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DELAY TO ACCESS ANTIRETROVIRAL THERAPY IN PEOPLE LIVING WITH HIV/AIDS IN POTCHEFSTROOM.

DIRIISA SEMAKULA

A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, in the fulfillment of the requirements for the degree

of

Masters of Family Medicine

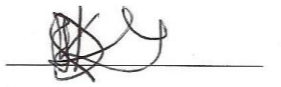
Johannesburg 2010

SUPERVISOR'S NAME: Dr. Claire Van Deventer

DECLARATION

I, **Diriisa Semakula,** declare that this research report is the result of my own work. It has been submitted for the degree of Masters in Family Medicine, to the University of Witwatersrand, in Johannesburg. This research has never been submitted before for any other examination or degree at any other institution or University.

An approval from the ethics committee for research on Human Subjects (Medical) was obtained upon submission, and the approval number is **M090479**.



DIRIISA SEMAKULA

ABSTRACT

Background: The government of South Africa rolled out free anti-retroviral treatment in 2004 but many people living with HIV still present late for treatment while others choose to die rather than accessing this free treatment. This qualitative study was done at Potchefstroom Provincial Hospital Wellness Clinic to establish why many people living with HIV in Potchefstroom present late for treatment.

Aim: To establish why people living with HIV/AIDS in Potchefstroom delay in accessing antiretroviral therapy.

Objectives: 1.To conduct interviews with selected patients, in order to understand why they delayed accessing antiretroviral treatment**.**

2. To assess the demographics of patients who delayed in accessing antiretroviral treatment.

Methods: This is a qualitative study carried out at the Wellness clinic of the Potchefstroom provincial hospital in the North West province of South Africa. Eight adult participants (3 females and 5 males) were interviewed individually in English, in one-on-one free attitude interviews and the conversations were audio-taped by the researcher. All the respondents were from the nearby black township of Ikageng. The respondents were selected after meeting the inclusion criteria of the study.

The researcher asked the respondents to freely describe the reasons why they started antiretroviral treatment late. In addition, a semi-structured open ended questionnaire was also used by the researcher to prompt responses. Interviews went on until saturation point was reached.

The audio-taped interviews were transcribed verbatim and the responses were analyzed. Responses from the different participants which bore similarity were assigned a similar color code. By using the cut and paste method, all responses bearing the same color code were pasted on one page resulting into the themes.

Results: Four broad themes emerged as the reasons responsible for the late accessing of ART by the respondents. These themes were: **1. Stigma and discrimination, 2. Ignorance and lack of perceived risk of infection, 3. Denial, and 4. Health care system constraints.**

Conclusions: This small study though not exhaustive by any means, has highlighted some of the reasons why people living with HIV present late for help. The study was done using participants from only one peri-urban population. It is therefore not easy to generalize the results to the whole of South Africa, a country with a lot of social and economical diversities among its people. A bigger study over a wider geographical area might reveal different findings.

ACKNOWLEDGEMENTS

I would like to thank the management of Potchefstroom Provincial hospital and the Northwest Provincial department of health for having granted me permission to carry out my study at Potchefstroom Hospital Wellness Clinic.

I am also grateful to the whole staff of the Potchefstroom Wellness clinic especially Mr. George Nkosi who helped me with the selection of participants. Matrons Dlhamini and Letshwenyo; and Sister Motsamayi for all the support and encouragement they offered me.

Many heartfelt thanks to my wife and children who have sacrificed and suffered a lot to put up with me during the process of this research.

I am eternally grateful to my Supervisor, Dr. Claire Van Deventer whose guidance and direction as well as encouragement has enabled me to shape and carry out this study to its conclusion.

Most of all I would like to extend my sincere gratitude to those patients who agreed to take part in this study for without their participation all this would have come to naught.

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ABBREVIATIONS USED IN THE STUDY

AIDS: Acquired **I**mmuno-**D**eficiency **S**yndrome.

ART: Anti-**R**etroviral **T**herapy/ **T**reatment.

ARV's: **A**nti-**R**etr**o**virals.

HAART: **H**ighly **A**ctive **A**ntiretroviral **T**herapy/**T**reatment

HIV: Human **I**mmuno-deficiency **V**irus

HREC: Human **R**esearch **E**thics **C**ommittee.

PLWHA: People living with HIV/AIDS.

TB: Tuberculosis

WHO: World **H**ealth **O**rganization.

INTRODUCTION:

This qualitative study was done at Potchefstroom Wellness Clinic the **aim** of which was **to establish why people living with HIV/AIDS in Potchefstroom delay in accessing antiretroviral therapy** despite the fact that the government of South Africa has made antiretroviral treatment free to all who need it throughout the country since 2004.

The **objectives** were: 1) to conduct interviews with selected patients, in order to understand why they delayed accessing antiretroviral treatment**.** 2) To assess the demographics of patients who delayed in accessing antiretroviral treatment.

Importance of the study

By the end of 2005, there were five and half million people living with HIV in South Africa, and almost 1000 AIDS deaths occurring every day[1]. 71% of deaths among those aged between 15 and 49, are caused by AIDS[2]. So many people are dying from AIDS that in some parts of the country, cemeteries are running out of space for the dead[3].

Although the government of South Africa has rolled out free anti retroviral treatment since April 2004[4] at many primary health care facilities all over the country, many patients still seek help very late despite the knowledge and evidence there now is, that ARV's halt the progress of the disease process and reverse the damage done to the body by HIV[5,6].

The health status of patients at the time of ART initiation plays a crucial role in the success of treatment. Patients with advanced HIV disease at the time of ART initiation are less likely to respond to treatment, more likely to place financial strain on health services and have a higher mortality rate compared to those who initiate earlier.[7]As with any other ailment, delayed help seeking behavior in people living with HIV/AIDS tends to be associated with poor outcomes for a number of reasons. First the individual is unable to benefit from therapeutic advances which include: effective antiretroviral therapy (ART), prophylaxis of opportunistic infections, immunizations, and behavioral interventions through counseling[8]. ART has also clearly been shown to reduce mother-to-child (vertical) transmission.[9] Patients can only benefit from all this through early linkage to medical care.

Secondly, with late presentation, many potential public health benefits are missed. Various medical interventions provided to individual patients are of huge public health benefit. An example is prophylaxis for tuberculosis, which prevents infection in TB-exposed individuals receiving it. Treatment of patients with active tuberculosis prevents spread to others who would be potentially exposed[10]. Needy patients can also benefit materially from social services like access to temporary social grants and supplementary foodstuffs.

In sexually transmitted diseases, ART has been hypothesized to reduce infectivity, potentially reducing sexual transmission of HIV[11]. Another study has revealed that treating sexually transmitted diseases results in reduced sexual transmission of HIV.[12] Health care providers' discussions with

patients about health promotion provide opportunities to influence sexual behavior and substance abuse. All these tangible benefits are missed if medical care is delayed.

Thirdly, late help seeking has adverse socio-economic implications. When one is bedridden because of late stage HIV/AIDS, one automatically loses one's income as work is no longer possible. Very ill patients will also need one or two family members to take care of them for their activities of basic daily living. They would require hiring a vehicle for hospital visits and accompanying family members would also miss work. All this puts a big burden on the family physically, emotionally and financially. Multiplied nationally, this microcosm results in a huge loss of man-hours in the national economy.

A delay in presentation for treatment not only increases the chance of clinical disease progression for that patient but also increases the risk of ongoing transmission. Early effective antiretroviral treatment can lower the viral load, thereby reducing the risk of HIV transmission.[13] Patients who learn they are infected with HIV may reduce their viral load with effective antiretroviral treatment and may reduce their risk-taking behavior, consequently resulting in reduced risk of transmitting HIV to others.[14] The HIV pandemic being experienced in South Africa is mainly spread through unprotected sexual intercourse. Hence, it is safe to say that those patients that seek help late may theoretically be contributing to the further spread of the disease.

Because of these reasons it is necessary to try and establish the factors that are responsible for so many patients seeking help late. Identifying these factors may help the health planners to improvise

ways of alleviating them in order to enhance the ART roll-out programme which is one of the main long term solutions in the fight against HIV/AIDS.

LITERATURE REVIEW

This literature search was mainly done by using PubMed. The search terms used were: late, presentation, HIV, Treatment.

Reasons for late presentation

HIV infection without antiretroviral therapy in the vast majority of infected individuals progressively destroys the immune system leading to opportunistic diseases and death.[15] The introduction of ART has offered hope to people living with HIV/AIDS and has resulted in better quality of life and reduced mortality. However, access to ART remains limited, especially in developing countries the majority of which are in sub-Saharan Africa.[16] However, late presentation for HIV care in PLWHA is not only a third-world problem. A large proportion of HIV-infected individuals in the developed world (approximately 15-43 %) present at clinics for care with advanced or severe disease (WHO stage 3 or 4).[17]

In many parts of the world, studies (some of which are mentioned in this section) have been carried out about late presentation and access to health care seen in people living with HIV/AIDS. Such studies have revealed that late presentation for help in people living with HIV /AIDS is still a big problem. Late presentation prevents people living with HIV/ AIDS from obtaining the maximal benefit of being screened and treated for tuberculosis and sexually transmitted diseases, receiving timely antiretroviral therapy, and benefitting from educational and prophylactic interventions that are more effective when implemented early.[18] Patients with advanced disease at the time of ART

initiation are less likely to respond to treatment, are more likely to pose financial strain on health services, and have a higher mortality rate compared to those who initiate earlier[19]. In addition, late presentation poses a higher cumulative risk of HIV transmission to others, considering that earlier presentation and HIV suppressing treatment might otherwise reduce viral load and risk of transmission.[20]

Since the advent of ART, it has become established that early diagnosis and early access to HIV/AIDS care is associated with good outcomes.[21] Therefore, initiatives to improve early detection and access to HIV services have increased over time, which should imply an increase in patients presenting for HIV care earlier in the course of the disease.[22]

A cohort study[23] was done which analyzed data on the immune status of patients at initial presentation for HIV care between 1997 to 2007 from 44, 491 HIV-infected patients enrolled in the North American-AIDS Cohort Collaboration Research and Design (NA-ACCORD). The results of this study which utilized data from many centers in the United States and Canada showed that although the observed mean CD4 count at presentation has increased since 1997, most patients continue to first present for HIV care with a CD4 count below 350 cells/mm, the level at which initiation of ART is currently recommended by the majority of authorities in the developed countries. This study demonstrates that late presentation is not only due to lack of facilities and resources but there are other factors that are at play. A recent study among US veterans suggested that delayed presentation for HIV care is not a result of lack of medical care access for this population.[24]

A case-control study[25] the purpose of which was to explore the demographic, behavioral and clinical barriers to HIV/AIDS care was conducted from 1 -31 March 2010 in Dessie referral hospital and Borumeda district hospital in south Wollo Zone north-east Ethiopia. A total of 320 patients took part in the study (160 cases and 160 controls). The cases were the late presenters of CD4 counts less than 200 or WHO stage 3 and 4 at the time of presentation and the controls were those patients who were WHO stage 1 and 2 or with CD4 counts of more than 200 at the time they presented for care. The study had both a quantitative and a qualitative aspect. The qualitative aspect of the study found the following to be the reasons for late presentation in people living with HIV/AIDS: low level awareness/inadequate knowledge about HIV/AIDS, inadequacy of HIV testing facilities and HIV/AIDS care, perceived HIV stigma, perceived side effects of ART drugs, inadequacy of social support, inadequate coverage of health education provided to the community, low participation of the community, unavailability of transportation to ART clinic/VCT center, and substance abuse.

In multivariate analysis, from the same Ethiopian study, the following were associated with late presentation: PLHA living with their families, living in a rented house, non-pregnant women, those who perceived ART to have many side effects, those who perceived HIV/AIDS as a stigmatizing disease, those who tested with symptoms/sickness, those who did not disclose their status to their partners, frequent alcohol users and those who had spent more than 120 months with their partners.

An earlier study[26] was carried out at a central Haiti hospital, the objective of which was also to identify factors associated with late presentation for HIV care. Thirty one HIV-positive adults participated in this partly qualitative and partly quantitative study. A two-part research tool that

included a structured questionnaire and an ethnographic life history interview was used to collect both qualitative and quantitative data about demographic factors related to presentation for HIV care. 65 percent of these patients presented late as defined by a CD4 cell count below 350cells/$mm^{3.}$ Factors associated with late presentation included male gender, older age, patient belief that symptoms are not caused by a medical condition, long distances from the health facility, lack of prior access to effective medical care, previous requirement to pay for medical care, and prior negative experience at local hospitals. Harsh poverty was a striking theme among all patients interviewed. In conclusion, delays in presentation for HIV care in rural Haiti are linked to demographic, socioeconomic and structural factors many of which are rooted in poverty. This study was carried out in a rural setting and in a country with a far worse infrastructure than South Africa. However poverty is still a common factor. Irrespective of the different reasons given by the participants for their delays, it is important to note that 65 percent of the participants presented late for HIV care.

In a study[27] done in Kampala, Uganda, to identify barriers to HIV care for women living with HIV, 22 HIV service providers in Kampala were interviewed and illness narratives from 101 HIV positive women receiving care at one site were recorded. The key findings were that both providers and patients reported delays in seeking HIV testing and treatment. 82 percent of the providers reported that clients enter into care too late to receive maximum benefit from the treatment. Some of the reasons advanced for the delays are: lack of proper information about ARV's, lack of money, hesitancy to get tested, fear of stigma, fears and concerns about risks and side effects of the ARV's.

The Immune Suppression Syndrome (ISS) Clinic of the Mbarara University Teaching Hospital in Uganda did a cross-sectional analysis of records of initial visits to the ISS clinic involving 2,311 WHO staged patients who presented at the clinic between 1st February, 2007 and 29th February, 2008.[29] The results showed that 40% presented late at the ISS clinic i.e. with severe WHO disease stage 3 and 4. The socio-economic factors associated with late presentation were: lesser education, informal occupation, no household water source, and more time required to travel to the ISS clinic. All these factors are directly linked to poverty since 80% of all the participants reported a monthly income equivalent to or less than 60 US Dollars. The researchers admit that 40% late presentation could have been a gross under-estimation simply because their HIV staging of the patients was based on only observable clinical signs and may have missed asymptomatic patients with advanced immunological disease. For example in a study in rural Uganda, 19 % of those classified as stage 1 or 2 HIV disease actually had CD4 counts of below 200 cells/ml.[30]

Another big short coming with this Ugandan study was the fact that the data used was collected from the initial visit form which did not include any questions regarding perceived or experienced HIV stigma, which has been shown to discourage HIV testing and counseling in sub-Saharan Africa.[31] Patients' HIV care attitudes and beliefs, for example, perceived eligibility for ART were not captured. Ignorance of the first positive HIV test made the researchers unable to determine whether the late ISS clinic presentation was attributable to HIV testing or to accessing treatment upon diagnosis. This made it difficult to formulate useful recommendations towards hastening the initiation of HIV care.

Uganda has been at the forefront of public campaigns against HIV/AIDS for long, but such factors like stigma and poverty are still an issue to contend with. The findings of the above two Ugandan studies would probably be similar to what is likely to be found in the South African environment which has a much shorter and more problematic HIV/AIDS management history in the sense that the South African government was for years reluctant to deal with the problem of HIV decisively.

Since delayed diagnosis of HIV reduces survival,[32] there is clearly a need for earlier HIV diagnosis and intervention[33]. It is therefore important to highlight the role played by testing in the management of the disease.

In Venezuela, a cross-sectional survey[34] was done at the regional HIV Reference Centre (CAI) in Carabobo Region. 225 patients diagnosed with HIV at CAI between 1st May 2005 and 31st October 2006 were included and their demographic, behavioral and medical characteristics were collected from their medical files with the aim of identifying factors influencing delay in presenting for HIV-diagnosis. 40% were defined as late presenters. The main barriers to HIV testing were low knowledge of HIV/AIDS, lack of awareness of the free HIV program, lack of perceived risk of HIV-infection, fear of HIV-related stigma, fear for lack of confidentiality at testing site and logistic barriers. This Venezuelan study shows that the impact of ART on the prognosis of HIV-infected individuals has not substantially influenced people's behaviors and beliefs towards HIV testing in Venezuela. Despite free HIV testing and treatment, an important proportion of individuals present late for HIV diagnosis, which results into delayed initiation of treatment.

HIV testing is entering a new era as practice guidelines have recently changed to address the need for increased, earlier testing and linkage to care. In September 2006, the Centers for Disease Control and Prevention released Revised Recommendations for HIV testing of adults, Adolescents, and Pregnant Women in Health-Care settings.[35] These recommendations advised routine HIV screening in health-care settings of adults and adolescents aged 13-64 years and of all pregnant women with prior notification and opt-out allowed. Separate informed consent, a barrier to HIV testing,[36] is no longer recommended. If we are to make any impact on improving the health of HIV infected individuals and reducing the spread of the virus, public health officials, clinicians and all health-care givers will need to adopt these recommendations in practice and change policies to ensure that more persons are screened and referred for early treatment.

The effect of stigma on delayed presentation.

One of the most important barriers to accessing prevention, care and treatment services by PLWHA is stigma. HIV/AIDS related stigma is invoked as a persistent and pernicious problem in any discussion about effective responses to the epidemic.[37] Consequences of stigma can vary from mild reactions like silence and rejection to ostracism and physical violence, all of which ultimately lead to delay in accessing treatment.[38]

The way in which individuals discover and disclose their positive HIV status to others, as well as how they cope with their HIV status, is influenced by cultural and community beliefs and values regarding causes of illness, learned patterns of response to illness, social and economic contexts, and social norms.[39] Whatever the form of stigmatization, it inflicts suffering on the people living with

HIV and interferes with efforts to fight the AIDS pandemic. In this regard, research has found that sometimes knowing one's HIV status, especially if it is likely to be positive, is preferable to being tested.[40] The fear is that confidentiality is usually breached in many settings, leading to inappropriate disclosures and the patient can then face prejudice, discrimination, loss of a job, strains on or the break- up of relationships, social ostracism or even violence[41].

The WHO cites fear of stigma and discrimination as the main reason why people are reluctant to be tested, to disclose HIV status or to take antiretroviral drugs.[42] One study found that participants who reported high levels of stigma were more than four times more likely to report poor access to care.[43] An unwillingness to take an HIV test means that more people are diagnosed late when the virus has already progressed to AIDS, making treatment less effective and causing early death.

The widespread fear of stigma is held accountable for the relatively low uptake of prevention of mother-to-child transmission (PMTCT) programmes in countries where treatment is free. In Botswana for example where the PMTCT service is available at every antenatal centre in the country, between 1999 and 2003, only 26 percent of pregnant women availed themselves of the opportunity to protect their unborn babies. Over half refused to take the HIV test and nearly half of those who tested positive did not go on to accept treatment.[44]

The uptake of PMTCT has almost doubled since 2004 when Botswana's President declared that HIV testing should be "routine but not compulsory" in medical settings.[45] Similar results were seen in another study done in Uganda.[46] This slight variation in policy from voluntary(opt-in) to routine

(opt-out) counseling and testing, has received a lot of support from antenatal clinic attendees who are less fearful of accepting HIV-testing because the opt-out approach was perceived by their partners and families as "standard of care" given to all pregnant women in the antenatal clinic.

Stigma and Health care systems

In general, literature suggests that people living with HIV/AIDS are stigmatized and discriminated against by health care systems much more than patients with most other health conditions. Stigmatization ranges from withholding treatment, non-attendance to patients by staff, HIV testing without consent, breach of confidentiality and denial of hospital facilities and medicines.[47] Such HIV/AIDS related stigma and discrimination can reduce the quality of care offered to the patients.[48] It also negatively affects the experience and self-esteem of HIV-positive patients.[49] That medical staff should perhaps have a better understanding of HIV makes discrimination in healthcare settings all the more damaging.[50]

In 2002 a study[51] was conducted in four Nigerian states among 1,021 Nigerian health care professionals (physicians, nurses, and mid-wives) to assess the level of discrimination against people living with HIV/AIDS in the health sector of that country. Some of the disturbing findings were:

- One in 10 doctors and nurses admitted having refused to care for an HIV-positive patient or had denied an HIV-positive patient admission to hospital;
- Almost 40 percent thought that a person's appearance betrayed his or her HIV-positive status;

- 20 percent felt that people living with HIV/AIDS had behaved immorally and deserved their fate, and
- Stigma persisted among doctors and nurses because of fear of exposure to HIV as a result of lack of protective equipment.

Other studies have revealed that gaps still exist in the knowledge of health care workers about HIV infection therefore necessitating additional and ongoing training for health care workers.[52,53]

In light of the above, it is clear that something must be done to lessen stigma amongst the health care givers. A review of research into stigma in healthcare settings advocated a multi-pronged approach to tackling it, necessitating action by the individual, the environment and policies.[54] Health care workers need to be made aware of the negative effect that stigma has on the quality of care patients receive; they should have accurate information about the risk of HIV infection, the misperception of which can lead to stigmatizing actions as seen above. They should also be encouraged not to associate HIV with immoral behavior.[55] Facilities should have sufficient equipment and information for health workers to carry out universal precautions and prevent exposure to HIV.[56]

Policies within the health care system should be effective in reducing stigma. Such programmes would involve participatory methods like role play and group discussions, as well as training on stigma and universal precautions. The involvement of people living with HIV could lead to a greater understanding of patients' needs and the negative effects of stigma. [57]

METHODS

Design:

This is a qualitative study of selected patients recruited into the ART treatment programme at Potchefstroom Wellness clinic who fulfilled the inclusion criteria of the study. The free attitude one-on- one interview method was used. A semi-structured questionnaire (see appendix) was used as a back-up to prompt respondents where they were not spontaneously offering adequate information.

Site of study

The interviews were conducted over the months of August and September 2009. The site of this study was the Wellness clinic of the Potchefstroom Provincial hospital situated in the city of Potchefstroom in the North West province. This clinic receives patients from all the outlying community clinics as well as from all the outpatient clinics and the wards of the Potchefstroom hospital. These are patients with a positive HIV test along with a CD4 count less than 200 or with any AIDS defining illness. The patients are then incorporated into the HIV/AIDS treatment programme by the staff of the Wellness clinic in order to start taking anti-retroviral therapy. This programme includes taking a detailed bio-psychosocial history of the patient and their illness, protracted counseling and advice on behavioral change and living a healthy positive life style, dietary advice, routine laboratory investigations, screening for and managing of opportunistic infections and any other ongoing illnesses, general health promotion, immunizations and prophylaxis, and advice on government welfare benefits.

The clinic staff comprises of doctors, professional nurses, enrolled nurses, enrolled nursing assistants, a pharmacist, counselors, a dietician, a social worker and clerks. The clinic caters for all categories of patients who fulfill the criteria for starting on HAART i.e. children, adults, and pregnant women. Prisoners or inmates from the nearby correctional service facilities and police stations are also catered for. Any patients who necessitate hospitalization are readily admitted into the hospital and those who require specialist attention for other maladies are referred to the relevant specialist outpatient clinics within the hospital.

All patient records are kept at the clinic premises for safety. The clinic runs from 07h30 to 16h00 every weekday and the service is free of charge to all patients.

Study population

Potchefstroom hospital Wellness clinic has been rendering HIV/AIDS care services from 2005, the year after the South African government national ART roll-out programme was launched. It recruits patients from all its outlying clinics and health centres, private general practitioners, referrals from the hospital inpatient services, hospital outpatient clinics, self-referrals and until recently, patients from Ventersdorp hospital as that district hospital did not have its own ART clinic. At the time of the interviews there were about 3000 patients receiving ART from the Potchefstroom wellness clinic and the number is still increasing. The majority of the patients come from the predominantly black township of Ikageng about 5 km west of Potchefstroom city centre. There are four local primary care clinics in this township manned by professional nurses with regular visits by doctors to each one of them.

Most of the people are unemployed, of very low socio-economic status, and live below the poverty line. The population of this township is dynamic in that many men leave to go searching for work in bigger cities and come back on weekends or even at the end of the month to visit their families. This in itself could be a big factor in the high incidence of HIV/AIDS in this area.

Selection criteria

Inclusion criteria

It is very difficult to establish when a patient was first diagnosed with HIV because patients are from diverse testing facilities, they cannot recall accurately and also because there is no centralized laboratory data system accessible at the Wellness clinic where one can retrieve such information from the past. Because of this, the following was used as the ***inclusion criteria*** in the study:

1. One of the counselors at the Wellness Clinic helped the researcher in screening and identifying the suitable respondents for the study. All patients were recruited after they were asked the following question: "*How long did it take you to go to a clinic or hospital for treatment after your HIV positive result?"* If the time delay between receiving the positive result and presenting to a health facility for help was 1 year or more, they would then be included.

2. All respondents selected were *compos mentis* adults aged 18years or more presenting for ART for the first time at the Potchefstroom Wellness clinic with an AIDS defining illness/ WHO stage 3 or 4 disease. The aspect of a CD4 count of less than 200 was not part of the criterion since this study was done at a treatment centre, and not a screening one, almost all the patients that are received there fall in that category. CD4 count is the gold standard by which patients are referred

to the Wellness clinic. In some patients, their healthy clinical outlook may belie their very low CD4 counts.

3. Respondents were those who could understand and converse meaningfully in English. This is because the researcher is not familiar with the vernacular spoken in the area. Since the number of respondents required was small, there were more than enough patients to meet this criterion.

HIV infection results in a chronic disease with a median time to the development of AIDS of 11 years[58]. So any patient presenting for help with AIDS defining illness or WHO stage 3 or 4 should be deemed as a late presenter.

Exclusion criteria

1. Pregnant women or those whose diagnosis of HIV was made during antenatal care. This is because the PMTCT initiative makes the ART programme more accessible to the pregnant women than it is for the population in general.
2. All mothers who have ever been on any form of ARV drug programme for PMTCT. This is for the same reason as in 1 above but also because the PMTCT programme could have had some effect on the course of the progression of the disease as well as influencing the perception of the mother towards ART.
3. Prisoners or inmates, because the choice to seek care, or not, may not entirely depend on their own decision making. They may be people from other areas who may have been brought to the area just to serve their jail terms.

4. Children below the age of 18 years, because of their limited autonomy.

Measuring tool or instrument

The overarching question was: *what were the reasons that delayed you before coming to start on antiretroviral treatment?* The respondent would then be free to give his or her reasons. A semi structured questionnaire (see appendix) was also used to prompt responses where participants were not spontaneous. Individual patients were personally interviewed by the researcher until there was no more new information elicited. The point of saturation was reached after interviewing 8 respondents (3 women and five men).

Data collection

The researcher collected data by personally conducting one- on-one free attitude interviews along with the use of a semi structured questionnaire (see appendix 2) where necessary i.e. where the responses were not spontaneous enough and needed prompting. The researcher carried out the interviews in English and audio-taped the conversations. The recordings were then transcribed verbatim.

Prior to doing these interviews, the researcher had attended a workshop on qualitative methods offered over four sessions of three hours each, at the University of Witwatersrand.

Interviews were conducted after seeking proper informed consent from each patient and were properly scheduled and conducted in a secure, comfortable and private room to ensure confidentiality. Each interview lasted just under one hour.

All participants were told the purpose of the research and that they would be informed of the ultimate findings if they were interested.

The information collected was transcribed verbatim, then analyzed by using the cut and paste method, interpreted and formulated into themes that were used to make proper sense of what the respondents felt were the main reasons why they delayed accessing treatment.

Sources of bias

1. The researcher already had some preconceived answers in his mind.

2. Only patients who could speak English were included in the study which might have been a bias towards patients with a better education.

3. The counselor may have favored certain patients and included them in his screening.

4. Because HIV is an intimate illness and the question has the potential to sound judgmental, there might have been some limitation in the information given by the respondents.

ETHICS

The study was approved by the Potchefstroom hospital management, the North West provincial research and ethics committee and the Wits University HREC (see letters of approval attached as appendices).

Informed written consent was sought and secured from all participants who were told that it is a voluntary exercise and that they are free to withdraw at any time if they so wished without compromising their care (see appendices 1 and 3).

Confidentiality was guaranteed by using codes (Mr. A, Miss B, Mr. C, Mr. D, Mr. E, Miss F, Miss G, and Mr. H) instead of proper names. In other words, there was no mention of names of the respondents when recording the interviews.

As there was no administration of any form of substance or medication for the purpose of this study, there were no safety concerns to the participants.

The original audio recordings of the interviews have been kept in a safe place under lock and key and will be destroyed only after 5 years.

DATA ANALYSIS AND HANDLING

After transcription, the interviews were analyzed and the responses were ultimately sorted into four themes using the cut and paste method. For each interview, a different color code was used for a specific theme. These four broad themes are ultimately the reasons as to why the respondents delayed in coming forward to receive treatment.

A copy of the final report will be given to Potchefstroom hospital and to the North West department of Health as well as to the participants if they so wish.

RESULTS

In this study, eight patients were interviewed; three women and five men coded for confidentiality as Mr. A, Miss. B, Mr. C, Mr. D, Mr. E, Miss F, Miss. G, and Mr. H.

Personal background of the respondents

Mr. A is a 38 year old primary school teacher who is currently unemployed due to the fact that he has suffered neurological complications of HIV and has been in a wheel chair for years. It is only now that he has started using walking aids and is still undergoing intense physiotherapy. His walking ability is slowly but steadily improving. Educationally, he attended a teacher training college after his matric. He was studying for his bachelor's degree when he fell ill and abandoned it partly due to depression and partly to physical incapacity as a result of complications of HIV. He has never been married but he has one son of 12 years.

He fell ill with conditions like TB (twice), gastro-enteritis, peripheral neuropathy and stroke for a long time and he used to go to the health facilities for help. However, for several years, no health care worker advised or asked him to do an HIV test. Although other factors contributed to his delay in starting ART, to him this was the main reason and he did not hide his bitterness about it in the interview. He was deserted by his girlfriend when he disclosed to her that he was HIV positive.

Miss B is a 52 year old clerk at one of the Government Departments. For her formal education, she only completed matric. She is a mother of three daughters who are themselves in their twenties and

married with children. Her husband deserted her when she disclosed her HIV status to him but he died in the year 2000 due to AIDS related conditions, according to Miss B. She was also abandoned by her parents and relatives when she disclosed to them her HIV positive status.

Miss B also works as a community motivator and helps to mobilize people in campaigns against HIV/AIDS both in her home community and at her worker place. The main reason she took long to start on treatment was the stigma associated with HIV. She started falling sick along with her husband, but she could not gather up courage to go for the HIV test for a long time.

Mr. C is a 40 year old man who stopped working as a foreman at a local production plant when he became very ill due to AIDS. He is a father of one 10 year old girl and has never been married. He went as far as standard 8 in his studies and has always been learning his trade on the job. He is hopeful that, as he is getting better on his ARV's he will one day go back to his job. He also was deserted by his girlfriend after he disclosed to her that he was HIV positive. She went into denial until she died of HIV/AIDS related illness, according to Mr. C.

He was diagnosed HIV positive in 2001 and his CD4 count then was 198, but he only started on ART in 2005 with a CD4 count of 34 and WHO stage 4 disease. Although other factors contributed, Mr. C says the most important reason why he delayed to start ART was because the government had not started to roll out its free treatment to the public and he could not afford to buy the drugs privately.

Mr. D is an unemployed 40 year old who volunteers as a community lay-counselor in his area especially on matters concerning HIV and the youth. He has never been married and has no children. For his education, he just finished matric and from then on worked in the mines until he became too sick from AIDS and was retrenched. By the time he started his treatment he was WHO stage 4 disease and his CD4 count was zero. His main reason for delaying to start on ART was mainly because he did not know that he was living with HIV (ignorance and lack of perceived risk of infection) despite the fact that he was sickly for long and that his girlfriend at the time was also showing suspicious signs and symptoms of the disease. His partner deserted him when he started getting very ill.

Mr. E is a 37 year old store keeper at one local supermarket. He has never been married, has a girlfriend but no children. He went up to standard 8 at school. He started his ARV's with a CD4 count of 29 because he lived in denial for quite a long time before he could get the courage to do his HIV test. He only did it because he was on the verge of dying. He still suspects his former girlfriend infected him with HIV because according to him, she was very promiscuous. Their relationship ended when he started getting sickly.

Miss F is a very energetic lady of 29years of age with a very positive attitude towards living with HIV. She completed her matric and never got into any formal employment. She is single and has no children. She lives with her mother and helps as a volunteer counselor at a health facility.
She started her treatment in October 2007 with a CD4 count of 96 and was very ill with WHO stage 4 disease. She has done very well on treatment and has regained her weight.

She is the only patient who admitted to not having suffered from feelings of internal stigma nor stigmatization from people towards her. Her reasons for starting treatment late were; lack of perceived risk of infection, denial, and even when she got very sick, no health care worker advised her to take the HIV test until she requested for it herself.

Miss G is a 28 year old lady who finished her matric and never studied any further as she did not have the finances to carry on with school. She works as a casual domestic worker and lives with both her parents. She has no child and has never been married. She has had a number of sexual relationships. The main reasons why she delayed to start ART were: stigma, lack of perceived risk, ignorance, denial, and failure by the heath care providers to advise her to test for HIV. She started her ART in February 2008 with a CD4 count of 115 and WHO stage 4 disease.

Mr. H is a 36 year old who started his ART in June 2008 with a CD4 count of 149 and WHO stage 4 disease. He could not accept the fact that he was living with HIV for two complete years (denial) and within that time he became very ill and was only saved by his parents who finally convinced him to access medical help. He has never been married but has had a few girlfriends and one 8 year old son. He used to work as a petrol station attendant but stopped working when he became very ill. He is getting better and was hoping to go back to his work soon. His last girlfriend, refused to take the HIV test herself, supported him for some time but left him when he became very ill.

Themes

When the interviews were transcribed and analyzed by the cut and paste method, it emerged that the reasons why these respondents delayed to start on antiretroviral treatment could be broadly categorized into the following four themes:

1. **Stigma and discrimination**
2. **Ignorance and lack of perceived risk of infection**
3. **Denial**
4. **Healthcare system constraints**

When analyzing the interviews, responses with similarity by the different respondents were coded with the same color and thereafter they were cut and pasted on a common page for all the respondents in the study. This was done for all the different responses that bore similarity. In the end the above four broad themes emerged.

Analysis of results

Every respondent had a number of factors that led to the delay in their starting ART. The extent to which each factor contributed varied greatly.

Stigma and discrimination

This turned out to be the commonest reason for delaying the starting of antiretroviral treatment for most of the respondents.

In his responses, Mr. A highlighted a few instances where he suffered stigma. On receiving his first HIV positive test results.....…."*I felt guilty a lot……..I asked myself, as a good Catholic I mean why should it happen to you, how did you, did you close your eyes, what went wrong with you?"*
These feelings of guilt are common with people living with HIV and are indicative of internal stigma.

Asked how the positive HIV result affected his behavior, *"I didn't want to interact with anyone, I started to withdraw from the community, some community participation".... ... "I thought it is my problem let me deal with it"……..*

Mr. A could hardly bring himself to confide in any family member or friend about his HIV positive status saying..... *"Yes, the other thing is, in the African concept when you tell somebody something you will just hear from even friends and neighbors about it, and then I think from that it created a real fear for me at other stages because my family is well respected. I realized that maybe it is going to be demoted by the reputation that I set."*

Out of his deep love for his girlfriend of the time, Mr. A disclosed his HIV positive status to her in the hope that she will also agree to do the test herself. On the contrary she just ended the relationship and deserted him..... *"After I did my second testing, I told her that the result is still the same, positive. It seems she had to take her own decision. I did not force her, I encouraged her to go for test, and unfortunately she ended the relationship and decided to take another way. We lost contact and didn't see each other till today."*

Miss. B remembers with bitterness the stigma and discriminations she suffered from people including her own family members and husband. She says she was stigmatized even before she did her HIV test by those who saw some symptoms on her body. Her entire family abandoned her and even the husband deserted her.

From her story, Miss B was so isolated and without any family support. She said…. *"I went through this all alone…"*

"You know most of my time was spent behind closed doors. I even resorted to drinking because I couldn't think properly."

She lost her self worth and confidence, therefore losing her face in the process, evident from when she asks: as a good Christian, a supposedly good mother, a role model to her children, how could this happen to her?

Living with HIV is a cross that the sufferer carries all the time. There are so many aspects of life that will never be the same as before. Miss B is so lonely and longs to have a partner in her life. When asked if it bothers her that she has no intimate partner, she said; …. *"It does Dr. and I am telling you the truth, it does. Even recently I had to wake up during the night and cry a lot "Come on is there no man who is positive who can look at me. Sometimes you can feel so lonely and then now sometimes people fear even if you say that one he loves me , they think "Wow if he can sleep with me…." even if you know you are not supposed to sleep without a condom they fear coming to approach you, so I*

am always lonely. Sometimes I just need those manly words and whatever just to reassure me, not sex and whatever but really sometimes it is that".

For sometime, Mr. C suspected that he might be infected with HIV but could not take the test and his main fear in this regard was what the people around him would say in case he turned out to be HIV positive. *Initially I was very suspicious of myself that I might be having HIV, but I had a fear of the unknown. I feared, I didn't know what was going to happen to me. Immediately when I know, what is going to happen when people know about it? I had a fear.*

"*When you are HIV positive every one thinks you are sexually reckless."*
He only did the test because he wanted to have a child with the girlfriend because in his opinion he never wanted to have an infected baby born to him.

He admits to getting angry and embarrassed when he hears people talk about his positive HIV status behind his back. He hates it and feels that it should be no one else's business. *I don't like to be, nobody should discuss it. It is like my private matter to discuss about it, I only trust doctors and professionals. I don't like everybody looking at it around me and asking me questions about HIV and AIDS.*

Mr. C also admits that even though he is much better on his ART now, but because of fear of stigma, he would not want to get his medication from a nearby health facility like a village clinic where he is known by everybody. He would rather travel far to hospital. *....a lot of us don't like going next to*

where we live because when we go next to where we live it is like going in public everybody sees you there, but the further it is, the better it is.

Mr. D did not say much about suffering stigma but what little he said summarised the weight he carries with him by living with HIV*: I did not want to live with HIV. It is a shame. Everywhere you pass people talk about you and how sickly you look. You also fear to interact with people and so you become isolated.*

Mr. E has always feared to get known that he is HIV positive and he only decided to access the health care facilities for help after realising that he was on the verge of dying. He could not stand the fact that other people should get to know his HIV positive status. *"I was only brought to hospital when I was almost a corpse!"*

Up to now, Mr. E feels very ashamed and embarrassed coming for his appointment at the wellness clinic for his monthly check-ups and treatment. This is despite the fact that he is doing very well on treatment.

Miss G also wondered *"what will people say on learning that I am HIV positive?"*

She has been hurt a lot by her closest friend who has been spreading the news of her having HIV. She also laments about her colleagues from her church that used to be very supportive to her during the time she was ill but only to keep telling every body about her HIV positive status. She is so hurt from this that she even cries about it at night.

Stigma was not only a factor in delaying the respondents to present for care, but it contributed greatly to their emotional suffering because most were abandoned by their life partners at their most critical hour of need.

Ignorance and lack of perceived risk of infection

Ignorance and lack of perceived risk of infection with HIV were also given as reasons for delaying to take the test and therefore presenting late to health facilities.

The researcher has found it difficult to separate ignorance from lack of perceived risk of infection because of the responses given by the respondents as to why they did not think of themselves as at risk of contracting HIV. From some of their statements the respondents surely were ignorant. For example, some had partners who were sickly all the time, with non healing genital and skin sores, others had partners who had multiple lovers at the same time and yet they went on to have unprotected sex almost daily. Such behavior simply means one is ignorant and therefore cannot perceive the danger in their actions.

Although nowadays there is a lot of information out there concerning HIV and ART, in the past this kind of information was scanty and confusing, fueling a lot of myths and misconceptions among people. There was a long period of time when the then South African national minister of Health, Manto Tshabalala Msimang (RIP), used to malign ARV's to the extent that they are only poisonous

and toxic to the body! Without the proper information and knowledge, it is clear that many people would feel helpless at the time of their HIV diagnosis. It was synonymous with a death sentence.

Mr. A was in the main; very ignorant about HIV when he got his diagnosis. *You know after I got the results, because at that time I was still admitted at the hospital, it was a shock I had the fear of the unknown, I stopped my studies, I told myself what is the use to go on and study anyway because I am going to die soon. At that time I knew HIV is a death sentence at the end of the day. Slowly I realized that I needed to take time for myself and look at it another way round how I am going to deal with it. Because I was alone, I couldn't find answers to certain questions that I had, but I realized that I had to stay now and start taking my medication, At that time the information was like you go for this you get the medication, but it was never explained to you what you will get there. I didn't have a clear picture about the ARV's it was just you go for treatment, you started with the treatment then from there I started to see that really this can give me a better life.*

His ignorance was not helped by the confusion created by the then state president of South Africa, Thabo Mbeki, when he used to question whether HIV causes AIDS:

Yes, there were a lot of fears like when I heard from the State President of the country, talking about HIV/AIDS, and then I didn't know exactly what is first, what is last. There was a lot of confusion, also I was just taking the medication because I did not know where to go in the end, and this was like my last option at that time.

Miss B has lived with HIV from the late 90's and she realized at that time there was very little information about the disease. She decided to look for information about HIV so as to live better with it. She went on HIV sponsored workshops and courses and became a community mobilizer against HIV. However, there were moments in her life where she would be overwhelmed by her emotions and tended to behave contrary to what is expected. *It went on for some time because I started drinking and the religion that I was in didn't accept me to drink, I was a ZCC member. But I felt I had to drink and we had a support group, I opened a support group with some friends who were positive. So whenever we had these meetings after this I would say, "Ag! Man! Let's take a glass of beer to celebrate being so brave". We took it to be a joke, but deep down it was destroying us inside because it was becoming a habit, and at the same time, in the morning when we wake up all of us that same thing the stigma it is still there.*

Mr. C admitted that he also saw being HIV as a death sentence and knew nothing about ARV's at the time. *Yeah it was like a death sentence. By that time I did not have any knowledge about the ARV's, particularly the side effects. I did not know how they work. But I hear that they only prolong your life.*

As for Mr. D, his CD4 went down to zero without him knowing that he was living with HIV!
His girlfriend was showing some suspicious lesions on her legs but he continued to have unprotected sex with her: *By the time when my CD 4 count was zero I didn't know at all.*

At that moment in time the lady that I was involved with, she knew that she was HIV positive but she never told me anything. Her legs were like those people having skin cancer and I didn't use protection at first. I was just sleeping with her without using protection.

Mr. D clearly knew that living with HIV is a death sentence so, he became suicidal. He tried, unsuccessfully, to kill himself: *I did attempt suicide many times, thrice. Because I went to the railway line, it failed. I went to the river still it failed. Yeah, I couldn't still I went for the third time. Then I said it is better for me to die being intoxicated and that is how, how do you call it, my CD 4 count dropped away just to zero. I got the belief that my body could not resist alcohol, HIV and then it was the smoking thing at the same time. I did all these things to kill myself. You can say the main reason was I had very limited knowledge about HIV at that time and I therefore did not know much of what was happening to me and I did not know about ARV's.*

Mr. E certainly had no perceived risk of infection. He admits to having known that his girlfriend used to cheat on him but continued to have unprotected sex with her: *Yes. Because I am someone who really takes good care of myself, you know. But my problem was the girlfriend I got and stayed with. She was not faithful. My friends used to tell me "Your girlfriend is naughty She does this and this and this when you are at work." Yes, and I didn't listen, one day, they told me "But one of these good days she is going to get you sick".*

Miss F said that she presented late for help because she was unaware that she was HIV positive. Despite the fact that she used to get sick with various illnesses, she did not perceive herself as

someone who could be living with HIV: *The reason why I did not come earlier to the hospital is because I wasn't aware that I was positive so the time that I decided to come into the hospital I was very ill, I had diarrhoea and I was vomiting a lot, so I was admitted. There might be probably another reason because each and every person knows how she lives or how he lives, so I didn't think it was very stupid of me, I didn't think that I could be positive, maybe that was a reason why I delayed taking the treatment.*

She also thought that because at that particular time she was not in any sexual relationship, she could not be living with HIV: *Uhm! By then I didn't have anyone in my life, so I didn't think the sickness could be with me.*

From what Miss G answered it is evident that she was totally ignorant of how one gets infected with HIV and therefore could not perceive herself as some one who could be infected: *You know I can tell, I can tell you in my mind it is like "No I have been faithful, there is no way". You know what I told myself that I am an Christian, I go to church, I am faithful to one partner and then there is no way that I might be HIV positive, so and then I told myself that. And then from the moment that I found out that I am HIV positive, I never dated anyone for a very, very long time. Maybe for more than four or five years, I was just staying alone. You know I started getting sick, I was working I think I was in Klerksdorp, I was far from my home and then staying with a relative in Klerksdorp because of my work, then I saw that I am getting weaker. I could see that I was getting weaker and losing weight, but I just told myself it might be flu.*

Mr. H also did not think he could contract HIV:

I Okay before that did you know anything about ARV's?

R *I did hear about it because people talk about it. Even though HIV was here and I used to hear people talk about it, but I never expected to be a victim of it.*

I Okay, it has taken you two years to accept you are HIV positive so that is what we call denial, you were denying, denying, denying but why? Why were you denying so much after even taking three tests?

R *As I have said before I was having one partner, trustfully.*

I Okay, you thought because you were faithful to your one and only partner, you could not get infected with HIV?

R *Yeah.*

From these responses, many of the respondents never perceived themselves as at risk of contracting HIV. This tends to be the thinking of many people in the general population and that is why the disease is still spreading a lot. The reasons given by the respondents were ranging from being faithful to one partner to being a good Christian, to not being stupid. From all these responses, it is clear that the actual problem is ignorance of how HIV is transmitted.

Denial

Denying the fact that one is afflicted by a debilitating or life threatening disease like HIV/AIDS is one of the stages the human mind goes through before finally accepting the inevitability of the

situation. Unfortunately, with some people it might take quite a long time to get through it and some people fail to overcome it and therefore die without being helped.

From what came out of the interviews in this study, denial was the main reason why some respondents delayed to start on ART. On the other, there are those who were not so much affected by it. However, denial seemed to have affected not only the respondents but also close family members and especially sexual partners. Because of the stigma attached to HIV, many of the respondents lost their sexual relationships when they went on to disclose their positive status to their partners. The partners just preferred to deny that they could be living with HIV and most of them did not even want to do their HIV test. Some died of AIDS related illnesses without ever testing!

Six out of the eight respondents had their sexual partners leave them after disclosing their HIV positive status and two respondents reported that their partners died of AIDS without ever going for any help thereafter. For a long time, many of the respondents could not perceive themselves as being infected with HIV despite their failing health.

In the South African context, denial also has had another aspect, that of the government of former president Thabo Mbeki. The time that elapsed when Thabo Mbeki was denying that HIV causes AIDS resulted into a lot of confusion with the people at the grassroots. Three of the respondents in this study mentioned it as something that kept them confused for long, as to whether they should even go for help or not.

Personally, Mr. A did not have a problem believing that he was living with HIV when he was finally tested, because he was ill for a long time and had visited clinics and the hospital on several occasions where he was frustrated as he was not getting better. It was only one of his sisters who could not believe that he was infected with HIV. He mentioned in passing that former President, Thabo Mbeki's stance on whether HIV causes AIDS really confused him for some time. His partner deserted him after he disclosed to her his HIV positive status.

Mr. C went into denial for a long time after knowing that he was living with HIV: *Yeah I was in denial because I did not want a lot of people to know. I did not tell everybody, I only told my family when they saw I was very sick. But in the process when I was not sick I did not tell anybody. I will say time heals that whole time that went away, then I started accepting myself.*

His girlfriend was even worse than him because she refused to do her HIV test until she died of AIDS: *Hmm I told my partner but she was in denial for a very long time. She couldn't want to be seen because she thought that she is well educated, she was an auditor. She didn't believe that people should know that. She died with it secretly, only I and her knowing, but she did not want to accept it.*

On receiving his HIV positive result, Mr. D went into denial too: *It was so bad, so bad, so bad, so bad and it was still difficult for me to accept and tell my family that I am HIV positive because I was being, how to put it, they told me about that lady and I must end the relationship but I never listened*

as such because I was so deeply in love and secondly I was blaming myself why didn't I listen to my parents advise.

He kept asking himself that proverbial question: "why me?" *Yeah, Yeah I never thought it would be and questionably why me again, of which I was not supposed to ask myself that question.*

Mr. D also thinks that President Mbeki and his government had a role to play in his delay to start ART*: Doctor. That also caused a lot of confusion, hearing President Mbeki saying there is no HIV or HIV cannot cause AIDS. The government because of that did not give out treatment for a long time and this I can say also delayed me because I did not know what to do.*

His relationship with his girlfriend also ended after he got to know he was HIV positive.

Mr. E also admitted he was in denial for long: *No initially, I did not believe I had HIV and I was asking myself, how did I get this, then afterwards it is whereby I reminded myself of that girlfriend.*

Although Mr. E believes he has overcome denial, he compares himself to his brother in law who he thinks is still in denial: *Exactly, now I have got a younger brother-in law who married my younger sister, who I told. But he is afraid to tell me that he is positive, but me I was open to him, he is afraid. Most of them are I think. He is a soldier. Yeah he didn't tell me, but the thing is that I saw his tablets, sometimes he tells me no it is just tablets that I drink for high blood. I have got high blood but I saw that they are the same as the tablets I drink. This is how I also felt for a long time. I did no want to admit that I have HIV!*

His girlfriend also left him after he disclosed to her his HIV positive status.

Miss G due to her strong lack of perceived risk of infection went into denial*: I could see that I was getting weaker and losing weight, but I just told myself it might be flu. You know I can tell, I can tell you in my mind it is like "No I have been faithful, there is no way".*

Of all the respondents, Mr. H is the one who had the worst case scenario of denial. His health was failing, he tested positive on three different occasions by three different doctors in different places but still could not believe that he was living with HIV*: At night I used to become so cold and after a while so hot and I sweat even though I wear four T Shirts it was full of water every night. Then I went for a check up. The doctor told me that I was HIV positive after the test. I did not believe it. So, late by that year 2006 December I went to another medical doctor, she wrote me a letter to the hospital to take some blood tests. After those tests the doctor told me I was HIV positive.*

I Even in the hospital?

R *Even in the hospital, but I didn't believe because I was having only one girlfriend. I didn't believe I had HIV.*

It took him two more years and the fact that he was almost dying for him to agree to be taken for another test by his parents:

R *Yes at the hospital they wrote me a letter to go to the nearest clinic, but I didn't go there.*

I why?

R *Because it was unbelievable*

R *Until such a time I was critically ill. Then my parents advised me to go to do the test again and I did it with their support.*

I Okay and when was that?

R *Last year.*

I That is 2008, a whole two years in between.

R *Yes.*

I Okay so it is now that you are almost dying and then you think "Okay so let's go and check again". So it is now that you are going to do it for a third time.

R *Yes.*

He now acknowledges that he lived in denial for a long time:

I Okay, so you lived in what we call denial for a very long time.

R *Yes.*

I Okay, uhm what other problem, what other difficulties were there in your mind at that time, knowing okay you have had three HIV tests, and three doctors have already told you, you have HIV, but you still believe you don't have it. What was going on in your mind at that time?

R *You know Doc I don't know. Even now I still ask myself the same question. I was very ill, very weak, very thin, rushing to toilet all the time, TB, but I still did not believe I could have HIV.*

R *Hey in my own view you see, in the beginning, it is hard to believe you have HIV. It really takes time.*

His girlfriend also left him. She used to accompany him to hospital but she refused to do her own HIV test for a long time until they broke up.

Health care system constraints

Some of the respondents were seriously affected and delayed by factors they encountered at the different health facilities they attended. Some actually showed a lot of bitterness towards the system because they deteriorated to near death before even an HIV test was suggested to them. This was so, despite the fact that they used to attend the facilities for different maladies like TB which, in their opinion, would have prompted the health care givers to at least suggest voluntary counseling and testing for HIV.

During the interview, Mr. A displayed a lot of anger towards the fact that he had to suffer from TB twice and was so sick, at the brink of death, before one of the health care workers could advise him to take his HIV test. He had the first episode of TB in 2003-2004 and then a second one in 2005. The following are his exact words..... *"Okay Doc uhm I started with my treatment because at that time I was admitted in Potch hospital. I had repeat of TB then after all the treatment I was still admitted and still ill when they did their checkups then, there was nothing they could see. So, they asked me to do the HIV test and I agreed then after that I was given the results that I am HIV positive. I was delayed actually, not by myself, but by the system of the clinics, because I used to go repeatedly to them when I had the continuous coughing. If they asked me to do the HIV test when they used to ask me for the sputum, I am sure I could have agreed to do it, then I could have known this earlier, rather than when I only got to know at the time when my life was really in danger."*

He also added this*: "..... Yes lack of counselors, and resources for counselors in the clinics. We must have more counselors in the clinics with information that is really very correct and also that*

they can deal with the huge number of patients when they come and help educate them to take this test."

Although the delay for Mr. A to start on ARV's was multi-factorial, he insists the main reason was the failure of the many health care workers he encountered at the different facilities he attended to suggest to him to test for HIV until it was very late.

Miss B starting on ART was not personally delayed by the health care system, but she made some observations that affect other patient. She mentioned the fact that some patients especially the very low social class and illiterate ones are not treated the same as her for example: *There are some times that I feel bad when I go to hospitals or Doctors seeing the others who are so sick with a little knowledge, being ill-treated because they are illiterate, sometimes they just judge them then they don't give them first hand service like what they do to me, I even have sometimes to move people to go with me so that I can be their mouthpiece because they can't explain everything and I think several times there at Potchefstroom I have to call a sister and say "Man look here at this woman, she is like one, two, three, I saw her when she started, but it seems she is deteriorating please come do this, this and this." So they lack information if maybe there was a way that those who are disadvantaged can be all also given more care like those who are educated. We are not treated on the same level.*

She also mentioned the problem of long queues: *Another last thing is long queues, people fear queues. Because sometimes you come there the queue is so long there are these things, there are*

these people who come from correctional services. We come there we want to go back to work or whatever, those people are not working but they should by-pass us and go before us and then when it is two o clock sometimes they say "We are going to cut you off". So you get so angry then you say, so I am not going to get there anyway, because I went there eight o clock, the bandits, I am sorry the offenders have come at eleven o clock but they bypassed us. Taking long in the queue for ARV's is problematic, because some patients even leave the premises without having got their treatment, saying I am hungry I am going back home.

Mr. C felt that it took long for the doctors to initiate him on treatment, yet he was very ill: *Then I came to the hospital but unfortunately there was no wellness clinic in Potchefstroom, then I came and slept. Initially they tested me for TB, TB they couldn't find it from the blood then eventually they find it from the sputum. Then they said they were not going to give me antiretrovirals and I felt that I am sick, I am going to die. Then, I made an appointment in Klerksdorp, because in Potchefstroom there was no wellness, so I made an appointment in Klerksdorp. Then my appointment they couldn't fulfill, the Dr's kept changing my appointment, they did not want to release me and then I decided Okay it is fine let me wait a little bit. But I was getting worse and worse because my CD4 count was 34 at that time.*

During the early days of the government ARV roll-out, there were very few designated centres where treatment would be accessed and at that time it was in Klerksdorp, a bigger centre than Potchefstroom hospital. The process before a patient would be started on treatment used to be several months. Mr. C was delayed by this. This fortunately has changed over the years with opening

up of many treatment centres at smaller facilities as well as the fast tracking of the process of initiation of treatment.

Mr. C also decried the long queues and the long waiting times at the wellness clinic every month he has to come for treatment: *The reason that a lot of us when we come and fetch our tablets we spend the whole day, it is not like we can have an appointment, the whole day and sometimes we feel that we have some other appointments to fulfill, we have some other things to do outside. Then you feel no I can see them tomorrow, no I wanted to finish. You only come when all your tablets are finished, you try to finish them all when you know you don't have any treatment left, it's only when you try to say I must go to hospital. Up to now, I still think about that whole day that I am going to spend, the queues, the stigma, especially when you meet people known to you. It is better to meet strangers. I would say I would prefer an appointment, a time appointment not a day appointment. If they could control, say somebody is going to meet a doctor at twelve o' clock or half past or quarter past. Even though it can't be accurate but it shouldn't be more than 30 minutes when you have an appointment with the doctor. I think that will work because at least when you know that you have a particular appointment let's say past one you should see the doctor; the other group must see the doctor past two or past ten then at least you know what time to come.*

According to Mr. C, some health care workers harass and rebuke patients: *sometimes other doctors when you do not come at your own appointment, maybe when you missed your appointment you would hear the others saying you don't need these tablets because you don't come in time, maybe we*

must take them away from you. It is only few but a lot of the doctors have been very supportive to me I must say.

Mr. C also said he was delayed because the government of the day took long to roll out the free ARV programme: *Yeah the thing about starting late, I would say particularly with me was the government because the government was the main problem according to myself that I felt if it was not because of the government I could have long taken the ARV's, because I was afraid even if I could buy them what would happen in future that if I can't afford. That is the thing that made me not to take them. So I was scared that in the future if maybe I can't afford, what is going to happen to me? That is the thing that worried me.*

Mr. C also laments the fact that the government of the day delayed to roll-out the ARV programme and this also contributed to his delay: *Yeah, particularly the thing that I would say, is the delay by the government. Because if they could have, if the government should have given it in time, because a lot of people I think have died before when there were useless arguments on whether HIV causes AIDS and those debates of the Scientists and the Politicians. With me I think they could have given us treatment earlier!*

Mr. D and Mr. E did not have any problems with the health care facilities.

Miss F was admitted with diarrhea and vomiting and wasting and had to be re-admitted even after a month with TB but no health care worker suggested to her to take the HIV test. She had to ask for it

herself: *For the first time I was admitted here they didn't do any tests. They actually did the TB test only and then I was admitted for about a week, after which I was discharged. So I came back again in about a month's time for the second time. The second time I came I asked the doctor who was helping me in casualty to do the HIV test and the results came back positive. So that was when they referred me to wellness clinic where I got the treatment.*

This response by Miss F is a big indictment on the health care system. There are still many health care givers who treat patients symptomatically and do not stop to think about encouraging patients to do VCT.

Miss G used to fall sick a lot and used to go to her general practitioner who never at any one visit suggested to her to test for HIV: *My boss used to say "go to the doctor" and I used to take the money and then go to the doctor but the thing is at the doctor they didn't take, they didn't do blood tests.*

Finally when she came to the hospital, she was tested but for some reason, the healthcare workers lost the courage to give her the result and out of fear, she stopped going to the hospital. This resulted into her losing a lot of time before accessing ART as her HIV status was yet to be known to her. *You know what, here at the hospital they did make the blood test, but unfortunately the time I came to check my results it was the 4 October 2007, when I came to take my blood results, they said to me, I don't know, there is one sister who said they couldn't find my file and then unfortunately they said*

the doctor who was in charge was removed from here, he was somewhere else I must come another time. And then that moment I started to have fear in my heart to come back again.

Such things still happen where the health care worker fails to gather the courage to break the news of an HIV positive result to the patient and instead creates stories to get rid of the patient at that time. This is what happened to Miss G. She got lost to the system for sometime because of that and she was fortunate to have come back later to access treatment. The fact remains she lost valuable time unnecessarily.

DISCUSSION

In this study, the researcher interviewed eight respondents (3 women and 5 men) using the one on one interviews and their responses were analyzed by use of the cut and paste method. On analysis, their responses seemed to fall into four major themes which are:

1. **Stigma and discrimination**
2. **Ignorance and lack of perceived risk of infection**
3. **Denial**
4. **Healthcare system constraints**

Stigma and discrimination

Majority of the respondents in this study reported having suffered Stigma and discrimination and this along with ignorance and lack of perceived risk of infection turned out to be the commonest factors that led to their delay in starting on ARV's. This is in line with what is seen in similar studies elsewhere[59,60].

Etymologically, the term stigma derives from a Greek word referring to a tattoo mark. It generally has two meanings. One derived from Christianity and denotes bodily marks which resemble those of the crucifixion of Jesus Christ. The second meaning is secular, namely marks of disgrace, discredit or infamy.[61]

AIDS-related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV/AIDS. This can result in being shunned by family, peers and the wider community; poor treatment in healthcare and education settings, an erosion of rights; psychological damage; and can negatively affect the success of testing and treatment. In this study, it emerged that all but one of the respondents experienced stigma and discrimination in one or more of its various forms. In all these cases this seems to have been the most important reason that contributed to delays in reporting for help at health facilities.

Why is there stigma towards people living with HIV/AIDS?

Sources of stigma include fear of contagion, fear of illness and fear of death. Along with these fears are negative value based assumptions about people who are infected with HIV. Stigma is one means of coping with the fear that any contact with a member of the affected group will result in contracting the disease.[62]

Factors that contribute to HIV/AIDS-related stigma:[63, 64]

- HIV/AIDS is a life threatening incurable disease and therefore people react to it in very strong ways.
- HIV infection is associated with behaviors (such as homosexuality, drug addiction, prostitution or promiscuity) that are themselves already stigmatized in many societies.
- Most people become infected with HIV through sex which often carries moral baggage.
- There is a lot of inaccurate information about how HIV is transmitted, creating irrational behavior and misperceptions of personal risk.

- HIV infection is often thought to be the result of personal irresponsibility.
- Religious or moral beliefs lead some people to believe that being infected with HIV is the result of moral fault (such as promiscuity or deviant sex) that deserves to be punished.

Broadly speaking, stigma can be external or internal.[67] External stigma refers to the actual experience of discrimination. Internal stigma, otherwise felt or imagined stigma, is the shame associated with HIV/AIDS and the sufferer's fear of being discriminated against. Internal stigma is a powerful survival mechanism to protect oneself from external stigma and often results in thoughts or behavior such as reluctance to disclose a positive HIV status, denial and shying away from help. [65, 66]

One of the respondents in this study, Miss B, was abandoned by her family for 5 years! Her husband deserted her. She lost her self-worth and started drinking alcohol and keeping herself in doors most of the time.

All in all, 6 of the 8 respondents were abandoned by their sexual partners after learning that they were living with HIV and disclosing to their partners. These are just but two examples of external stigma.

Many of the respondents expressed the fact that they feel ashamed to be living with HIV and others said they hear people talk about them whenever they are passing by. This creates anger in them and some of them resorted to isolating themselves from society.

Many talked about the stigma they face when they attend their monthly clinic for check up and collection of medication because the wellness clinic is a facility which caters only for people living with HIV. So, whoever is seen going there, to the onlookers, it is obvious that they are living with the disease. Three of the respondents admitted that when they were diagnosed with HIV they worried a lot and asked themselves the question: "what will the people say?" It is such feelings that mainly kept them away from attending health facilities to get help. This is what is known as internal stigma.

Stigma enhances secrecy and denial which are also catalysts for HIV transmission[67]. HIV/AIDS stigma negatively affects seeking HIV testing, seeking care after diagnosis, quality of care given to HIV patients and finally the negative perception and treatment of people living with HIV/AIDS by their communities and families including partners. It isolates people from the community and affects the overall quality of life of HIV patients[68].

Stigma is a common reaction to disease. Throughout history many diseases like tuberculosis, leprosy, cancer, mental illness and sexually transmitted diseases have carried considerable stigma. HIV/AIDS is only the latest to be stigmatized.[69] AIDS stigma and discrimination exist worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals. They occur alongside other forms of stigma and discrimination such as racism, homophobia or misogyny and can be directed towards those involved in what are considered socially unacceptable activities such as prostitution and drug abuse.

In sub-Saharan Africa, stigma and discrimination is particularly common because what happens to one person concerns the whole community.[70]

Stigma not only makes it more difficult for people to come to terms with HIV and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole. On a national level, HIV-associated stigma can deter governments from taking fast, effective action against the epidemic, whilst on a personal level it can make individuals reluctant to access HIV testing, treatment and care.

In South Africa, counseling, testing and treatment for HIV are all free to anyone living with the disease but there are still many HIV/AIDS related deaths occurring largely because of the stigma associated with HIV.

Because of the stigma associated with HIV/AIDS, different names have been coined in different parts of Africa to refer to the disease. Apparently this is more acceptable in these societies. For instance, in Uganda they use terms like ***kamuyoola*** (was caught in a trap), ***kakokolo*** (scarecrow);[71] in Nigeria ***ashawo*** (prostitute), to refer to someone living with the disease. In South Africa ***amagama amathathu*** (the three lettered word) refers to HIV and in Malawi lay people refer to the disease as ***kaliwondewonde*** (slim disease) or ***ntengano*** (the disease which leads the husband and wife to die together or one after the other).[72]

Family and stigma

Family support is an important factor in the outcome of all kinds of illness, but especially in chronic illness and disability.[73]

In the majority of developing countries, families are the primary caregivers when somebody falls ill. It is of utmost importance that families play an important role in providing support and care for people living with HIV/AIDS as it is a very debilitating disease both physically and psychologically. In this study, 5 out of the 8 respondents were nursed and helped by their family members to cope with their illness. They all admitted that it is through the encouragement and insistence of family members that they finally accessed ART even as they were still procrastinating.

However, not all family responses are positive. HIV-infected members of the family can find themselves stigmatized and discriminated against within the home. There is concern that women are more likely to be mistreated than children and men. This happened to one of the respondents in the study, Miss B.

Another example of family mistreatment of someone with HIV:

"When I was in hospital, my father came once. Then he shouted that I had AIDS. Every one could hear. He said: this is AIDS, she is a victim. I wasn't allowed to eat from the same plates with my brother and his wife, I was given a plastic cup and plates and I had to sleep in the kitchen. I was not even allowed to play with the kids." *HIV-positive woman, Zimbabwe*.[74]

Clearly it is so unfortunate that these are some of the things that still happen to people living with HIV/AIDS within their own families.

Stigma in the community

Community level stigma and discrimination towards people living with HIV/AIDS is found all over the world. A community's reaction to somebody living with HIV/AIDS can have a huge effect on that person's life. If the reaction is hostile, a person may be ostracized and discriminated against and may be forced to leave their home or change their daily activities such as shopping, socializing or schooling. In this study, several of the respondents intimated that they withdrew from social activities and that it is uncomfortable for them to fulfill their appointments on the days they are supposed to visit the wellness clinic to get treatment due to the fear of being seen by someone they know.

Community-level stigma and discrimination can manifest as ostracism, rejection and verbal or even physical abuse. It has even sometimes resulted in murder! AIDS related murders have been reported in countries as diverse as Brazil, Columbia, Ethiopia, India, South Africa and Thailand. In December 1998, Gugu Dhlamini was stoned and beaten to death by neighbors in her own township near Durban, South Africa, after speaking openly on World AIDS day about her HIV positive status.[75]

The UN Secretary-General, Ban Ki Moon, has summarized stigma in relation to HIV so nicely thus: "Stigma remains the single most important barrier to public action. It is the main reason why so many people are afraid to see a doctor to determine whether they have the disease, or to seek

treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is the chief reason why the AIDS epidemic continues to devastate societies around the world".[76]

What can be done to lessen stigma?

In the fight against HIV/AIDS, combating stigma has become as important as it is to develop a cure or vaccine to prevent or control the spread of HIV. Change of peoples' attitude is not easy. Eliminating stigma completely remains a pipe dream at this stage but main research does suggest that something can be done through a variety of interventions such as focused information dissemination, counseling, coping skills acquisition and direct contact with people living with HIV/AIDS[77].

Some of the interventions are:

- People living with HIV/AIDS should be educated about their human rights to enable them to access and enjoy all legal provisions;
- Institutions should implement their HIV/AIDS policies based on sound information and taking into account the rights of everybody

HIV negative people should also be educated for it is only through imparting facts and knowledge about HIV/AIDS that can dispel biased social attitudes and stereotypes towards the disease and people living with it

Ignorance and lack of perceived risk of infection

HIV/AIDS is a life threatening, incurable disease and for that matter many people might choose to think that it is a calamity that cannot or should not befall them.

Despite the fact that it is now a well established fact that the most important mode of HIV transmission in sub-Saharan Africa is through the heterosexual route, six out of the eight respondents in this study started falling sick with different ailments and still could not think of HIV as the possible cause. This is a common occurrence in many people living with HIV.

Some people are still ignorant of the basic facts about HIV transmission which simply are: anyone who is sexually active, is at risk of infection and that being faithful alone does not guarantee protection simply because the partner might not be faithful or even if they were, they could be infected already and therefore having unprotected sex with them could result into infection. This might seem to be basic knowledge but probably it is not yet well understood by many of the people at the grassroots and could be contributing to the high number of new cases seen everyday.

Denial

When calamity befalls any one, it is a very painful experience and the mind takes time to digest the situation before acceding to the finality of accepting reality. This is very true with a life threatening condition like HIV/AIDS. Many people on receiving the initial information that they are HIV positive tend to go into a period of varying length trying to deny that it is happening to them.

Denial is a way of reinforcing that HIV/AIDS is a disease of others not of the self,[78] as one of the ways to respond to this frightening or intolerable situation. Many patients would rather try and find their own explanations for their illness rather than accept that they have HIV. The commonest in Sub-Saharan Africa are beliefs like witchcraft, 'poison' or 'body pollution'. This self-diagnosis which leads to self treatment is culturally more acceptable as it helps to avoid the personal shame associated with HIV/AIDS.[79]

Many people prefer to claim that they are bewitched or have what they call 'normal' Tuberculosis other than accept that they have HIV/AIDS.[80] In this study, several respondents admitted to having been in denial for varying times. Some of them informed their sexual partners about their newly diagnosed HIV positive status but the partners also went into denial and two of them died without ever going for help.

Denial seems to stem from the fact that HIV is a stigmatized disease but also because of the sexual nature of its transmission by which the sufferer is perceived as 'dirty', 'sinful', 'loose' and also because it is debilitating and most importantly, incurable yet.

After the initial HIV positive test, usually a big conflict ensues in the mind of the patient. To accept is to start on a process that would take him or her to the healthcare system and also get to reveal this 'terrible' secret to a few other people in order to get to what can help preserve life –and that is antiretroviral therapy. This road is not as easy as stated because of stigma attached to the disease.

On the other hand, there is the option of 'keeping the secret' from everybody else and not even going to the health care facilities, still because of the fear of stigma attached to HIV/AIDS. The problem with the later choice is that every passing moment, the disease progresses and if nothing is done perpetually, the person with the disease becomes ill and ultimately death inevitably ensues. This battle of the mind goes on for varying periods of time in different patients and some finally choose to opt for going for help but surprisingly, there is a big number that still opt to keep it to themselves and end up dying.

Health care system constraints

In this study, several of the respondents cited problems they encountered at the health care facilities as part of reasons that delayed them in starting antiretroviral treatment.

When one falls sick the natural response is to seek help from family, community or the health care facilities. Not with HIV, a disease that is so much stigmatized that many sufferers prefer not to reveal their situation to even their immediate family and life partners. This reluctance to let out the secret for fear of stigma is usually one of the reasons why many people living with HIV/AIDS keep away from even their local village clinics and hospitals. For one to take an HIV test there is usually the initial stage of counseling and this usually takes place in a segregated room which is known by all to be for that purpose. Usually, many people would feel intimidated to be seen entering or leaving such a facility.

When people report to health facilities already showing signs of the disease like wasting, they always feel the internal stigma as well as the stigma from the health care providers. Many studies have revealed that health care givers treat people living with HIV differently.[81,48]

And then there is always the problem of fear of breach of confidentiality. Lack of confidentiality has been 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. Studies by the WHO in India, Indonesia, the Philippines and Thailand found that 34% of respondents reported breaches of confidentiality by health workers.[82]

Health care workers are also people who usually come from the local communities and so people living with HIV always have a fear to go to their local clinic for HIV testing just in case the health care worker may happen to be someone familiar and thereafter might reveal the information to other members of the community.

In one study[83] done in China to investigate HIV- related stigma among health service providers it was found that for the majority of providers, their reported personal attitudes matched their perceived social norms. This is because the person and society should not be understood in isolation as the 'self' is a product of interaction with other human beings. Since service providers are part of society, it follows that their prejudicial attitudes mirror the social construct of HIV stigma in society. There was a very long delay before the government of South Africa agreed to roll out free antiretroviral therapy to the multitudes of people living with HIV/AIDS. Actually, the government

had to be compelled by the courts of law to accede after its indictment by the NGO called Treatment Action Campaign (TAC). At that time, there were conflicting messages from the government national department of health and the then President of the country, Thabo Mbeki, was still questioning how a virus can cause a syndrome. This caused a lot of confusion among the public because the health care workers and government of the day seemed to be pulling in opposite directions. In the meantime so many people were dying and others did not know what exactly to do.

The decision by the then President of South Africa, Thabo Mbeki, to debate the scientific orthodoxy and treatment of HIV/AIDS as well as his views had real-time effects and consequences for AIDS-policy making in South Africa which ultimately delayed the implementation of the national ARV rollout programme until 2004. As a result both Mbeki and the South African government were criticized by commentators in the media and elsewhere for lacking the political will and leadership to prioritize AIDS. This was seen as a contributor to an already heightened climate of AIDS stigmatization and misinformation in South Africa.[84]

Before the South African Government rolled out the free- for-all anti-retroviral therapy programme in 2004, there was a lot of planning that went into this process. Many different calibers of healthcare workers were trained to equip them with the skills to handle the programme. There was also provision of special facilities and new infrastructure within hospitals specifically designed for treating people living with HIV/AIDS. This therefore meant that these patients had to be segregated from the rest of the hospital patients. Whereas this was done with the best of intentions, i.e. to centralize and therefore expedite the service, it has sometimes worked to the detriment of the very

programme it was meant to serve. So many patients feel intimidated and ashamed to be seen going to such facilities, whose only purpose is known; to serve people with HIV. This fear of being seen attending the HIV clinic was admitted to by four of the respondents in this study. Several of the respondents brought up this matter of segregation at health facilities as one of their biggest fears whenever it is their day to go for the monthly review and collection of medication.

Because South Africa has the highest number of people living with HIV in the world[85], the established facilities are so overwhelmed by the sheer numbers and therefore, there are always long queues of patients at every facility and the waiting periods are always very long. This is because there are very few heath care workers relative to the number of patients. This sometimes becomes a deterrent to some patients to come for help.

Even though the HIV/ aids epidemic has been around for more than 25 years, and there is a lot of knowledge about the disease, there are still some health care workers that are not vigilant enough or are still not bold enough to suggest to patients to take an HIV test. Sometimes these patients are presenting with WHO AIDS defining illnesses. One of the respondents in this study, Mr. A, was enraged that he had TB twice and used to be admitted to hospital many times for various ailments but no healthcare worker suggested to him to have an HIV test until he was at the brink of death.
When asked as to why none of the healthcare workers advised him to test for HIV, Mr. A said: *"I think they are not properly skilled in dealing with patients, because if ever a patient has TB they must also consider the possibility of HIV testing as one of the options, as it might highlight the problem of HIV when it is still early."*

What Mr. A said in the above statements is a basic principle in managing any patient who has TB. There is a very close association between HIV, TB, and Sexually Transmitted Infections (STI's), such that if a patient presents with any one of them, then it is proper patient management for the healthcare worker to look out for the others. Dealing with any one of these three problems in isolation is a futile exercise. Hence there is a comprehensive national department of health program called HAST (HIV/AIDS, STI's and TB).

At many primary care facilities, there may be one or two or sometimes no designated HIV counselors. This then can mean that either there is no HIV counseling going on or one of the nursing staff who has had a chance to attend a counseling course will double up as a counselor at the expense of her nursing role. This results in a compromised service to the patients and that is why patients like Mr. A can end up missing VCT at their local facilities, despite utilizing the facilities regularly.

In this study, Miss F and Miss G also had similar problems. They saw private practitioners and were admitted in hospital several times with conditions related to HIV but no health care worker advised them to take an HIV test until the respondents themselves asked for it.

Some important factors that did not contribute to delay in this study

1. Poverty

Despite the fact that all respondents in this study were people of low socio-economic status and can be classified as poor, none of them mentioned poverty as the reason why they delayed to start on ART. In the course of the interviews the researcher specifically asked all the respondents if at any

one time they failed to go to a health facility because of lack of means to get there and all of them answered no.

This is because of a number of factors. In their township, there are four clinics and so, most of the people stay within walking distance from such a facility. The ambulance service is also easily accessible for any patient who would want to be taken to the nearest health facility or hospital. No patient is denied medical attention for lack of the nominal fees charged at any health facility in South Africa. It is African tradition for family members or even privileged neighbors to help, voluntarily, with transporting the sick to hospital. Therefore poverty, *per se,* was not a factor that contributed to delay in accessing treatment among the respondents in this study.

2. Witch craft

Another possible factor that the researcher asked all respondents to comment about as to whether it might have contributed to their delay in accessing treatment was if they believed at any time of their illness that they had been bewitched and, if they had consulted traditional healers. All of the respondents said they had had no such thoughts and that if anything; the illness had just increased their faith in God and the church. All my respondents were of the Christian faith.

It is popularly known that in African culture, when mysterious or life threatening diseases occur, many people would tend to think of witch craft and would also consult traditional healers. Given the debilitating nature of HIV/AIDS, one would tend to think that many would have to consider that

option, after all witches and witchcraft remain an option for self diagnosis of illnesses as well as for diagnosis by traditional healers. Commonly people say that HIV hides behind witchcraft since it is more culturally acceptable and avoids personal shame.[86]

The respondents could have felt uneasy to admit to having gone that route, even if they had, for a number of reasons some of which are; although the researcher is a black person, he is not from their tribe and was even unable to speak the local language hence the interviews were carried out in English. Also, it might sound out of place to admit to a medical doctor that you believe in witchcraft or have even been consulting traditional healers. There could therefore have been some bias in these responses.

PROBLEMS/ LIMITATIONS

The researcher was challenged by the fact that he is not well versed with the local language. This may have been a limiting factor in communicating perfectly with the participants.

This study was done at Potchefstroom provincial hospital and on people living in one township of Ikageng next to the city of Potchefstroom. The reasons why people living with HIV/AIDS in other areas of South Africa delay to access antiretroviral treatment might be different from those unearthed in this study. This is especially true since different parts of the post-apartheid South Africa have different problems with some being unique to specific areas. A much wider survey covering a bigger part of South Africa would probably be more revealing.

Whereas this study focused on HIV/AIDS, it is possible that people suffering from other diseases also experience similar problems.

Although respondents in the study were assured that their answers will not affect the way they are perceived by the researcher, the question under study has an element of being judgmental and therefore has the potential of yielding inaccurate answers from the respondents in an effort to conceal what can be perceived as 'incorrect' behavior.

CONCLUSION

Despite the above limitations, this study documents four important reasons that are responsible for late initiation of antiretroviral therapy in people living with HIV in the area of Potchefstroom namely: **stigma and discrimination, ignorance and lack of perceived risk of infection; denial;** and **health care system constraints.**

This study like others done elsewhere has revealed that stigma surrounding HIV/AIDS is the biggest contributing factor as to why people living with the disease tend to present late to health care facilities for help. The ever-presence of stigma and its persistence even in areas where HIV prevalence is high makes it an extraordinarily important yet difficult problem to eradicate. One would expect stigma to decrease with increased visibility of HIV but this is not the case, especially in much of sub-Saharan Africa. Given the fact AIDS stigma has caused enormous barriers to public health programs- from denial to silence, to problems with disclosure, health seeking behavior, and to communal violence, it would be fitting for the public health providers to begin using more creativity in designing AIDS stigma interventions and to implement them on a significant scale. In fact it is now generally accepted that efforts to reduce stigma should be an integral part of all HIV/AIDS programmes.[87]

Although the HIV/AIDS pandemic has been with us for almost three decades and so much has been done in terms of informing and educating people but, as seen from this study, there is still lack of proper knowledge and sheer ignorance of the basic facts about the disease, especially on how it is

transmitted. This unfortunately results in lack of perceived risk of infection with many people and therefore contributes to the high number of new cases still seen.

Although HIV/AIDS is still incurable, Anti-retroviral therapy has been proven to tremendously improve and restore the health of people living with the disease. One would think that automatically everyone who is living with the disease would eagerly come forward to receive treatment, but because of the stigma surrounding the disease, so many people tend to live in denial on learning that they are infected until very late, and some rather choosing to die than accepting the hard fact in order to come forward for help.

Compassion to people living with HIV/AIDS, according them their rights and addressing all the other issues related to stigma will go a long way in addressing the problem of denial.

This study has also revealed that the healthcare system itself is not blame free when it comes to why people present late for treatment. Factors found at healthcare facilities and among health care workers like: inadequate knowledge; lack of adequate, appropriate infrastructure, equipment and staff; and of course stigmatization of people living with HIV/AIDS are some of the issues that need serious attention in order to make the healthcare facilities less intimidating and more user friendly to the people living with the disease.

The researcher recommends that the authorities at Potchefstroom Hospital, where the study was carried out, and the Northwest department of Health try to put in place strategies to address the four

broad themes revealed in this study as the reasons responsible for the late presentation for medical care by PLWHA in Potchefstroom.

REFERENCES

1. UNAIDS/WHO (2006), "ÚNAIDS 2006 Report on the global AIDS epidemic", Annex 2: HIV/AIDS estimates and data, 2005

2. Centre for Actuarial Research , South African Medical Research Council and Actuarial Society of South Africa (2006, November), The Demographic Impact of HIV/AIDS in South Africa- National and Provincial Indicators for 2006"

3. The New York Times (2004, 29th July) "South Africa recycles graves for AIDS victims"

4. WHO (2008), "Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector"

5. Giradi E, Sampaolesi A, Gentile M, Nurra G, Ippolito G. Increasing proportion of late diagnosis of HIV infection among patients with AIDS in Italy following introduction of combination antiretroviral therapy. J Acquir Immune Defic Syndr. 2000;25 (1):71-6

6. Castilla J, Sobrino P, De La Fuente L, Noguer I, Guerra L, Parras F. Late diagnosis of HIV infection in the era of highly active antiretroviral therapy: consequences for AIDS incidence. AIDS. 2002;16 (14): 1945-51

7 Badri M, Lawn SD, Wood R. Short-term risk of AIDS or death in people infected with HIV-1 before anti-retro therapy in South Africa: a longitudinal study. Lancet 2006; 368: 1254-59.

8. Samet JH, Ratendo MJ, Freeberg KA, Stein MD, Heeren T, Libman H. Factors associated with initiation of primary medical care for HIV-infected persons. Am J Med. 1994; 97:347-353.

9. Centers for Disease Disease control and prevention. Recommendations for the use of zidovudine to reduce perinatal transmission of human immunodeficiency virus. MMWR Morb Mortal Wkly Rep. 1994; 43(11): 2-4.

10. Des Prez RM, Goodwin RA. Mycobacterium tuberculosis. In: Mandell GL, Douglas RG, Bennett JE, eds. Principles and Practice of Infectious Diseases. 2ND ED. New York, NY: John Wiley & Sons Inc; 1985: 1384-1387.

11. Anderson DJ, O'Brien TR, Politch JA, Martinez A, Seage GR 3rd, Padian N. Effects of disease stage and zidovudine therapy on the detection of Human immunodeficiency virus type 1 in semen. JAMA. 1992; 267:2769-2774.

12. Grosskurth H, Mosha F, Todd J, Mwijarubi E, Klokke A, Senkoro K. Impact of improved treatment of sexually transmitted diseases on HIV infection in rural Tanzania; randomized controlled trial. Lancet. 1995; 346: 530-536.

13 Quinn TC, Wawer MJ, Sewankambo N, Serwadda D, Li C, Wabwire-Mangeni F, et al. Viral load and heterosexual transmission of human immunodeficiency virus type 1. N Engl J Med. 2000; 342: 921-29.

14 Marks G, Crepaz N, Senterfitt JW, Janssen RS. Meta-analysis of high-risk sexual behavior in persons aware and unaware they are infected with HIV in the United States: Implications for HIV prevention programmes. J Acquir Immune Def Syndr. 2005; 39: 446-53.

15 Wolbers M, Bucher HC, Furrer H, Wolbers M, Cavassini M, Weber R, et al. Delayed diagnosis of HIV infection and late initiation of antiretroviral therapy in the Swiss HIV cohort study. HIV Med. 2008; 9:397-405.

16 Kigozi IM, Dobkin LM, Martin JM, Geng EH, Muyindike W, Emenyonu NI, et al. Late disease stage at presentation to an HIV clinic in the era of free antiretroviral therapy in sub-Saharan Africa. J Acquir Immune Defic Syndr. 2009; 52:280-289.

17 Posse M, Meheus F, Van Asten H, van der Ven H, Baltussen R. Barriers to access antiretroviral treatment in developing countries: a review. Trop Med and Int Health. 2008; 13: 904-13.

18 Sterling TR, Chaisson RE, Keruly J, Moore RD. Improved outcomes with earlier initiation of Highly Active Antiretroviral Therapy among HIV infected patients who achieve durable virologic suppression: longer follow up of an observational cohort study. J Infect Dis. 2003; 188: 1659-1665.

19 Castilla J, Sobrino P, De lA Fuente L, Nouger I, Guerra L, Parras F. Late diagnosis of HIV infection in the era of highly active antiretroviral therapy: consequences for AIDS incidence. AIDS. 2002; 16: 1945-51.

20 Sterling TR, Keruly J, Moore RD: Improved outcomes with earlier initiation of Highly Active Retroviral Therapy among HIV infected patients who achieve durable virologic suppression: longer follow-up of an observational cohort study. J Infec Dis. 2003; 188: 1659-65.

21 Egger M, May M, Chene G, Phillips AN, Ledergerber B, Dabis F, et al.. Prognosis of HIV-infected patients starting highly active antiretroviral therapy: a collaborative analysis of prospective studies. Lancet. 2002; 360 : 119-129.

22 Hammer SM, Eron JJ Jr, Reiss P, Schooley RT, Thompson MA, Walmsley S, et al. Antiretoviral treatment of adult HIV infection: 2008 recommendations of the International AIDS Society-USA panel. JAMA. 2008; 300: 555-570.

23 Althoff KN, Gange SJ, Klein MB, Brooks JT, Hogg RS, Bosch RJ, et al. Late presentation for Human Immunodeficiency Virus care in the United States and Canada. Oxford Jounals Medicine Clinical infec Dis. 50 (11): 1512-1520.

24 Ghandi NR, Skanderson M, Gordon KS, Concato J, Justice AC. Delayed presentation for Human immunodeficiency virus (HIV) care among veterans: a problem of access or screening? Med Care. 2007. 45:1105-09.

25 Abaynew Y, Deribew A, Deribe K. Factors associated with late presentation to HIV/AIDS care in South Wollo Zone Ethiopia: a case-control study. AIDS research and therapy. 2011; 8: 8.

26. Louis C, Ivers L.C, Smith Fawzi M.C, Freedburg K.A, Castro A. Late presentation for HIV care in central Haiti: factors limiting access to care. Aids Care. 2007: 19(4): 487-491.

27. McGrath J, Rundall S, Kaawa-Mafigiri D, Kakande N. HIV treatment for women in Uganda: Increasing access through integrated service provision. Online at: http://www.aids2006.org/web/MOAE0205. PPT. (accessed on 04/10/2008)

29 Kigozi IM, Dobkin LM, Martin JN, Geng EH, Muyindike W, Emenyonu NI, et al. Late disease stage at presentation to an HIV clinic in the era of free antiretroviral therapy in sub-Saharan Africa. J Acquir Immune Defic Syndr. 2009; 52:280-9

30 Kagaayi J, Makumbi F, Nakigozi G, Wawer MJ, Gray RH, Serwadda D, at al. WHO HIV clinical staging or CD4 cell counts for antiretroviral therapy eligibility assessment? An evaluation in rural Rakai district, Uganda. AIDS. 2007; 21: 1208-10.

313131 Weiser D, Heisler M, Leiter K, Percy-de Korte F, Demonner S, Phaladze N, et al. Routine HIV testing in Botswana: a population-based study on attitudes, practices, and human rights concerns. PLoS Med. 2006;3: e261.

32 Kitahata MM, Gange SJ, Abraham AG, Merriman B, Saag MS, Justice AC, etal. Effect of early versus deffered antiretroviral therapy for HIV on survival. N Engl J Med. 2009; 360: 1815-26.

33 Klein D, Hurley LB, Merrill D, Quesenberry CP Jr. Review of medical encounters in the 5 years before a diagnosis of HIV-1 infection: implications for early detection. J Acquir Immune Def Syndr. 2003; 32: 143-152.

34 Bonjour MA, Montagne M, Zambrano M, Molina G, Lippuner C, Wadskier FG, et al. Determinants of late disease-stage presentation at diagnosis of HIV infection in Venezuela: A case-case comparison. AIDS Research and Therapy. 2008; 5: 6.

35 Branson,BM, Handsfield HH, Lampe MA, Janssen RS, Taylor AW, Lyss SB, et al.. Revised Recommendations for HIV testing of adults, Adolescents, and Pregnant Women in Health-Care settings. MMWR Recomm Rep 2006; 55: 1-17.

36 Lyons MS, Lindsell CJ, Ledyard HK, Frame PT, Trott AT. Emergency department HIV testing and counseling: an ongoing experience in a low-prevalence area. Ann Emerg Med. 2005; 46: 22-28.

37 Mahajan AP, Sayles NJ, Patel VA, Remien RH, Ortiz D, Szekeres G, Et al. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. AIDS. 2008; 22: S67-9.

19. Mokae LN, Portillo CJ, Uys LR, Dlamini PS, Greeff M, Chirwa M, et al. The Impact of Taking or Not Taking ARVs on HIV Stigma as Reported by Persons Living with HIV Infection in Five African Countries. AIDS care. 2009; 21: 1357-62.

39 . Petrak JA, Doyle A, Smith A, Skinner C, Hedge B. Factors associated with self-disclosure of HIV sero-status to significant others. Br J of health psychology. 2001; 6: 69-79.

40 Bwambale FM, Ssali SN, Byaruhanga S, Kalyango JN, Karamagi CA.Voluntary HIV counselling and testing among men in rural westernUganda: Implications for HIV prevention. BMC Public Health.2008;263.

41. http://www.psychology.ucdavis.edu/rainbow/html/aids.html (accessed 24/01/2009)

42. WHO (2008) 'Towards Universal Access: scaling up priority HIV/AIDS interventions in the health sector: progress report 2008'

43 Daftary A, Padayatchi N, Padilla M. HIV testing and disclosure: a qualitative analysis of TB patients in South Africa. AIDS Care. 2007; 19: 572-7.

44. CHG (2000) 'Securing our future: Report of the commission on HIV/AIDS and governance in Africa'

45 Creek TL, Ntumy R, Sepone K, Smith M, Mogodi M, Legwaila K, et al. Successful introduction of routine opt-out HIV testing in antenatal care in Botswana. J AIDS. 2007; 45: 102-7.

46 Byamugisha R, Tylleskar T, Kagawa MN, Onyango S, Karamagi CAS, Tumwine JK. Dramatic and sustained increase in HIV-testing rates among antenatal attendees in Eastern Uganda after a

policy change from voluntary counselling and testing to routine counselling and testing for HIV: a retrospective analysis of hospital records, 2002-2009. BMC Health Serv Res. 2010; 10: 290.

47. Deacon H, Boulle A. Commentary: Factors affecting HIV/AIDS-related sigma and discrimination by medical professionals. International Journal of Epidemiology.2006; 36:185-6.

48. Yang Y, Zhang KL, Chan KY, Reidpath DD. Institutional and structural forms of HIV-related discrimination in health care: a study set in Beijing. AIDS Care. 2005; 17:129-40.

49. Surlis S, Hyde A. HIV-positive patients' experiences of stigma during hospitalisation. J Assoc Nurses AIDS Care. 2001; 12:68-77.

50. Stutterheim SE. HIV- related stigma and psychological distress: the harmful effects of specific stigma manifestations in various social settings. AIDS. 2009; 23:17.

51. Reis C, Heisler M, Amowitz LL, Moreland RS, Mafeni JO, Anyamele C, Lacopino V. Discriminatory attitudes and practices by health workers towards patients with HIV/AIDS in Nigeria. PLoS Med. 2005;2 (8): e246.

52. Hentegen V; Jaureguiberry S; Ramilarisoa A; Andrianantoandro V; Belec M. Knowledge, attitude and practices of health personnel with regard to HIV/AIDS in Tamatave (Madagascar). Bull Soc Pathol Exot. 2002 ; 95(2): 103-8

53. Danziger R. Discrimination against people with HIV/AIDS in Poland. BMJ. 1994;308(6937): 1145-7

54 Nyblade L, Stangl A, Weiss E, Ashburn K. Combating HIV stigma in health care settings: what works? J Int AIDS Soc. 2009; 12: 15.

55 Reiss C, Heissler M, Amowitz L, Moreland R, Mafeni J, Anyamele C, Iacopino V. Discriminatory attitudes and practices by health workers towards patients with HIV/AIDS in Nigeria. PLoS Medicine 2005; 2(8): e246

56 Ghaidane AM, Zahiruddin QS, Khatib N, Shirivastav T, Johrapurkar SR. Occupational Exposure to HIV and practices of universal safety precautions among resident doctors. The internet Journal of Health. 2009; 8 (2).

57. Nyblade L, Stangl A, Weiss E, Ashburn K . Combating HIV stigma in health care settings: what works?' AIDS. 2009; 12:15

58. Bachetti P, Moss AR. Incubation period of AIDS in San Francisco. Nature. 1989; 338:251-253.

59. Tarwireyi F. Stigma and discrimination: coping behaviours of people living with HIV and AIDS in an urban community of Mabvuku and Tafara, Harare, Zimbabwe. Centr Afr J Med. 2005;51(7-8):71-6

60. Ulasi CI, Preko PO, Baidoo JA, Bayard B, Ehiri JE, Jolly CM, Jolly PE. HIV/AIDS related stigma in Kumasi, Ghana. Health Place. 2009; 15(1): 255-62

61. Gilmore N, Sommerville A. Stigmatization, scape-goating and discrimination in sexually transmitted diseases: overcoming "them" and "us." Social science and medicine. 1994; 39(9) 1339-1358.

62. Herek G.M; Mitnick, L. AIDS and Stigma. A conceptual frame work and research agenda. 1998. http://psychology.ucdavis.edu/rainbow/html/stigma98 (accessed on 1/12/2008)

63. UNAIDS 2008 Report on the global AIDS epidemic.

64. Otolok-Tanga E, Atuyambe L, Murphy CK, Ringheim KE, Woldehanna S. Examining the actions of faith based organisations and their influence on HIV/AIDS-related stigma: a case study of Uganda. African Health Sciences. 2007; 7(1) 55-60.

65. Simbayi LC, Kalichman S, Strebel A, Cloete A, Henda N, Mqeketo A. Internalized stigma,discrimination and depression among men and women living with HIV/AIDS in CapeTown, South Africa. Social Science and Medicine. 2007; 64(9): 1823-31.

66. Wood K, Lambert H. Coded talk, scripted omissions: the micropolitics of AIDS talk in South Africa. Social Science and Medicine. 2007; 22(3): 213-33

67. Rankin WW, Brennan S, Schell E, Laviwa J, Rankin SH. The stigma of being HIV positive in Africa. PLoS Medicine. 2005;2 (8): 247

68. Campbell C, Nair Y, Maimane S, Nicholson J. "'Dying twice': a multi-level model of the roots of AIDS stigma in two South African communities." Journal of Health psychology.2007;12(3):403-416

69. Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma. What have we learned? AIDS Education and Prevention. 2003;15(1): 49-69.

70. Miller AN, Rubin DL. Factors leading to self disclosure of appositive HIV diagnosis in Nairobi, Kenya: people living with HIV/AIDS in the sub-Sahara. Qualitative Health Research. 2007;17(5) 586-598.

71. Muyinda H, Seeley J, Pickering H, Barton T. Social aspects of AIDS-related stigma in rural Uganda. Health and Place.1997;3(3): 143-147

72. Muula AS, Mfutso-Bengo JM. When is public disclosure of HIV seropositivity acceptable?. Nursing Ethics. 2005 12(3): 288-295.

73. McWhinney IR, editor. A textbook of Family Medicine. 2nd ed. (NY): Oxford University press; 1997.

74. Woudenberg, J (1998). Women coping with HIV/AIDS. Royal Tropical Institute *Bulletin* 344

75. The Associated Press (1998) 'HIV Positive South African woman murdered'

76. Ban Ki-Moon op-ed (2008, 6th August), "The stigma factor", The Washington Times.

77. Brown, L; Macintyre, K; Trujillo, L. Interventions to reduce HIV/AIDS stigma. What have we learned? AIDS Education and Prevention. 2003;15(1): 49-69.

78. Petros G, Airhihenbuwa CO, Simbayi L, Ramlagan S, Brown B. hiv/aids 'othering' in South Africa: the blame goes on. Culture, health and sexuality. 2006; 89(1):67-77.

79. Duffy L. Suffering, shame and silence: the stigma of HIV/AIDS.Journal of the Association of Nurses in AIDS care. 2005; 16(1): 13-20.

80. Halchett LA, Kaponda CPN, Chihana CN. Health seeking patterns for AIDS in Malawi. AIDS Care. 2004; 16(7): 827-833.

81. Li I, Wu Z, Zhao Y, Lin C, Detels R, Wu S. Using case vignettes to measure HIV-related stigma among health professionals in China. Int J Epidemiology 2007; 36: 178-84.

82. WHO (2008) ‘Towards universal access: scaling up priority HIV/AIDS interventions in the health sector: progress report 2008’

83. Li Li, Li-Jung Liang, Zunyou Wu, Chunqing Lin, Yi Wen. Individual attitudes and perceived social norms: Reports on HIV/AIDS-related stigma among service providers in China. Int J Psychol. 2009; 44(6): 443-450.

84. Forsyth B, Vandormael A, Kershaw T, Grobbelaar J. The political context of AIDS-related stigma and knowledge in a SouthAfrican township community. Sahara J. 2008; 5(2):74-82.

85. Shishana O, Rehle T, Simbayi LC, Packer W, Zuma K, Bhana A, et al (2005). South African national prevalence, HIV incidence, behavior and communication survey. HSRC Press. Cape Town, 2005.

86. Duffy L. Suffering, shame and silence: the stigma of HIV/AIDS. Journal of the Association of Nurses in Aids Care.2005; 16(1) 13-20.

87. Campbell C, Foulis CA, Maimane S, Sibiya Z. “I have an evil child at my house”: stigma and HIV/AIDS management in a South African community. Am J Public Health. 2005; 95 (5): 808-15.