discrimination so that culprit will be persecuted.
- People need information so that they can respect PLHAs
- Involvement of media in fighting against stigma and discriminations
- Case of stigma and discrimination should be reported to the headmen and relevant authority
- Meeting with community members and give them information about stigma and discrimination of PLHAs
- Law need to be passed to protect PLHA against stigma and discrimination
- Those who have negative attitude against PLHAs need to be told so that they will stop.

Chapter 5 Discussion, conclusions and recommendation

5.1. Discussion

According to Lesta (2005) in phenomenological research separating the discussion of the finding from the presentation of the findings allows one to intrude into the study through interpretation and linkages relating to the finding to previous research, personal experience or common sense. The following chapter will therefore include a discussion of the findings as presented in the previous chapter, the implication of these findings, and recommendation for future research.

In the discussion of the results the following items will be discussed: the experience of HIV and AIDS as an illness, experience HIV in the community, experience of stigma in the clinic. It is evident from the results that PLHAs do not experience HIV and AIDS in the same manner although some similarities do occur. Mickelson (2000) and Pinel (1999) conclude from their studies that individual do not experience stigma uniformly although they have the same socially stigmatized stressor.

Both internal stigma and enacted stigma were identified. In term of enacted participants provide examples that included avoidance, rejection, and moral judgment, stigma by association, discrimination and abuse. In term of internal stigma participants provided examples such as negative perception of self, social withdrawal, fear of disclosure and overcompensation.

Some participants interviewed reported they did not experience stigma and discrimination. Participants indicated that there are positive things in the community that are supporting PLHAs. Examples cited included projects in the community and awareness campaigns to educate the people. Some participants indicated that doctors and nurses are treating them very well at the clinic, some show support and empathy. However this can be seen from two angles: it might be that they don't want to say anything bad about the nurses and doctors. PLHAS are likely to hold negative view of HIV as an illness and themselves due to them internalizing the stigma associated with the illness. Various studies indicate that PLHAs experience stigmatizing behavior and attributes in the health care setting they have attended

(Bond, 2003; Niang 2003; Bond 2002) in their studies reported that amongst the forms of stigmatization reported were denial of drugs and treatment, being dealt with last and this was also supported by one of the participant in this research who reported that health workers sometime treat those whom they know first.

This study also found that the participants reported that the health workers feel empathy for the PLHAs. Two studies in Scotland support the positive experiences the participants in the present study have had in health care centre. In study conducted by Green and Platt (1999) results indicated that as health care professional become familiar with treating HIV patients the stigma appeared to decline. The positive experience could be as a result of the health care workers gaining experiences in dealing with HIV and therefore treating them well. The Oshakati Hospital ARV clinic has been on existence since 2004.

In terms of abuse it was found out that participants are being abused in the community and called names, for example “don’t care” and labeled by others as the people who spread the disease. According to Kalipeni et al. (2004) and Nord (1997), PLHAs have struggled with process as long as the illness has been around. Goffman (1963) says that stigmatized individuals are seen as having a spoiled identity and as possessing an undesirable difference. Parker and Aggleton (2003) add to this by saying that stigma reproduces relations of power and control which result in some groups being devalued and others feeling superior.

The findings also indicate that participants have a problem in disclosing their HIV status. This was also noted in the study done by Chin and Kroens (1999) which looked at disclosure among HIV-positive American women. It was found out that there was fear of stigmatization which influenced individual to not disclose her status.

5.2 Conclusion

The findings from the study show that PLHAs attending ARV clinic at Oshakati Hospital do not feel much stigmatized or discriminated against in the clinic they attended. They do however feel that there is stigma related to HIV and AIDS within the community. Some of them revealed internal stigma such as low self perception, guilt feelings, and overcompensation. A lot is being done in the health facilities and in the community to educate the people on HIV/AIDS. Further research needed to determine the extent of stigma

in the community. Research is also needed to understand the extent to which PLHA understand and can identify various acts of stigma and discrimination especially in the health care facilities. The results of this study provide information how PLHAs experience and perceive of the illness which they have.

5.3 Recommendations of study

There is a need to develop strategies to address stigma and discrimination in the community. Various structures example the MOHSS (Ministry of Health and Social Services), Ministry of Education, Ministry of Information and Broadcasting, Ministry of Justice, Community leaders, Regional AIDS Coordinating Committees, Support Groups, Development partners, NGOs/Community Based Organizations, People living with HIV and AIDS, the government should develop a comprehensive approach for breaking the cycle of stigma and discrimination and internal stigma. There are keys strategies to address stigma. For pre existing stigma there is a need to sensitize the key professional and community leaders. This was supported by one of the participants. There is a need to enhance visibility of positive image of population affected by HIV and people living with HIV. Emphasis should be put on public sanitization and focusing on prevention campaign.

For HIV related stigma there is a need for information packages developed for specific group, training and capacity building of key professionals and community organization, model development of better or promising practice. For enacted stigma there is need for political leadership in the community as well as institutions and organization, affirmation of policy, code of ethics and good conduct and intervention related to positive prevention. To address discrimination there based on human rights as a conceptual base by building capacities related to knowledge of rights, gender, documenting violations and presenting and defending complains, strengthen capacities related o advocacy and documenting examples of laws and policies as promising practice, develop effective system of lodging and dealing with complains as this was also supported by one other participants. Improving media coverage and response, Imposing sanctions for non compliance of laws and regulations, develop policies and regulations of testing and confidentiality. Internal stigma , internalization of context there a need to built capacities in areas related to personal growth and increasing self esteems and sense of worth, improving individual social capital. In the context of self perception when participants felt shame ,guilty and fear there is need to ensure quality of care

using a holistic approach and build personal capacity for economic independent and maintain confidentiality in the work place. In the case of protection action there is need to provide more positive role model, build leadership skills and strengthens self support groups. The results indicate that the participants in the study experience stigma to a large extent in the community and in the families. Future research could therefore focus on stigma experience in the community and family and how PLHS deal with it. The participants in this study indicated that nurse and doctors were very helpful to them, but it might be that they do not want to say anything bad about health workers since the interview was done at the clinic. The interview done might have an impact on individual how they understood stigma and discrimination. It therefore advisable to held the interview at different venue in any future.

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Enquiries:	Ref:	Date: 05 November, 2009
<p>Ms. Loide Nghifikwa PO Box 2696 OSHAKATI</p> <p>REQUEST TO CONDUCT A RESEARCH</p> <p>Your letter on the above issue refers.</p> <p>The Intermediate Hospital Oshakati Management granted you a permission to do your research, on condition that you must adhere to the rules and regulations of the institution.</p> <p>During your practice period, you must under the supervision of the Registered Nurse in charge of the section concern.</p> <p>Yours Sincerely</p>  <p>DR SHANNON KAKUNGULU MEDICAL SUPERINTENDENT</p> <p>Cc: CCRN Registered Nurse in charge of the Section</p>		

Medical Superintendent: Dr. Shannon Kakungulu Chief Control Registered Nurse: Ms. Kashupi Hilina Chief Control Officer: Mr. Ifingula Ben

STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

THE PERCEPTION OF EXPERIENCE OF STIGMA AND DISCRIMINATION OF HIV POSITIVE PEOPLE AT OSHAKATI ARV CLINIC

You are asked to participate in a research conducted by Mrs Loide Nghifikwa, an Mphil student in HIV/AIDS Management from Africa Centre for HIV/AIDS Management, Department of Industrial Psychology and the Principal Investigator, Dr. Thozamile Qubuda at the University of Stellenbosch.

PURPOSE OF THE STUDY

To explore the perceptions and experiences of stigma and discrimination by people living with HIV at Oshakati ARV clinic.

PROCEDURES

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

To feel free and answer all the questions, ask me to repeat the question where you don't understand. The interview will take place here at the clinic in one of the consulting room and you will be interviewed one by one. The interview will take approximately 45 minutes long.

POTENTIAL RISKS AND DISCOMFORTS

There are no risks associated with the research interview schedule apart from certain question that might be uncomfortable to answer. The session will be taped which might cause a certain level of discomfort. Stigma and discrimination is a sensitive issue to be discussed and most people may feel uncomfortable to reveal their experiences and perceptions and sometimes it

can be emotional. You are encouraged to feel free and express your feelings and opinions on the issue. You are rest assured that confidentiality will always be maintained.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

You will derive no personal benefit from the study. Your participation will benefit you and others by enabling decision makers to learn more about the perceptions and experiences of stigma and discrimination of people living with HIV/AIDS at the clinic and in the community. Additionally it may assist you to better understand stigma and discrimination in the community. This information may also help in the development of guidelines or strategies to mitigate the impact of HIV/AIDS stigma and discrimination at the clinic and in the community.

PAYMENT FOR PARTICIPATION

There will be no reimbursement for participation, although the information you provide will benefit you and others by enabling decision makers to learn more about the perceptions and experiences of stigma and discrimination of people living with HIV/AIDS at the clinic and in the community. Additionally it may assist you to better understand stigma and discrimination in the community.

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 and no names or other personal details will appear on the interview question. Data will be kept in the computer and memory stick with a password.

The researcher and principal investigator are the only people that will have access to the data collected. The findings of the research study will be presented in a report without identifying you by name and with the permission granted by the Ministry of Health and Social Services for the benefit of improving the health care delivery of people living with HIV/AIDS. Data

will be audio-taped and only the researcher will be allowed to review and edit the recorded tape. After data analysis the data in the tape will be erased.

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.

IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Mrs Loide Nghifikwa on (26465) 222851 .cell 264812470759, or Dr Thozamile Qubuda, on (021) 8083999, e mail tqubuda@sun.ac.za

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 Malenè Fouchè (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*, ----- by Mrs Loide Nghifikwa in Oshiwambo /English and I am command of this language or it was satisfactorily translated to *me*. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

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

Name of Participant

Name of Legal Representative (if applicable)

Signature of Participant/legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____.
[He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in (Oshiwambo and *English*). No translator was used/ this conversation was translated into -----by-----.

Signature of Investigator

Date

Interview schedules

The perceptions and experiences of stigma and discrimination of people living with HIV/AIDS at Oshakati ARV Clinic.

What are your views about HIV and AIDS?

What do you think influenced you to hold these views?

Is your views shared by others in the community?

What are some positive things in the community that are supportive of PLHAs?

What are some of the negative things in your community that are against PLHAs?

How about at Oshakati ARV clinic here?

What are some specific treatments you have had at Oshakati ARV clinic?

Mention some treatment provided by nurses, physicians, other health care providers

Are women treated differently? Explain, support?

What about men? Explain, support

Tell me more about a situation whereby you have been mistreated and discriminated because of being HIV positive and how were you feeling?

To what extend do you think health care personnel consider factors like gender when treating you?

a. Are there other factors do you think health care personnel consider?

b. Is there a health care facility that you consider is more friendly and helpful towards PLHAs?

How do you think health care provider feels toward PLHAs?

What are some positive or negative feelings?

What should be done to remove the negative feeling towards PLHAs?

What should the community do to remove discrimination against PLHAs?