

# Delays by people living with HIV/AIDS in accessing antiretroviral therapy

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## Abstract

**Objective:** To understand, by qualitative enquiry, the underlying reasons and narratives for patients that delay in accessing antiretroviral treatment.

**Design:** A qualitative design was used, where patients were interviewed using the free attitude interview technique, after being selected based on a screening question: "How long did it take you to present at a clinic or hospital for treatment after receiving your human immunodeficiency virus-positive result?"

**Setting and subjects:** Eight patients from the human immunodeficiency virus clinic at Potchefstroom were interviewed.

**Outcome measures:** The interviews were transcribed verbatim and organised into themes.

**Results:** The following themes were identified: stigma and discrimination, ignorance and lack of perceived risk of infection, denial and healthcare system constraints. These are discussed and quotations from the interviewed patients included.

**Conclusion:** This qualitative study has contributed to an understanding of why patients delay in accessing highly active antiretroviral therapy. Some of the reasons supplied by patients have been documented globally. Others are poignantly coloured by personal stories. By understanding patients' perspectives and feelings, emphasis can be placed on the reduction of stigma, denial, practical clinic constraints and appropriate types of health education.

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## Introduction

A qualitative study was conducted to establish the reasons why many people living with human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) in the area of Potchefstroom, North West province, presented late for treatment despite the fact that since 2004, the government of South Africa has offered free antiretroviral (ARV) treatment to whoever needs it.<sup>1</sup>

By the end of 2005, there were five-and-a-half million people living with HIV in South Africa. Almost 1 000 AIDS deaths occurred every day.<sup>2</sup> Seventy-one per cent of deaths among those aged between 15 and 49 were caused by AIDS.<sup>3</sup>

Although the South African government has offered free antiretroviral treatment since April 2004<sup>4</sup> at many primary healthcare facilities around the country, many patients still only seek help very late, despite the knowledge and evidence that ARV drugs halt the progress of the disease

process and reverse the damage that is inflicted on the body by HIV.<sup>5,6</sup>

As with other ailments, delayed help-seeking behaviour in people living with HIV/AIDS tends to be associated with poor outcomes for a number of reasons. Firstly, the individual is unable to benefit from therapeutic advances. Secondly, many potential public health benefits are missed when patients present late. Thirdly, late help-seeking behavior has adverse socio-economic implications. Being bedridden because of late-stage HIV/AIDS results in automatic loss of income as work is no longer possible. Because of these reasons, it is necessary to try and establish the factors that are responsible for so many patients seeking help late.

## Method

This was a qualitative study of selected patients recruited into the ART treatment programme at Potchefstroom Hospital Wellness Clinic who fulfilled the inclusion criteria. The free attitude, one-on-one interview method was used.

Because of the difficulty in establishing when a patient was first diagnosed with HIV, the following were used as inclusion criteria in the study:

- One of the counsellors at the Potchefstroom Hospital Wellness Clinic helped the researcher to screen and identify suitable respondents for the study. Patients were recruited after being asked the following question: “How long did it take you to present at a clinic or hospital for treatment after receiving your human immunodeficiency virus-positive result?” If the time delay between receiving the positive result and presenting to a health facility for help was a year or more later, the patient would be included. This was to allow him or her the benefit of overcoming practical difficulties within a certain time frame.
- All selected respondents were *compos mentis* adults, aged 18 years or more, presenting for ART for the first time at the Potchefstroom Wellness Clinic with an AIDS-defining illness/World Health Organization (WHO) stage 3 or 4 disease, or with a CD4 count of below 200, and who could converse meaningfully in English.
- HIV infection results in a chronic disease with a median time of 11 years to the development of AIDS. So any patient who presents for help with an AIDS-defining illness or WHO stage 3 or 4 was deemed to be a late presenter.

Exclusion criteria were:

- Pregnant women, or those whose diagnosis of HIV was made during antenatal care. This was because the prevention of mother-to-child transmission (PMTCT) initiative makes the ART programme more accessible to pregnant women than to the population in general.
- Any mother who had ever been on any form of ARV drug programme for PMTCT.
- Prisoners or inmates, because the choice of seeking care may not have entirely been their own initiative.
- Children below the age of 18 years, because of limited autonomy.

The interviews were conducted during August and September 2009. The site of this study was Potchefstroom Hospital’s Wellness Clinic in the North West province. At the time of the interviews, approximately 3 000 patients were receiving ART at the clinic. The majority of patients originated from the predominantly black township of Ikageng, about 5 km west of Potchefstroom city centre. Four local primary care clinics in this township are manned by professional nurses. Doctors pay regular visits to each of them.

Most of the people were unemployed, of very low socio-economic status, and lived below the poverty line. The population was dynamic. Many men had left in search of work in larger cities, returning on weekends or at the end of the month to visit their families. This could be a significant factor in the high incidence of HIV/AIDS in this area.

The predominant question that was asked was: “What were the reasons for your delay in starting on antiretroviral treatment?”

The collected information was transcribed, then analysed by using the cut-and-paste method, interpreted and formulated into themes that were used to make proper sense of the main reasons cited by respondent for delaying in initiating treatment.

Permission for this research was granted by the ethics committee of the University of the Witwatersrand (clearance certificate number M090479).

## Results

In this study, eight patients were interviewed: three women and five men, coded alphabetically for confidentiality, e.g. Mr A, Miss B and Mrs C.

When the interviews were transcribed and analysed, it emerged that the reasons why respondents delayed initiating antiretroviral treatment could be broadly categorised into four themes: stigma and discrimination, ignorance and lack of perceived risk of infection, denial and healthcare system constraints.

### Stigma and discrimination

Seven out of the eight respondents reported having suffered from some form of stigma and discrimination. This was the most important reason why they delayed initiating ART treatment. On learning that he was HIV-positive, Mr A said: “I felt guilty a lot 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?” and “I think from that it created a real fear for me at other stages because my family is well respected.” Mr C: “When you are HIV-positive, everyone thinks you are sexually reckless”. Fear of stigma propelled him to use the hospital, rather than the nearby clinic. Mr D: “I did not want to live with HIV. It is a shame. Everywhere you pass people talk about you and how sickly you look”.

Miss B remembers the stigma and discrimination that she suffered with bitterness. Her entire family abandoned her and her husband left her. “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.”

### Ignorance and lack of perceived risk of infection

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

Mr A: “At that time, I knew HIV is a death sentence at the end of the day. The information was like you go for this, you get the medication, but it was never explained to you what

you will get there". He was also affected by the national South African policy on HIV/AIDS at the time: "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".

Mr D: "By the time my CD 4 count was zero, I didn't know at all. 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". Miss F: "The reason why I did not come earlier to the hospital is because I wasn't aware that I was.... uhm! By then, I didn't have anyone in my life, so I didn't think the sickness could be with me".

## Denial

Five of the eight respondents were affected by denial. Two reported that their partners died of AIDS without seeking help. Many of the respondents couldn't perceive themselves as being infected with HIV, despite their failing health.

Mr C: "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 died with it secretly, only I and her knowing".

Mr E: "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".

Miss G: "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 had the worst case scenario of denial. His health was failing, he tested positive on three different occasions by three separate doctors in different places, but he still couldn't believe that he was living with HIV.

## Healthcare system constraints

Some of the respondents were seriously affected by factors that they encountered at the different health facilities that they attended.

Mr A displayed a lot of anger: "I had repeat of tuberculosis, then after all the treatment I was still admitted and still ill when they did their check-ups, 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".

Miss B: "There are some times that I feel bad when I go to hospitals. 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. I even have sometimes to move people to go with me so that I can be their mouthpiece because they can't explain everything".

Miss G was often sick, and yet despite numerous visits to her general practitioner, the suggestion that she should test for HIV was never made. "My boss said '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 do blood tests".

Finally, when she visited the hospital, she was tested. However, for some reason, the healthcare workers lost the courage to give her the result. Out of fear, she didn't go back. This resulted in considerable time being lost before she was put on ART as her HIV status was unknown 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 4 October 2007, when I came to take my blood results, they said to me: 'I don't know'. There was one sister who said they couldn't find my file. Then unfortunately, they said the doctor who was in charge was removed from here, he was somewhere else. I must come another time."

## Discussion

The majority of respondents in this study reported having suffered stigma and discrimination. This, together with ignorance and a lack of perceived risk of being infected, were the most common factors that led to delays in ARVs being initiated. This is in line with what has been reported by similar studies elsewhere.<sup>7,8</sup>

## Stigma and discrimination

Etymologically, the term "stigma", derives from the Greek word that refers to a tattoo mark. Generally, it has two meanings. One is derived from Christianity and denotes bodily marks that resemble those of the crucifixion of Jesus Christ. The second meaning is secular, denoting marks of disgrace, discredit or infamy.<sup>9</sup>

Factors that contribute to HIV/AIDS-related stigma are:<sup>10,11</sup>

- HIV/AIDS is a life-threatening, incurable disease. So, people react to the knowledge that they have it in very strong ways.
- HIV infection is associated with behaviour, such as homosexuality, drug addiction, prostitution or promiscuity, that is already stigmatised in many societies.
- Most people become infected with HIV through sex, which often carries moral implications.
- There is considerable inaccurate information on how HIV is transmitted. This creates irrational behaviour and misperceptions of personal risk.

- HIV infection is often thought to be the result of personal irresponsibility.
- Religious or moral beliefs have led some people to believe that being infected with HIV is the result of a moral blunder, such as promiscuity or deviant sex, which they believe deserves to be punished.

Six of the eight respondents were abandoned by their sexual partners after learning that they were living with HIV and after disclosing this to their partners.

Because of the stigma that is associated with HIV/AIDS, euphemisms have developed in different parts of Africa which refer to the disease. For instance, terms like *kamuyoola* (was caught in a trap) and *kakokolo* (scarecrow) from Uganda; and *ashawo* (prostitute) from Nigeria, refer to someone living with the disease. In South Africa, *amagamaamathathu* (the three-letter word) refers to HIV, while in Malawi, lay people refer to the disease as *kaliwondewonde* (slim disease) or *ntengano* (the disease that leads to the husband and wife dying together, or one after the other).<sup>12</sup>

## Ignorance

It is clear from the research that some people are still ignorant of the basic HIV transmission facts, namely that anyone who is sexually active is at risk of infection, and that being faithful alone does not guarantee protection simply because a person's partner might not be faithful, or even if he or she was, he or she could already be infected. Therefore, having unprotected sex could result in infection.

## Denial

Denial is a way of reinforcing that HIV/AIDS is a disease that affects others, and not oneself.<sup>13</sup> It is one of the ways of responding to a frightening or intolerable situation. Many patients would rather try and find their own explanation for their illness than accept that they have HIV. The most common explanations for HIV in sub-Saharan Africa are that it is caused by witchcraft, poisoning or body pollution.

Many people prefer to claim that they are bewitched, or have what they call "normal" tuberculosis, other than accept that they have HIV/AIDS.<sup>14</sup> In this study, several respondents admitted to having been in denial at varying times. Some of them eventually informed their sexual partners about their newly diagnosed HIV-positive status, but then their partners went into denial. Often, both of them died without ever going for help.

## Healthcare system constraints

Many studies have revealed that healthcare gives treat people who live with HIV differently.<sup>15,16</sup> Lack of confidentiality has been mentioned as a particular problem in healthcare settings. Many people living with HIV/AIDS are not able 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.<sup>17</sup>

There was a very long delay before the government of South Africa agreed to implement free ART therapy to the multitudes of people living with HIV/AIDS.<sup>18</sup> The government had to be compelled by the courts of law to accede after its indictment by the Treatment Action Campaign. At that time, there were conflicting messages from the government national department of health and the then president of the country, Thabo Mbeki, who questioned how a virus could cause a syndrome.<sup>19</sup> This caused considerable confusion among the public because the healthcare workers and government of the day held opposing viewpoints. In the meantime, many people were dying and didn't know what to do.

Because South Africa has the highest number of people living with HIV in the world,<sup>20</sup> the established facilities are often overwhelmed by the sheer numbers. Therefore, there are long queues of patients at facilities. This is because there are very few healthcare workers relative to the number of patients. This is sometimes a deterrent to patients trying to get help.

## Conclusion

While acknowledging the language limitations, as well as the sensitivity of the research, 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. These are stigma and discrimination, ignorance and lack of perceived risk of infection, denial and healthcare system constraints.

It is now generally accepted that efforts to reduce stigma should be an integral part of all HIV/AIDS programmes. Although HIV/AIDS is still incurable, ARV therapy has been proven to tremendously improve and restore the health of people living with the disease. The assumption is that everyone who is living with the disease will be able to access treatment, but because of the stigma surrounding HIV/AIDS, many people live in denial for a long time once they have discovered that they are infected.

Compassion towards people living with HIV/AIDS, affording them their rights and addressing all the other issues that relate to stigma will help considerably in addressing the problem of denial.

This study has also revealed that the healthcare system is partly to blame for why people present late for treatment. Inadequate knowledge, a lack of adequate infrastructure, equipment and staff, and stigmatisation of people living with HIV/AIDS, are some of the issues that need significant attention in order to make the healthcare facilities less intimidating and more user-friendly to people living with the disease.

## Conflict of interest

The authors declare that they have no financial or personal relationships which may have inappropriately influenced them in writing this paper.

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