

Understanding socio-demographic and behavioral factors that result in patients seeking care with advanced stage HIV/AIDS disease in the context of free public sector access to Antiretroviral Therapy

Introduction

In 2009, President Jacob Zuma announced major changes to the national AIDS treatment and prevention programme, that would see it become the largest Antiretroviral (ARV) programme in the world and banish the AIDS denialism inherited from the previous administration (Pillay, White & McCormick, 2012). He also announced the HIV Counseling and Testing (HCT) campaign. This campaign sought to test 15 million people for HIV and screen for Tuberculosis (TB) by 2011. In 2011, a further policy change was made. All those with a CD4 count less than 350 cells/ μ l and those co-infected with HIV/TB, regardless of their CD4 count, became eligible for ARVs, thus making South Africa fully compliant with the WHO ART guidelines (Pillay, White & McCormick, 2012).

However, despite all this, people are still failing to access ART. According to Statistics South Africa, in 2011, 10.6% of the total population of 50.59 million, were living with HIV. Of those living with HIV/AIDS, only 1 058 399 people were receiving ART (*StatsSA*, 2011). UNAIDS estimates that in South Africa only 40-59% of people eligible for ART are receiving treatment (*UNAIDS*, 2011). Little is known about the social circumstances around late presentation for care, and whether or not this is a factor of testing late in the course of HIV disease; denialism, limited access to services or fear of negative social consequences. We plan to conduct a prospective mixed methods study to investigate the reasons why patients with CD4 counts < 100 present for ART care so late in the course of their disease.

Literature Review

CD4 lymphocytes are an important part of the human immune system. As the AIDS disease progresses, a person CD4 lymphocytes are progressively depleted (Yarchoan et al., 1991). Thus, a person's CD4 count is a way of measuring the progression of HIV/AIDS (Yarchoan et al., 1991). A person with a CD4 count below 500cells/ μ l is at risk of developing various infections such as TB (Jung & Paauw, 1998). A person with a CD4 count of 350cells/ μ l is eligible for ART. When a person has a CD4 count of 200cells/ μ l and below, they are considered to be high risk of contracting opportunistic infections. A person with a CD4 count below 50cells/ μ l is considered extremely ill and the HI virus very far advanced (Jung & Paauw, 1998). Patients who present late (less than 200 cells/ μ l) tend to have poorer prognoses, receive less benefit from highly active ART (HAART) and incur more medical costs (Krentz, Auld, & Gill, 2004).

Failure to find treatment can be either an issue of access to healthcare facilities or an issue of health seeking behaviour. There has been much research conducted regarding access to ART especially in developing countries where access to medical care is often a struggle. Posse et al. (2008) did a meta-analysis of studies assessing the access to ART that HIV positive patients in the developing world have. They applied Aday and Anderson's (1974) model for accessing health services as a conceptual framework. This model provides a useful overview for understanding a person's relationship with the healthcare system and their propensity for seeking help. The model divides accessing health services into two levels: health system level and population level (Posse et al., 2008). Barriers to access can be present at both these levels.

Health System Level Barriers

Health system barriers fall into two categories: resources (labour and capital) or organisation (how the resources are put to use) (Aday & Anderson, 1974). The most commonly reported barrier was travelling long distances in order to access treatment facilities (Kunihira, Nuwaha, Mayanja, & Peterson, 2010; Mshana et al., 2006; Posse, Meheus, Van Asten, Van Der Ven, & Baltussen, 2008). Organisational impediments reported on include the reputation of healthcare facilities for being confusing and having long waiting lines (Mshana et al., 2006), lack of coordination within the healthcare facility and limited involvement of the community in the planning of healthcare delivery (Posse et al., 2008).

Population Level Barriers

Barriers at the population level can be grouped into three categories: predisposing (determines a person's propensity to seek help, e.g. age, gender, race), enabling (the means a person has available to them to access health services) and need (Aday & Anderson, 1974). Many of these population level barriers are factors which affect health seeking behaviour.

Common reasons for not accessing ART on a population level include the perceived stigma of having HIV/AIDS, a possible negative reaction from loved ones, and lack of information or education about treatment (Posse et al., 2008). Other disabling reasons include: the perceived high cost of treatment, financial barriers in accessing treatment (transport costs, taking time off work etc.), being too busy taking care of others, fear of being diagnosed as positive and fear of death (Day et al., 2003; Krentz et al., 2004; Kunihira et al., 2010; Posse et al., 2008).

Aims and Rationale

The aim of this research is to understand socio-demographic and behavioral factors that result in patients seeking care with advanced stage HIV/AIDS disease in the context of free public sector access to Antiretroviral Therapy.

A secondary objective will be to develop a measure that can be used to assess health seeking behaviours of HIV positive South Africans.

A low CD4 count has been identified as a leading cause of mortality. Therefore, those who present for care in the advanced stages of their disease are at greater risk. As such, this study could have implications at both a community and individual level by aiding in the development of a targeted public health intervention to reduce the morbidity and mortality of people in the advanced stages of HIV/AIDS.

Research Questions

The main research questions are:

1. What are the reasons, at a health system level, for participants only seeking treatment and or testing and once their CD4 count ≤ 50 cells/ μ l.
2. What are the reasons, on a population level, for participants only seeking testing and treatment once their CD4 count ≤ 50 cells/ μ l.
3. Are participants testing for the first time?
 - a. If yes, why?
 - b. If no, is this the first time the participant has sought treatment?
 - i. If yes, why?
 - ii. If no, what happened during their previous ART experience?

Methodology

Research Design

This research will be conducted utilising a two-staged, mixed method approach. The first stage will qualitatively explore the possible reasons why people present for care late. This will be done through conducting semi-structured focus group with participants who are HIV positive and present for care with a CD4 count of less than 50cells/ μ l. Qualitative research is primarily concerned with understanding human behaviour (Silverman & Marvasti, 2008) and by allowing participants to freely express themselves a better understanding of the issues at hand can be developed. The aim of this stage of the research is to develop a large pool of items, using the language and categories provided by the participants. In addition to participant focus groups, informal staff focus groups will also be held to better understand the issues and to gain another perspective.

This pool of items will then be used in the second stage of the research. The aim of the second stage of this project is to develop a quantitative scale to measure health seeking behaviour. By conducting the research in this manner, it is hoped that the possible tension (push-pull factors) surrounding health seeking behaviour can be captured and investigated.

Although this process is presented as two separate and distinct phases, it may be somewhat iterative. For example, after analysing the focus group(s) and creating the pool of items, it may become clear that a particular issue has not been fully captured and thus, more discussion regarding this issue will be needed.

Sample

The sampling criteria for this project is men and women over the age of 18, who are HIV positive and have a CD4 count below 50cells/ μ l. The sample will be drawn from the greater EThekwini area and will all be patients or people who sought care from the Caprisa EThekwini Research Site in Berea, Durban. For the scale, a group of HIV positive patients with a CD4 count between > 350 cells/ μ l will also be sampled in order to have a comparison group.

Due to the specific nature of the selection criteria, purposive sampling will be utilised. Eligible participants will be offered the opportunity to participate.

Phase One

Between six and ten people will be required for the focus group. If necessary, the focus group may be divided according to gender.

Phase Two

For the questionnaire, those who are willing to participate will be given the questionnaire and asked to complete it then and there. The questionnaire will require approximately 30 people to pilot the questionnaire and 70 for a final sample

Ethical issues in sampling

It is acknowledged that the population of interest, and therefore the sample, is a vulnerable one and as such, every care will be taken to act in the participants' best interests. Those who participate in the focus group and those who complete the questionnaire will be required to sign two different consent forms (see Appendix A and B respectively). The consent forms will explain the nature of the research and detail what is expected of the participants should they choose to participate. It will also, very clearly, state that their participation is voluntary and they can withdraw at any time.

The participants completing the questionnaire will be able to remain completely anonymous. Their healthcare worker can provide and collect the questionnaire from the participants and no personally identifiable information will be asked of the participants in the questionnaire.

While the participants involved in the focus group cannot remain anonymous, their confidentiality will be protected. The participants will be asked, both verbally (during the

focus group) and in writing (in their consent forms) not to discuss with anyone who participated in, and what was spoken about during, the focus group.

No personally identifiable information will be included, in any way, when the results of this project are disseminated.

Data Collection

Phase One

A focus group will be conducted with approximately 8 participants. The aim of this will be to explore the reasons for presenting late and create a large pool of approximately 120 items. The focus group will be arranged at a time convenient to the participants and facilitator. The focus group will take place in a private room at the Caprisa EThekweni Research Site in Berea, Durban.

It is likely that the participants will be *isiZulu* first language speakers. As such the focus group will be conducted in *isiZulu*. A first language *isiZulu* speaker will be asked to facilitate the focus group. (S)he will be given an overview of the research project and trained with regards to the focus group schedule, the types of responses to probe and the kind of information the project is specifically looking for. With the participants' consent, as stipulated in the informed consent form, the focus group will be recorded and transcribed verbatim. The transcriptions will be translated into English and once again back-translated into *isiZulu* to ensure the accuracy of the transcriptions. The person doing the transcribing will be trained in how to transcribe a recording verbatim. In addition, the people doing the translating, the first translation and the back-translation, will be two different people.

Phase Two

The second phase of data collection will require participants to complete the questionnaire developed as a result of the focus groups. The questionnaire will first be piloted on approximately 30 people and adjusted accordingly. An example of the type of items the scale will include can be found in Appendix D. The final scale will be administered to approximately 70 people. Of those 70, approximately 30 will be people with a CD4 count between 300 to 400cells/ μ l. This will be done to allow for comparison between the two groups and validation of the scale. No personally identifiable information of the participants' will be requested anywhere on the scale. The informed consent form and the completed questionnaires will be kept separately and in a locked, secure cupboard to ensure confidentiality. The questionnaire and informed consent forms will also be translated into *isiZulu*.

Data Analysis

Phase One

A thematic analysis will be done on the data produced in the focus groups and categories or themes will be developed. The five steps of thematic analysis as discussed by Terre Blanche et al. (2006) will be followed. These five steps are familiarisation and immersion in the data, inducing themes, coding, elaboration, and interpretation and checking (Terre Blanche et al., 2006). From the themes identified through the thematic analysis, instances of what said in the focus group will be categorised. These instances will then be developed into attitudinal items, which will then make up the pool of items for the pilot measures.

Phase Two

The pilot measure will be tested to see if participants understand the instructions and the meaning of the items. Item analysis will then be done on the scale to ensure that all the items correlate well with one another. In addition, those items that have no discriminatory power will be removed. A factor analysis will also be done to ensure that the scale has a whole is consistent and measures the same underlying construct, namely, health seeking behaviour. Once the scale has been appropriately adjusted, it will be implemented. Once the final scale has been administered, an one-way ANOVA will be computed.

Timeframe

Task	Task Completion Date
Ethics Approval Granted	End of March
Focus groups (conducting and analysis of data) and development of preliminary scale	19 April
Piloting scale	10 May
Analysis and adjustment of scale	31 May
Administering final scale	28 June
Analysis of results	19 July
Final write up	16 August

Dissemination of Results

The results of this project will be written up in the form of a journal article and submitted to a journal for publication. If the results prove to be of interest, paper may also be presented at social science conferences.

Budget

Item	Approximate Amount
Refreshments for focus group	R150
Reimbursement of travel costs for members	R30 x 8 people = R240

of focus group	
Photocopying	80c x 550 pages = R440
Translator	R100 x 4 pages = R400
Focus group facilitator	R100 x 1 hour = R100
Total	R1330

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Appendix A: Informed Consent form for Focus Group Participants

Short Title of study: **Why people with HIV/AIDS seek testing and/or treatment so late in the progression of their virus/disease: Developing a measure to assess the reasons why.**

Information for Participants

Principal Investigator: Dr. Kogieleum Naidoo

Address: Caprisa EThekweni Clinic

3 Richards Road

Berea

4000

Telephone: 031 307 3936

Contact: Ms Charlene Harichund

Email: Harichundc@ukzn.ac.za

Telephone: 031 260 4304/1889

Ethics committee: UKZN Humanities and Social Sciences Research Ethics Committee

Instructions:

1. Please read the information contained within this form carefully ensuring that you understand everything about the nature of this research and your involvement in it
2. If you have any questions please do not hesitate to ask either the researcher, counselors or nurses
3. Once you are sure that you have understood everything and are willing to participate in the study, you will be given a form to sign saying that you have read this document and are willing to participate in the study
4. **A Copy of this** document is yours to keep. Should you have any questions regarding the research or any difficulties arise as a result of your participation in this research, please feel free to contact **Ms Charlene Harichund**, whose contact details you will find above.

Introduction

This study aims to understand the reasons why people access healthcare services when they do. Often people will go seek care when they have been sick for a long time and could have received help sooner.

Why is this study being done?

If we can understand the reasons why people go for help so late, we can address them and perhaps improve the way healthcare services are delivered and improve the quality of life for many.

Who can take part in this study?

Anyone over the age of 18 who is HIV positive and has a CD4 count of less than 50cells/ μ l

Is it necessary for me to take part in this study?

No. Participation in this study is purely voluntary. If you choose to not participate in this study, your participation in other Caprisa studies and your care at the Caprisa EThekwini Clinic will not be compromised in any way.

What do I have to do if I participate in this study?

Your participation in this study will require you to partake in a group discussion. This group discussion will take approximately 30 to 45 minutes and there will be approximately 8 other people there. The researcher will ask the group questions about why you came to seek help, what has stopped you from seeking help in the past and how you find your experience at the clinic. You don't have to answer all the questions and you can leave at any time if you feel uncomfortable. In order to respect each others' privacy, we ask that once you leave the group discussion you do not tell anyone else about who was in the group or what they said.

How many people will take part in this study?

There will be only 8 people taking part in the group discussion. However, your answers will help with creating a questionnaire that will be given to approximately 100 people to complete.

What are the benefits of participating in this study?

You will not personally receive any benefits from participating in this study other than having a forum to express your feelings.

Will I receive payment?

You will not receive payment but you will be reimbursed R30 for travel expenses.

What are the costs to me?

We wish to make your participation in this study as easy as possible and hope that you won't incur any costs. However, we cannot reimburse you more than R30 for travel expenses.

What are my rights as a volunteer in a research study?

As a volunteer in this study you can withdraw at any time you choose. If you decide to withdraw then the answers you provided will no longer be used in any way. At no time after this study will any information that can personally identify you be reported anywhere.

What if I have question or problems?

If you have any questions about the study or experience any problems as a direct result of your participation in this study, you can contact either Dr. Kogieleum Naidoo or Rosemary Brown whose contact details can be found on the front page of this document.

Signature

Name of participant

Date

Signature

Witness

Date

Signature

Appendix B: Informed Consent form for participants completing the questionnaire

Short Title of study: **Why people with HIV/AIDS seek testing and/or treatment so late in the progression of their virus/disease: Developing a measure to assess the reasons why.**

Information for Participants

Principal Investigator: Dr. Kogieleum Naidoo

Address: Caprisa EThekwini Clinic

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4000

Telephone: 031 307 3936

Contact: Charlene Harichund

Email: Harichundc@ukzn.ac.za

Telephone: 031 260 4304/1889

Ethics committee: UKZN Humanities and Social Sciences Research Ethics Committee

Instructions:

1. Please read the information contained within this form carefully ensuring that you understand everything about the nature of this research and your involvement in it
2. If you have any questions please do not hesitate to ask either the researcher, counselors or nurses
3. Once you are sure that you have understood everything and are willing to participate in the study, you will be given a form to sign saying that you have read this document and are willing to participate in the study
4. **A Copy of this** document is yours to keep. Should you have any questions regarding the research or any difficulties arise as a result of your participation in this research, please feel free to contact **Ms Charlene Harichund**, whose contact details you will find above.

Introduction

This study aims to understand the reasons why people access healthcare services when they do. Often people will go seek care when they have been sick for a long time and could have received help sooner.

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If we can understand the reasons why people go for help so late, we can address them and perhaps improve the way healthcare services are delivered and improve the quality of life for many.

Who can take part in this study?

Anyone over the age of 18 who is HIV positive and has a CD4 count of less than 50cells/ μ l

Is it necessary for me to take part in this study?

No. Participation in this study is purely voluntary. If you choose to not participate in this study, your participation in other Caprisa studies and your care at the Caprisa EThekwini Clinic will not be compromised in any way.

What do I have to do if I participate in this study?

Your participation in this study will require you to complete a questionnaire about why you came to seek help and what has possibly stopped you from seeking help in the past.

How many people will take part in this study?

Approximately 100 people will be asked to fill in this questionnaire.

What are the benefits of participating in this study?

You will not personally receive any benefits from participating in this study.

Will I receive payment?

You will not receive payment for your participation in this study.

What are the costs to me?

You won't incur any costs from participating in this study.

What are my rights as a volunteer in a research study?

As a volunteer in this study you can withdraw at any time you choose. If you decide to withdraw then the answers you provided in your questionnaire will no longer be used in any way. At no time after this study will any information that can personally identify you be reported anywhere.

What if I have question or problems?

If you have any questions about the study or experience any problems as a direct result of your participation in this study, you can contact either Dr. Kogieleum Naidoo or Ms Charlene Harichund whose contact details can be found on the front page of this document.

Signatures

Name of participant

Date

Signature

Witness

Date

Signature

Appendix C: Preliminary Focus group schedule

(Questions loosely related to research question 1)

- 1.1.1. Is it easy for you to come to the clinic?
- 1.1.2. Is finding transport easy?
- 1.1.3. Do you have to take off work?
- 1.1.4. Are their people you normally look after?
- 1.1.5. Any other issues that make it easy/difficult for you to come to the clinic?

- 1.2. Did you tell anyone you were coming here today? ((probe: why, why not))

- 1.3. How does coming to the clinic make you feel?
 - 1.3.1. Do you feel comfortable coming to the clinic? ((probe: yes, most comfortable? no, most uncomfortable?))
 - 1.3.2. Do you feel anxious coming to the clinic? ((probe: yes, Why? No, why?))

- 1.4. Do you think anything could be done to make your experience at the clinic better? ((probe: what? Why not?))

(Questions loosely related to research question 2)

- 2.1. What do you know about HIV/AIDS?
 - 2.1.1. Where/how did you learn about it?

- 2.2. How did you feel when you were diagnosed HIV positive?
 - 2.2.1. How did you feel before you came to be tested? ((probe: sick/well? Long time/relatively short? Anxious you were HIV+))
 - 2.2.2. How do you feel about being on treatment? ((probe: relieved? Hassle? Anxious? Why?))

- 2.3. What do you know about ART?
 - 2.3.1. Do you feel like you know enough?
 - 2.3.2. Do you wish you knew more? ((probe: yes, why? No, why?))
 - 2.3.3. Where did you learn what you know?
 - 2.3.4. Did paying for ART ever bother you?
 - 2.3.5. If you were the government, how would you educate people about ART?

(Questions loosely related to question 3) (To be asked first)

- 3.1. Have you been tested before (most recent test date)
 - 3.1.1. If no, why not?

- 3.2. Have you undergone ART before?
 - 3.2.1. Why did you stop?
 - 3.2.2. What did you experience while on ART? ((probe: pleasant, why? not pleasant, daily hassle, stigma, side effects?))

Appendix D: Example of items that may be used for the final scale

Demographic Info

Age:

Gender:

Testing for the first time: yes/no

On ART for the first time: yes/no

CD4 count:

Participants will be asked to respond according to a Likert Scale. The options will be strongly agree (1), agree (2), disagree (3), strongly disagree (4).

Testing

1. I was scared to come here today
2. I have been feeling ill for quite sometime
3. When I first started feeling ill, I didn't think it was serious?
4. I am glad I came here today
5. I know how HIV is spread
6. I wanted to know my status
7. I am glad I know status
8. The fear of being HIV positive kept me from coming to find out my status
9. Knowing my status has changed the way I think about people with HIV/AIDS
10. Now that I know my status I feel...
 - a. Relieved
 - b. Depressed
 - c. Anxious
 - d. Hopeless
 - e. Anxious to start treatment
11. I waited to get tested because I was scared of what the result would be

Treatment

12. I feel less anxious now that I am on treatment
13. I worry about what others will think of me because I am on ART
14. I hide my ART from others
15. People respond negatively when I tell them I am on ART
16. People respond positively when I tell them I am on ART
17. I know a lot about HIV/AIDS
18. I have taken ARVS before
19. I talk to others about preventing the spread of HIV/AIDS
20. My partner knows I am HIV positive
21. It was easy for me to come to the clinic today

22. I had to travel far to come to the clinic today
23. I have to take the day off work to come to the clinic
24. When I need to come to the clinic I don't let what others think/say stop me from coming to the clinic
25. Sometimes I can't come to the clinic because I have to take care of someone