Barriers to Access to Antiretroviral Treatment in Babati, Tanzania

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Abstract

Sub-Saharan Africa is the region in the world most severely affected by HIV, and Tanzania is among the most severely affected countries in the region. The introduction of antiretroviral treatment has offered hope to people living with HIV/AIDS, improving their quality of life significantly. Still, there are individuals living with HIV who either lack access to ART, or choose not to make use of the available treatments. The purpose of this thesis is to identify underlying factors perceived as barriers for HIV-positive individuals to initiate and maintain Antiretroviral treatment in Babati District, Tanzania.

Twenty semi-structured interviews were carried out between the 15th of February and 6th of March 2016. The interviews were conducted with ART-patients, health workers and members of the community. An analysis was made within a theoretical framework based upon Goffman's notion of stigma and the Initial Behavioral Model by Andersen. The following obstacles to access to ART were indicated by the findings: HIV/AIDS related stigma issues, discrimination, economic barriers, ignorance due to lack of education, counseling on HIV treatment, and beliefs that HIV can be cured by traditional healers.

Keywords: Access to ART; HIV; Antiretroviral therapy; stigma; behaviours; Tanzania
**Acknowledgements**

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1. Introduction

HIV/ AIDS is a significant and growing public health concern worldwide. In 2013, an estimated 35 million people were living with HIV in the world, 2.1 million people became infected and 1.5 million lost their lives in AIDS-related illnesses. Sub-Saharan Africa is the world’s most severely affected region. Though it is home to only 10% of the world’s population, it shelters about two thirds of the total number of people living with HIV globally (UNAIDS, 2014).

Today in Tanzania as in most Sub-Saharan African countries, HIV and AIDS does not only cause tremendous human suffering, it has also become a socio-economic and developmental problem (Ramadhani et al, 2012). The introduction of antiretroviral treatment (ART) has offered hope to people living with HIV/AIDS, improving their quality of life significantly as well as reducing AIDS-related deaths (UNAIDS, 2014). Since November 2004, the Ministry of Health and Social Welfare of Tanzania (MoHSW) has been coordinating a nationwide care and treatment programme, aiming to provide ART to People Living with HIV and AIDS. The MoHSW in collaboration with implementing partners has realized significant improvements in this program. By December 2010, a total of 704,040 HIV infected people had been enrolled at 1100 health facilities throughout the country. However, out of the estimated 440,000 HIV-infected Tanzanians who are eligible, only 335,292 are currently on ART (UNAIDS, 2014). The cost of drugs is not a barrier to access to ART, since drugs are provided free of cost to eligible patients in Tanzania (Mkonyi, 2016). Therefore, other explanations must be sought for why some HIV-infected people do not take ARV drugs in Tanzania.

A few studies have focused on ART patients’ health-seeking behaviour. They have identified some factors affecting sustained attendance at treatment clinics in Tanzania (Nsigaye et al, 2009, Roura et al 2009). Other researchers have explored the experiences of patients with medication use, their perceptions about facilitators of and barriers to adherence and how adherence can be facilitated (Lyimo et al 2012). However, there has been limited research into barriers that prevent those who have not started taking ARV drugs from seeking treatment at clinics in Tanzania, which indicates the need for further research concerning this topic.

1.1 Objective & research question

The main objective of this thesis is to provide a deeper understanding of why some HIV-infected people in Babati do not start with ART, even though treatment is free. This will be done by describing and analysing factors perceived by health workers, ART-patients and members of the community to be barriers to ART access, followed by an attempt to identify underlying causes.
Research Questions

- What underlying factors are perceived by health workers, ART patients and community members to be the primary barriers to HIV/AIDS infected people’ to start antiretroviral treatment in Babati, Tanzania?

2. Theoretical framework

In this section I will describe the theories applied in the study to understand the phenomenon in focus. Access barriers to antiretroviral treatment will be analysed based on The Initial Behavioural Model by Andersen (1995). To further understand factors perceived as barriers to accessing ART, it is considered necessary to complete the framework with Ervin Goffman’s notion of stigma. These have been used because of the focus on individual behaviour and beliefs regarding health.

2.1. The initial behavioural model

The model was initially developed by Andersen in the late 1960s to assist the understanding of why families use health service. Andersen’s aim was to define and measure equitable access to health care, and to assist in developing policies to promote equitable access (Andersen 1995).

Figure 1. Conceptual framework, adapted from Andersen (1995).
The behavioural model suggests that people’s use of health services is a function of their predisposition to use services, factors that enable or impede use, and their need for care. Propensity of individuals to use services may depend on demographic factors such as gender and age that represent biological imperatives, which in turn suggests the likelihood that people will need health services (Hulka and Wheat 1985). However, demographic variables are judged as having low mutability, since gender or age cannot be altered to change utilization (Andersen 1995).

The social structure determines the status of a person in the community, her or his ability to cope with presenting their health problems and commanding resources to deal with them. Health beliefs refer to individuals’ attitudes, values and knowledge about disease and health service that might influence their subsequent perceptions of need and use of health service (Andersen 1995). Health beliefs have medium mutability since they can be altered and sometimes effect behavioural change.

Enabling factors refer to the means that individuals or their community may have availability to facilitate the use of services. Andersen (1995) argued that both community and personal enabling resources must be present for use to take place. First, health personnel and facilities must be available close to where people live and work. Second, people need to have the means and know-how to access those services and make use of them. At community level, enabling factors may also include social support from family and nearby inhabitants.

Need factors refer to how people view their own general health and functional state, as well as how they experience symptoms and worries about their health and whether or not they judge their problems to be of sufficient importance to seek professional help. People’s perceived need for care may be increased or decreased through health education programs, changing their financial incentives to seek services. Evaluated need represents professional judgment about people’s health status and their need for medical care (Andersen 1995).
2.1.1. Specific selection of factors

As the figure shows, a specific selection of factors has been made to be used in the analysis. This study is based on the perspectives of health workers, ART-patients and members of the community on factors they perceive to be barriers for individuals who are not on ART. Since no HIV-positive individuals could be interviewed about their reasons for not engaging in ART treatment, and due to a lack of reliable objective demographic data about such individuals, this study will not focus on evaluated need or demographic factors as influences on treatment-seeking behaviour.

2.2. Stigma

Within a society there exist categories of persons that are seen as ordinary and natural. Social settings establish the categories of persons likely to be encountered there. The routines of social intercourse in established settings allow us to create normative expectations of how other people should behave. If an individual possesses a trait that makes him different from others and from normative expectations then he could be considered as less desirable. He is thus reduced in our minds from a normal person to a tainted, discounted one. The famous sociologist Goffman (1986) provided the traditional definition of stigma as a discrepancy between an individual’s actual and virtual social identity. The author means that stigma is created through symbols that construct a person as processing certain discrediting characteristics, which further may lead to humiliation and production of “spoiled identity”.

Goffman identifies three types of stigma: physical stigma, stigma of character trait, and stigma of group identity. Physical stigma refers to physical deformities of the body. Stigmas of character traits are
perceived blemishes on individual character, such as weak will, domineering or unnatural passions, or treacherous and rigid beliefs. Finally, stigma of group identity is a stigma that comes from being of a particular race, nation, or religion. Within these categories a further distinction is made between discredited and a discreditable individuals. The first is associated with a stigma evident to others whereas the second refers to a hidden one. Individuals living with a stigmatized trait that is physically invisible to others are often struggling with feelings of shame towards both the family and strangers.

Stigma concerns not only discrediting attributes, it also includes relations between individuals and groups: Stigmatized, Normals and Wise. Normals refer to individuals who do not deviate from particular expectations. A person who possesses a stigma has undesired differentness from what is anticipated or expected. Wise could be described as normal individuals that have experience with a stigmatized group and has more insight and sympathies about their situation. Goffman (1986) discusses the issue of Normals and their reactions to Stigmatized individuals. The author means that attitudes Normals have towards Stigmatized are based on the assumption that they are not quite human. On this assumption Normals exercise varieties of discrimination towards Stigmatized, which effectively reduce their chances of living fulfilling lives. Further insecurity concerning the attitudes of Normals could affect the behaviour of stigmatized individuals around Normals because they may experience difficulties in knowing how a perceived Normal would react to becoming aware of a hidden stigma. This situation can make the Stigmatized individual more self-conscious and calculating about the impression he is making on others whom he assumes are not Stigmatized (Goffman 1986).

3. Previous research

A study from 2008, "Barriers to access to antiretroviral treatment in developing countries: a review", presented a review of barriers impeding people living with HIV/ AIDS in developing countries from accessing treatment and made recommendations for further studies. As their empirical data collection method they used electronic databases, websites of main global agencies and international AIDS conferences to search for relevant articles published between 1996 and 2007. This literature review included 19 studies from developing countries. The barriers, most frequently cited at the population level, were lack of information about antiretroviral therapy and stigma. Barriers at the health system level were long distance from home to health facility. This review revealed paucity in evidence on access barriers to ART in developing countries both in terms of population representativeness and geographic coverage. Instance, only 19 studies from total of 13 countries were identified. This study indicated the need for more research especially in developing countries (Posse et al 2008).

Previous research from 2007 examined the prevalence of discrimination experience and
internalized stigmas. A quantitative approach has been used to study 420 HIV-positive men and 643 HIV-positive women from AIDS services in Cape Town, South Africa. The anonymous surveys found that 40% of the respondents had experienced discrimination because of their HIV status. Further, more than one of three participants indicated feeling ashamed or guilty because of the HIV-infection. This study can be criticized because a convenience sampling was applied but also because there was an under-representation of men in the study. The authors also highlighted the limitations of the survey method. The research was conducted in Cape Town, South Africa, a city with more economic resources and greater racial diversity than other regions in South Africa. Therefore this study may represent a more optimistic view than in other areas of South Africa. Because of those limitations this study cannot be generalized to other regions in South Africa (Leickness et al. 2007). However, the results from this study could be used to compare the results of my investigation to confirm the validity.

In 2009 an article was publishes by Laura et al and highlighted some of the potentially important factors affecting HIV-infected women’s decisions to start taking ART and to continue with ART. Two qualitative data collection methods were used in this study: Free listing and Key informant interviews. 20 interviews were conducted with participation of 16 women and 4 men at age range from 20 to 50 years. The finding suggests that women don’t start to take ART because of stigma, lack of information, fear that their marriage will end and failure to accept HIV status. Many respondents indicated that local women do not start or continue with ART as the medications are difficult to hide (Laura et al 2009).

2009, a qualitative study was conducted to identify ART patients’ health-seeking behavior factors affecting sustained attendance at treatment clinics in Kisesa of North Tanzania. The findings suggest that personal motivation and self-efficacy contribute to program retention and are affected by other individual-level experiences such as perceived health benefits or disease severity. However, the researchers argued that these determinants are influenced by others' opinions and beliefs in society, which in turn limit an individual's willingness to maintain treatment. For example beliefs that HIV is caused by witchcraft and that it can be cured through spiritual healing or traditional medicine are common in Kisesa and other semirural communities in Sub-Saharan (Roura et al 2009).

In 2015 a survey was conducted aimed to assess the association between being on ART and sexual risk behavior among people of reproductive age 15-49 living with HIV in a nationally representative sample from South Africa. The author assessed the following among those who reported sexual activity in the past 12 months and the consistency of condom use to later comparing those on and not on ART. The result shows evidence of increased sexual risk behavior among people living with HIV not on ART, compared to those who are on ART. Nearly two-thirds of HIV positive individuals not on ART reported inconsistent condom use and over half of the same individuals did not use a condom at last sex. This suggests that those who are not on ART have greatest potential for onward transmission of HIV and put
their sexual partners at high risk of infection. However, the author couldn’t explain why this population has those sexual behaviors. The author highlighted difficulties to identify this population for behavioral prevention interventions because these individuals are less likely or willing engage with public health or clinical medicine (Risher et al 2015).

4. Method

This chapter describes the methodological approaches and justifications for the choice of method. It will be followed by a discussion of the sampling and description how empirical data were gathered. The chapter ends with discussions from a critical point of view on the quality from the collected material.

4.1 Choice of method

As a researcher, there are several basic scientific approaches that can be used depending on the purpose of the study and the question in issue. The main purpose of this study is to provide a deeper understanding of why some HIV-infected people in Babati do not start with ART. For this reason, the nature of this study is descriptive and a qualitative approach is used. In this way, participants are encouraged to share their reflections on past and ongoing experiences, which generate a vivid picture of their reality (Fridlund & Hildingh 2000).

This study has been carried out as a case study, meaning “an investigation of a specific phenomenon” such as an event, a person, an institution or a social group (Merriam 1994). A similar definition is made by Yin (2009) “A case study is an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context”. The focus of this study has therefore been directed toward individuals who have experience or knowledge related to HIV/AIDS. The survey was conducted during a field trip to Babati rural district and Babati town council in Manyara region, Tanzania. The empirical material was collected from 15 of February until 6 of March 2016. The fieldwork was conducted in three selected sites located in close proximity to each other in Babati town.

4.2. Selection of respondents

The goal of the sample has been to interview HIV-infected individuals who are not on ART. This proved to be hard since it was difficult to find people that were willing to participate. Instead, the primary data in this thesis has been based on the perspectives of ART-patients, health workers and members of the community regarding factors they perceive to be barriers for individuals who are not on ART.
During the selection process of the respondents, a purposive sampling technique has been used. This technique allows the researcher to focus on particular characteristics of a population that are of interest, which enables them to answer the thesis main question (Yin 2009). However, this type of sampling technique can be hard or impossible to generalize and draw conclusions to all the HIV-positive individuals in Tanzania (Repstad, 2007).

Experts from Mrara Hospital, Wazazi Dispensary Hospital and Africcare were interviewed because of their knowledge in this subject, whereas the interviews with ART-patients were conducted because I assumed they could have the similar experience as those who are not on ART, therefore they could possibly have many kinds of meaningful data. Further, the interviews with members in the community were conducted because their opinions and perceptions regarding HIV-positive individuals is interesting and it could be important since both HIV-positive individuals and members of communities are living in the same environment and are more or less influenced by each other.

4.3. Semi-structured interviews

All interviews in this study were conducted as semi-structured interviews with open questions related to informant’s perception of the topic. Semi-structured interviews were considered to be appropriate because questions are more open and offer greater flexibility than other types of questions. Respondents are given the opportunity to express themselves freely in the direction the interview moves (Denscombe, 2000).

A total of 20 semi-structured interviews were conducted. Each interview lasted between twenty minutes to one hour. This was deemed to be an appropriate length since it gave the respondents time to express their thoughts and understanding of the subject. Most interviews were conducted in the hospital facilities since both ART-patients and health workers were available during the daytime. The members of the community were interviewed in close proximity to where they worked in Babati town.

During the interview process, I have used digital recording and also written down the answers. The reason why I could not record all interviews is because of the sensitiveness of HIV / AIDS as topic. If interviews with HIV patients were recorded, it could make respondents feel uncomfortable and answers could be distorted.

The first interview was conducted as a pilot. The purpose of a pilot study is to test the function of the empirical instrument (Bryman 2012). To ensure that the quality of the interviews would be as high as possible, it was conducted to get feedbacks on deficiencies or ambiguities in questions. Appendix 1, 2 and 3 illustrates the interview questions used in the context of this study.
4.4. Collection of secondary data

In addition to gathering the primary data, it is important to do a literature review during research process (Merriam 1994). Therefore, a number of articles and rapports were read in order to take account of work carried out in previous researches.

The majority of the scientific articles were found by searching online databases such as SöderScholar and Google Scholar. In order to find relevant material, a combination of keywords and phrases such as "barriers to accessing ART", "Stigma", "Barriers to ARV Adherence among HIV/AIDS Positive Persons". Many of the relevant articles cited other investigators that are researching the similar subject, which in turn gave further relevant articles. After a literature review I selected sources that considered being relevant in use for this thesis.

4.5. Critical assessment of the study’s quality

Because a qualitative approach has been used in this thesis the conclusions cannot be generalized to all the HIV-positive individuals in Tanzania. The quantitative research is preferable if the aim is to draw generalized conclusions (Bryman, 2012), in such case, it would require a representative selection, and implementation of statistical tests. However, this was not possible due the time restriction during the procedure of data-collection. Despite the risk of not being able to generalize, it was considered suitable with a qualitative approach since the aim of this research is to provide a deeper understanding in the issue.

As mentioned earlier during the interview-process, I have been using semi-structured questions in order to obtain interesting information of a more spontaneous kind. Under certain circumstances, follow-up questions have been asked and they might have been leading questions, which in turn could have affected the respondent’s answers. However, it was not considered having a big impact on their answers since the respondents noted the topic before the follow-up questions were asked.

Nearly all of my interviews required a translator in order to translate both questions and answers between English and Swahili. For this reason, some data without doubt has been lost. Even though some details were left out I consider that no important data were lost.

Furthermore, HIV and sexuality are sensitive topics that can be difficult to openly discuss. In nearly all of my interviews a translator was present, which could affect the respondent’s behaviour or lead to different answers than they originally intended in the beginning. Because it was a male translator, the female respondents could have become insecure and the answers may not have been entirely honest. To ensure the respondents confidence I guaranteed that they would be anonymous.
However. The names of experts have been used as sources in this thesis since I got their permission. Finally, the primary data that have been used in this thesis are secondary sources since they are based on the perspectives of health workers, ART-patients and members of the community. It would be desirable to interview HIV-positive individuals who are not on ART to get more credible data. However, it was not possible since it was difficult to find people that were willing to set up on interviews.

Despite the limitations of this study, I believe however, there is an opportunity to reconnect with the theoretical bases and analyse the results in relation to previous researches.

5. Findings

The following section contains the findings of this case study. First, characteristics of participants are given. After this, based on the transcript that was made after the interviews, the main findings concerning the underlying causes and barriers are presented.

5.1. Basic information

Basic information regarding age, sex and health status from the respondents is summarized below (Table 1). Of the twenty respondents, three were healthcare workers. I deem their perspectives particularly important to present, because they possess professional knowledge on this topic.
Table 1: Characteristics of participants in the qualitative study

<table>
<thead>
<tr>
<th>Activity</th>
<th>Variable</th>
<th>Category</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-depth interviews (ART Patients)</td>
<td>Total</td>
<td></td>
<td>10</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Age</td>
<td>25-34</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>35-44</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>45+</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>In-depth interviews (Community in general)</td>
<td>Total</td>
<td></td>
<td>7</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Female</td>
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<td>2</td>
</tr>
<tr>
<td>Age</td>
<td>25-34</td>
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<td>3</td>
</tr>
<tr>
<td></td>
<td>35-44</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>45+</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>In-depth interviews (Healthcare workers)</td>
<td>Total</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Role</td>
<td>HIV/AIDS doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Coordinator of Africare</td>
<td></td>
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</tbody>
</table>
5.2 Identified factors

In this chapter, the identified underlying factors are presented one at a time for easier reading. Despite being presented separately, the factors and barriers are not to be seen as detached from one another. Instead, they are related to each other and give an overall picture and a deeper understanding of the issue.

Stigma

Experience and fears of HIV-associated stigma were widely acknowledged by both male and female respondents. When asked to explain what prevents HIV / AIDS infected persons from accessing ART, out of 20 respondents, 16 assume fear of stigma is the main factor. Received stigma refers to all type of stigmatizing behavior towards a person living with HIV/AIDS, as experienced or described by themselves or others. Some participants brought up the fear that others will find out about their HIV-status.

“At the beginning I was afraid that people would find out about my disease. It was a big chock for me and I almost gave up”…(ART-patient, 32)

Concern with HIV-associated stigma was emphasized as a barrier when it comes to voluntary HIV counseling and testing. Clinics offer people to test their blood but many are not willing to receive the test result because they are worried the test will show positive and what it would mean for their future and how to handle it. In some cases instead of starting treatment, some people just ignore their disease that in the worst cases leads to early deaths.

“Some of the HIV-infected people are afraid of knowing that they have HIV. They are so scared of what people would think about them and they will rather die than get treatment”…(Doctor Mkonyi)

Again, fear of disclosing their health status to family members, friends, neighbors or co-workers was mentioned as a barrier. For instance, the coordinator of Africare discussed HIV-positive individuals’ fear that taking medication would reveal their HIV status to family members.

“Some don’t take the ARV medicine because their husbands don’t know about their HIV/AIDS status. So what do they do? They take the drugs and put them under a pillow or somewhere else. Here is a person that is very sick and has the drugs but does not take them because of the husband.”…(Mavanza,
Besides stigma, participants also reported fears and experiences of discrimination and lack of social support. Some ARV users reported that after disclosing their HIV-positive status, they had been left by their partners and/or become isolated from their community.

“There is a group of people here in Babati that have separated me from them but luckily some take my disease as normal”…(ART-patient, 32)

An ART patient described how the neighbors were discriminating against her because of her HIV-status.

“The community used to point at me and tell other people that I’m the one who have HIV”…(ART-patient, 38)

**Economic status**

ART is available to patients free of charge by the Tanzanian government. A problem though is that people cannot afford the transport to and from the facilities that offer ART. The result shows that 5 out of 20 respondents believe that low economic status is an important factor that prevents patients to get access to ARV. All five respondents indicated that many could not afford to come to the hospital because facilities are too far away from their home. ART-patients in Tanzania are required to follow the schedule, and need to pick up their medication from the pharmacy and meet with counselor each month. It was noted that this might create a significant strain on the financial resources of some HIV-infected people.

“The geographic distribution is a factor because some HIV-infected persons need to travel 100 km on a tough terrain on a bodaboda and some people can’t afford for transportation”…(Mavanza, coordinator of Africare)

Further, financial ability to buy food was noted as a barrier to ART access since most men fail to come to the hospital because they don’t have money for food and transport. One ART-patient describes experiencing increased appetite while taking medication.

“Another factor is that the hospital is far away and they maybe don’t have money to come. I think that the government needs to give aid for them for the transport. Because they already lose their hope and if they don’t have money to get here, then it will be easy for them to give up. The medicine is very strong
so they need to have food while they are in the treatment” … (ART-patient, 35)

Ignorance/knowledge
Six of the respondents reported ignorance as one of the causes that prevents HIV-infected persons from starting their treatment. Although HIV is perceived as a common disease in Tanzania, there is limited access to education about HIV and a lack of information regarding the treatment process. Many people who are infected with HIV do not know much about the disease, basically because of insufficient counseling and education. In some cases the doctors do not have enough time for counseling and educating the patients about the disease in depth. Ignorance is an important reason why some don’t want to voluntarily test for HIV status or start treatment.

“Most of men they don’t want to do HIV-test and I think it is because of ignorance and even if they do they just don’t follow the schema for treatment”...(Doctor Mkonyi)

One of the ART-patients brought up her husband’s ignorance as a reason that he neither wants to investigate his HIV status or use ARV.

“My husband didn’t want to get tested because he don’t think that he have HIV. He said that he have a different blood type so it is not possible that I could transmit the virus to him”…(ART-patient, 43)

Traditional healing
The belief that a wide array of diseases can be caused by witches as a consequence of jealousy or revenge seems to be an important factor. Some believe that AIDS is caused by witches and can be cured by Traditional Healers specialized in “divination”. Out of 20 interviewees, 7 believed that traditional doctors are one important factor that prevents HIV-infected willingness to get professional help and treatment.

“Some people have this local belief that maybe somebody has put a spell on them so that’s why they got HIV”…(Member of the community, 45)

One of the respondents relayed a story about a person close to him who unfortunately died because of the belief that she could be healed with traditional methods.

“The traditional healers are a problem, at least some of them who insist that they can heal people and God will help them. I have an example, my sister died because someone told her that if he will pray for
her then she would be fine. The doctor told her that if she believes in him then she has to throw those ARV away. She believed him so she doesn’t use those medicines. She died just like that, on Valentines Day in 2011”…(Mavanza)

Further, an ART-patient explained that she encourages other in the same situation as hers to visit the hospital instead of the traditional healer.

“I knew some people that had visited the traditional doctor for treatment and I tried to convince them to go get treatment in the hospital instead”...(ART-patient, 38)
Table 2: Summary of factors mentioned by respondents

<table>
<thead>
<tr>
<th>Factors</th>
<th>Economic status</th>
<th>Ignorance/knowledge</th>
<th>Traditional healing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
<td>Experts</td>
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<td></td>
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<tr>
<td></td>
<td>Dr. Mkonyi</td>
<td>X</td>
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<td></td>
<td>Dr. Dawas</td>
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<td></td>
<td>Mavanza</td>
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</tr>
<tr>
<td>ART-patients</td>
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As can be seen in Table 2, there are coherent perceptions from all three different categories of respondents regarding stigma, ignorance/knowlegle and traditional healing as factors preventing HIV-infected people from ART. However, there are some differences in responses from different respondent categories. All experts and two of the ART-patients had the same perceptions regarding economic status as a factor, while no members of the community perceived economic status to be a barrier.
6. Analysis

In this section, results are analyzed and interpreted based on the theoretical framework of Andersen (1968), followed by Ervin Goffman’s notion of stigma (1963).

6.1. The initial behavioral model

Economic barriers to affording transportation to and from the health facilities, as well as lack of money to buy food, were noted by ART-patients and HIV-experts. This makes geographic distribution a factor in treatment initiation and adherence. This finding is in accordance with Andersen’s “Enabling factors” that emphasize the importance of personal enabling resources being present for use to take place (Andersen 1995). From this point of view, this means that if the individual doesn’t have the ability or means to make use of health services due to the long distance from home or workplace to health facilities, it can be assumed that he or she is less likely to initiate or continue ART.

Ignorance is perceived as another factor that keeps people from accessing ART. As mentioned earlier, HIV is perceived as a common disease in Tanzania. Despite this, there are some HIV-infected people that do not have much knowledge about the disease. One example of ignorance being a factor is the story relayed by an ART patient about her husband not believing that she could transmit the disease to him, due to them having different blood types. This relates to the category of Health Beliefs in Andersen’s model (1995), which concerns individuals’ attitudes, values, and knowledge about the disease, which can influence their perceived need to seek professional care (Andersen 1995). Her husband’s inaccurate beliefs about HIV resulted in a negative attitude towards seeking testing and/or treatment. The results also revealed the perception that HIV-infected persons are not receiving enough counselling and information about HIV, which in turn makes some of them unwilling to seek treatment. This can be understood in the context of Andersen’s Need Factors, which describe how people view their own health and functional states, as well as the extent to which they perceive symptoms and health concerns to be sufficiently important to seek professional help. When individuals lack the requisite knowledge or have received insufficient counselling about their illness, their ability to interpret symptoms and the gravity of their health problems is likely impaired, increasing the risk of misinterpretation and underestimation of the seriousness of their condition. These people may be less likely to seek treatment in time, if at all. According to Andersen (1995) this issue may be improved through health education programs, which possibly result in increased incentives to seek health services.

The findings show how one’s own fundamental beliefs about “cause and effect” can affect treatment patterns. For instance, one member of the community explained that some people believe that HIV can be caused by witches as a consequence of jealousy or revenge from another person. This can be linked to the category of Health Beliefs in Andersen’s model (1995). When an individual has limited
knowledge about the disease and has beliefs that HIV can be caused by witchcraft rather than being infected via blood or sexual contact, it can be assumed that the person has other values concerning how the disease can be cured. These prevailing beliefs around the causes and basic etiology of HIV could reduce motivation for biomedical treatment.

Further, the findings show how the personal social networks can affect a person’s valuation by creating misconceptions on antiretroviral drugs. Mavanzas sister was already on ARV-drugs and likely had a positive attitude toward the treatment. However, people in the social environment affected her health-attitudes and behavior by generating confusion and mistrust, which in turn adversely affected her motivation to continue treatment, resulting in treatment interruption. Although this case shows the negative impact on social relations, there were also people in the society who had a positive influence on HIV-infected people. An evidence of this is when an ART-patients described her willingness to encourage other HIV-positive individuals to engage in ART treatment instead of continuing with the traditional doctor. This can be interpreted using the concept of “The Social Structure” which determines the status of a person in the community, and his or her ability to cope with presenting their health problems (Andersen 1995). It can be assumed that these HIV-positive people have the ability to cope with presenting their HIV-status to the ART-patient. It is probably because the ART-patient has the same experience and thus can sympathize with their situation. Their common characteristics may later affect HIV-positive persons’ health beliefs and can result in behavioral change according to Andersens “Health Beliefs”.

6.2. Stigma

Perceptions of stigma from all three different actors was widely acknowledged. Nearly all participants described stigma as a major barrier to treatment adherence and retention in care. When receiving the diagnosis of HIV, one of the ART-patient described feelings of shock and fear that others would find out, and losing hope to live. This reaction could be compared with Goffman’s (1986) theory of stigma of character trait. The negative associations with the perception of the disease causing weakness, caused fear of what the “normals” would think of him as an HIV-positive and motivated him to hide his health-status. According to Goffman (1986) this is a common reaction for individuals living with a hidden stigma. In this case, the ART-patient experiences difficulty in knowing how a perceived “normal” would react when knowing his HIV-status, which could impose a psychological burden to him.

HIV-associated stigma is an issue when it comes to voluntary HIV counseling and testing. There are clinics that offer people to test their blood but many are not willing to receive the test result because they are worried the test will show postive. If this is the case, they may then feel different from the
others and the normative expectations, experiencing being of a less desirable kind in the society (Goffman 1986). In order not to deviate from the normative expectations they would rather risk their lives than being ostracized and discriminated.

When it comes to reveal HIV status to their family it seems to be tough for some because they experience difficulties in how their husband/wife would react. As described in the result some women do not to take the medication due fear of that their HIV-status would be disclosed. This behaviour can be compared with Goffman’s (1986) theory of stigmatized individuals’ relations with others. These women are living with a stigmatized trait and often struggling with feelings of shame towards their families. It is because those HIV-positive women cannot determine whether family members are "normal" or "wise". If their family had been the "wise" type, it can be assumed that they would have more empathy and understanding of the disease. Uncertainty regarding their reaction makes those HIV-positive individual choose to hide the disease, instead, they try to give the impression of being a non-stigmatized person.

Besides stigma, experiences of discrimination and exclusion was noted by ART-patients. The most common reaction by neighbours was to exclude them from the social community as well as single them out as HIV-infected. This is consistent with Goffman's assumption regarding the "normals" attitudes towards stigmatized individuals. The reactions from the "normals" towards stigmatized individuals are based on the assumption that they are not human beings. The neighbors' assumptions lead to different types of discrimination against HIV-infected individuals, which in turn effectively reduces their chances of living fulfilling lives.

7. Discussion

Some studies in Tanzania have focused on ART patients’ health seeking behaviour and structural barriers to successful treatment compliance (Nsigaye et al, 2009, Lyimo et al 2012). Instead, this study sought to identify underlying factors that prevent infected people to start ART in Babati, Tanzania. The findings indicated the following as obstacles to access to ART: HIV/AIDS related stigma issues, economic barriers, ignorance due to lack of education and counselling on HIV treatment, and beliefs that HIV can be cured by traditional healers.

However, the findings in my study suggest that structural factors also significantly restrict HIV-positive individuals’ ability to start the treatment. For example, health services facilities are located in urban areas, creating barriers for HIV-positive people who live in remote rural areas or during working hours when they are unable to come for treatment. While removing structural obstacles is essential, addressing sociocultural factors is also required. Through the application of Goffman’s notion of stigma
(1963) and Andersen’s (1968) theoretical framework, my aim has been to elucidate the barriers affecting health-seeking behaviour among HIV-positive individuals who are not on ART.

This study demonstrates how HIV-infected individuals’ health-seeking behaviour can be affected by their immediate social environment. For example, peoples’ negative assumptions about HIV-positive individuals make those carrying the virus feel guilty and ashamed of their health condition, which in turn reduces their motivation to start ART-treatment. Besides stigma, discrimination may be a relevant factor to consider. Even though discrimination wasn’t explicitly mentioned as a factor preventing HIV-infected people from initiating treatment, it cannot be excluded since this issue concerns ART-patients with the same health-status as those who are not on ART. Through their stories of experiences of discrimination, this factor could possibly be considered as another factor that prevents HIV-positive people from ART-treatment.

Another factor considered to be of importance when it comes to individual decision-making concerning the use of ARV is the social influence. In this study, social influence generally has been reported to have a negative impact on individuals’ intention to start or remain in treatment. Despite this, social influence as such should not be considered as negative. The results in this study have also shown how the power of social influence could act as a motivator and strengthen HIV-positive individuals’ self-efficacy to overcome other barriers. This finding reinforces similar results regarding the role of family and community social support on adherence from studies that have been conducted in both developed and developing countries (Campero et al 2007; Davies et al 2006; Diabate et al 2007; Kumarasamy et al 2005).

Finally, the results indicate the need of improved education of the individual and the community at large regarding HIV as well as the benefits of treatment. For example, ignorance was mentioned as a barrier to access to ART due to inadequate provision of information during counseling (and testing) sessions. This finding is similar to the results from a recent review by Posse et al (2008).

Although this survey has elucidated some significant factors, any interpretation must be made with caution since there were several limitations. It is a qualitative study relying on the perspectives of ART-patients, health workers and members of the community on factors they perceive to be barriers for individuals who are not on ART. Moreover, socially desirable, rather than entirely truthful, answers may have been given. The resulting data would have been more credible if HIV-positive individuals who are not on ART could have been interviewed. Finally, the sample is too small for the results to be generalized in Tanzania. The results do however correspond well with the theoretical bases and results from other studies. For example, recent reviews have cited factors such as stigma, lack of information about ART; and, at the health system level, long distance from home to health facility; difficulty of hiding medications; and beliefs that HIV can be cured through spiritual healing and traditional medicine.
9. Conclusion

This study attempted to identify underlying factors perceived as barriers for HIV-positive individuals to start Antiretroviral treatment in Babati, Tanzania. The study indicated four explicit factors as obstacles to access to ART:

1. HIV/AIDS related stigma issues
2. Economic status
3. Ignorance due to lack of education and counselling on HIV treatment
4. Beliefs that HIV can be cured by traditional healers

In addition, by analysing the results, discrimination emerged as a potentially relevant factor after a theoretical anchoring was made with Coffman’s (1986) theory of stigma.

However, the study’s limited scope makes it difficult to generalize the result in Tanzania, as well to other environments. The result do however correspond well with the theoretical bases and results from other studiers which supports the validity of the survey.

An idea for further research would be to combine surveys and interviews as data collection methods. This combination of qualitative and quantitative data gathering could generate more generalizable information. It would also be desirable to interview HIV-positive individuals who are not on ART to get a more credible inquiry.
9. References


UNAIDS (2014). *The Gap Report*


**Interviews**

Mkonyi, E. (2016). Doctor at Mrara Hospital, Mayara of Tanzania. Interview February 20th

Dawas, K. (2016). Doctor at Wazazi Dispensary Hospital, Babati town. Interview February 20th


**10. Appendix**

**Appendix 1. Interview guide to ART patients.**

1. **Background information**

Name

Age

**Main questions**

How did you know that you have HIV?

In the beginning when you find out that you are HIV infected, what are the problems facing you?
When you knew you got HIV, what did you feel or think?
How do you think other people perceived you as a HIV-positive person?
Do you have a partner?
Did you get HIV from someone you know?
What do your family think about your disease?
Are they supportive?
Do you feel that your life as an HIV-infected has been changed? If the answer is yes, what are the changes?
Do you hide your epidemic from people around you?
For how long have you been taking the ARV medicine?
Do you know someone that got HIV but don’t want to be treated?
Why do you believe they don’t want to be treated?
How do you think we can affect HIV infected persons willingness to receive treatment?

Appendix 2. Interview guide to health workers in Babati
What are the cost of ART treatment in Babati?
Are there people who are infected but avoid getting treatment?
Why do you think that the infected person don’t want to be treated?
When the patient find out that they have HIV, what was their reactions?
How do you work to make the patients accept theirs disease?
What are the most effective strategies in making the HIV-infected people’s willingness in getting treatment?
Now that I have interviewed a few patients, some of them see HIV as a normal disease like malaria. Is this a good way to think?

Appendix 3. Interview guide to the members of community
How much knowledge do you have regarding HIV/AIDS?
Do you know someone that is HIV positive?
What do you think about those who are HIV infected?
What do you think the majority of people in Babati think about HIV-infected individuals?
What do you think the HIV-infected individuals think about themselves?
Why do you think that some HIV-infected people don’t want to be treated?