

Experiences of HIV Positive Patients on ARV Treatment at the Thulamela Municipality in the Vhembe District of Limpopo Province, South Africa

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Abstract

Antiretroviral treatment (ARV) has improved the quality of life among people living with HIV. ARVs have been documented to decrease the morbidity and mortality of people in their introduction in the late 1980's.

The purpose of the study is to identify, explore and describe the experience of HIV positive patients on ARV treatment at the Thulamela Municipality in the Vhembe District of Limpopo Province, South Africa.

Methods: A non-probability purposive sampling was used. The target population was those HIV positive patients on ARV treatment who were eighteen years and above. A qualitative research method was used to explore and describe the experiences of HIV positive patients on ARVs in detail. In-depth individual interviews were used through the help of interview guide for data collection.

Results: The open coding method was used for data analysis. Three themes emanated from the study as presented underneath; each theme consists of sub-themes:

- Dominant tales of perceived family support for HIV positive relative resulting in feelings of despair and those of being accepted;
- Stigma and discrimination related to HIV positive diagnosis;
- Disclosure of HIV positive status

Conclusion: Community involvement and participation in HIV/AIDS matters is of utmost importance to reduce stigma and discrimination and bring unity in the fight against HIV/AIDS. Government should continually carry out workshops on families and relatives of those who are affected and make awareness campaigns to the community at large.

Keywords: Human immunodeficiency virus; Acquired immune deficiency syndrome; Antiretroviral treatment

Introduction

Makoae et al. [1] stated that the development of antiretroviral (ARV) medications in the late 1990's altered the face of HIV/AIDS, transforming it from a fatal disease into a chronic illness. According to Foundation of Professional Development (FPD) (2010) [2], since the use of the treatment, there have been records of impressive reduction in morbidity and mortality of Human Immune Deficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS), and the condition is now being treated as a manageable chronic condition. The success of ARV depends on the experiences of the HIV positive patient and the ability to make informed choices about the treatment [3]. In the United States of America (USA) and other parts of the developed world, HIV treatment has advanced rapidly through improved understanding of patients' experiences [4].

The Joint United Nations Program on HIV/AIDS (UNAIDS 2010) [5] stated that though ARV treatment is currently in use, HIV epidemic remains a major global public challenge, with a total people of 33.4 million living with HIV worldwide [5]. By 2009, the World Health Organization (WHO) [6] indicated that the total number of people in need retroviral treatment worldwide were 13 500 000-15 800 000, meanwhile those who were accessing treatment were only 6 million. In the sub Saharan Africa, 22 million people living with HIV/AIDS and only a few of these are on ARV.

Living with HIV has an emotional impact that is further complicated

by the effects of body changes many individuals experienced. According to Moskowitz [7], the body changes appear to be due to a combination of a number of risk factors, which include the effect of HIV and a compromised immune system, advancing age, history of obesity in the family, the shape of one's body before starting with HIV therapy, diabetic or genetic predisposition diabetic or insulin resistance, lack of exercises and period duration of HIV therapy. According to WHO, most HIV positive patients were satisfied with the quality of the treatment they were receiving because they were no longer emaciated, as they were now eating well with less vomiting. However, ARV can cause drug side negative effects for the HIV positive patients and these usually occur during the first months of starting treatment. According to Van Dyk [8], Byron et al. [9], patients experienced the following side effects: -weight gain or lipohyperatrophy with maldistribution of fats on

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the neck, abdomen shoulders and breasts, weight loss or lipoatrophy, which is evident on face, limbs and buttocks, nausea and vomiting.

According to Bravo et al. [10], HIV positive patients experience tough psychosocial needs and tough decisions to make concerning their life and these range from three aspects, -whether to disclose or not disclose, this need or decision is charged with worries related to judgment and being treated in a different way, i.e. stigma and discrimination, which exclude HIV positive patients from social support and make them to live in an isolated world where quality of life is affected. The second aspect of the HIV psychosocial needs of decision is involved in whether to choose to or not follow treatment explained in the reasons to desire to deny sickness, not feeling sick, interpersonal motivation of wellbeing of a relationship, having children who play an important role of wishing to live and have hope in life. The third psychosocial need is how to maintain active sexual life and how to manage it. HIV positive patients are concerned with protecting partners, safer sex practices and parenthood. Bravo et al. [10] state that HIV positive couple consider parenthood as the right which can bring them happiness and the hope to live, but they are aware of the health and psychosocial risks that could mean to a newborn, the mother and the HIV negative partner, in case of a serum discordant couple. These three aspects are attached with stigma and discrimination and isolation.

HIV positive patients from neighboring countries, such as Malawi, Swaziland, Zimbabwe, have been experiencing ARV and health staff shortages, making it very difficult for them to access ARV treatment [11]. These caused many of them to migrate to South Africa for treatment. According to the African and the Caribbean Council on HIV/AIDS in Ontario [12], immigration caused additional stress to those with HIV, as it causes them to be away from their families, whom they needed the most for psychological support. Furthermore, people who have HIV reported that racism; homophobia also played a big role in them being discriminated against.

Problem Statement

Mostly patients are weak due to side effects of ARV treatment. The situation hampers patient care because whatever explanation which must be given to the patient cannot be absorbed well, as the patients are ill. This leads to serious complications, such as poor adherence, hence the study seeks to document the experiences of HIV positive patients on ARV. When a person is eligible for ARV treatment, one has to disclose to a support buddy who will be able to encourage and support them to take treatment. The patients taking treatment are encouraged to join an HIV/AIDS support group, where they will learn from other patient's experiences. The researcher has seen patients at the clinic unable to finish a seven day course of antibiotics, or a six months course of tuberculosis treatment. The researcher in this study observed how difficult it was for those who are from other districts or provinces to obtain their ARV treatment, while at home to obtain treatment during festive seasons or holidays, in case it happens that they did not return back to their place of work in time. It seems there is no coordination of ARV treatment services between health facilities. This topic has been researched widely in other provinces and worldwide, with the exception of Vhembe District.

Purpose of the Study

The purpose of this study was to explore and describe the experiences of HIV positive patients on ARV treatment in the Thulamela municipality in the Vhembe district of Limpopo province of South Africa, in order to identify their problems.

Research Objectives

The objectives of this study were to:-

- Explore and describe the experiences of the HIV positive patients on ARV treatment.
- Develop recommendations on establishment of care and support of services of HIV positive patients on ARV treatment.

Materials and Methods

Study design

This study adopted a qualitative approach using an exploratory, descriptive and contextual design.

Study setting

Participants interviewed were twenty in number, all were Venda speaking people were interviewed in Tshivenda. They were from three different villages in Vhembe District Limpopo Province.

Population

Population refers to all (entire set of individuals), or complete set of persons that possess some common characteristics that are of interest to the researcher or that people, or group of persons meet the criteria the researcher is interested in studying [13]. The population for this study includes all HIV positive patients on ART residing in the Vhembe District, in Limpopo Province.

Target population

The target population in this study included males and females HIV positive patients on ART.

Sampling process

All the participants were contacted according to the specified criteria for stakeholder analysis, such as young adults.

Sample

The study sampling method utilised was nonprobability sampling, elements were chosen from the population using purposive sampling. Purposive sampling was utilised for participants based on specified criteria.

Sampling criteria

The participants were selected based on the following criteria

- Being HIV positive
- On antiretroviral for more than six months
- An adult from eighteen years and above

Size

Sample size depended on data saturation and only twenty participants were interviewed, fifteen females and five males. After twenty interviews, the information kept on repeating itself, so it was no longer necessary to continue with the interview, which is called data saturation. Rubin and Rubin [14] referred to saturation as getting similar data or ideas over and over again during the course of interviewing in a qualitative study that signifies completion of data collection in a particular phenomenon.

Data collection methods

In this study, in-depth individual interview was used in a form of

unstructured interview and field notes to collect data. The following question was asked from the participants. What are the experiences of HIV positive patients on ARV treatment at Thulamela municipality in the Vhembe district of Limpopo Province, South Africa?

Data collection process

All in-depth individual interviews were conducted at the clinic. The empty room at the clinic was used for data collection as the neutral venue. Participants seemed to be happy and eager to participate. Introduction of questions was done by the researcher and an audiotape was used with their permission. Each interview lasted for more or less 45 minutes. Paraphrasing, summarising and probing were used in order to ensure that the participants always stick to the question. During the interviews, data saturation occurred after interviewing twenty participants, that is why it was no longer necessary to go on with more interviews.

Data analysis

In this study, Tesch’s eight steps in Creswell [15] of data analysis were used. Themes, categories and subcategories were developed according to the data obtained from in-depth individual interviews and field notes. In each session, a tape recorder was used to record information.

Ethical considerations

Ethical considerations were adhered to in order to protect the participants, as presented in the subsequent descriptions. Ethical clearance was obtained from University after the following specific procedures as spelled out. The clearance certificate was issued and later the proposal together with the clearance certificate was sent to the Provincial Department of Health and Social Development, Limpopo Province. The proposal was then presented for the Provincial Ethics office members and later permission to conduct research was granted. Permission, together with a letter requesting for further permission from the institutions was later taken to villages in Vhembe District.

Measures to ensure trustworthiness of the study

The goal of qualitative research is to accurately represent the participant’s experiences. Lincoln and Guba [16] suggested four criteria to indicate trustworthiness, namely truth value, applicability, consistency and neutrality, which are relevant to the evaluation of the worth of research. In this study, credibility was achieved through continual interaction and the researcher remained with the participants for five to six months during data collection, and through continuous consultation with participations for reflections, and also used various experiences in data gathering (triangulation) peer debriefing [17,18].

The researcher addressed the issue of transferability in this study by providing sufficient descriptive data, peer review and triangulation to allow for transferability. Different methods of collecting data were used to ensure triangulation, namely field notes and in-depth individual interviews. Confirmability was achieved by the use of peer review, data triangulation and collection of field notes. Bracketing was used to ensure trustworthiness of the findings. Bracketing is the process of identifying and setting aside any preconceived beliefs and opinions one might have about a phenomenon under investigation, it involves laying aside what is known [17]. Burns and Grove [17] indicated that the researcher should enter the project with open mind and not an empty head. The researcher suspended information known to her, with regard to ART, to avoid misinterpreting the phenomenon as being experienced by the participants. Bracketing made it possible for the researcher to focus on participants’ experiences, and to shape the data collection process according to it. The reason for bracketing was to reduce bias, and the two aspects led to the necessity of bracketing of any preconceived ideas the researcher could have were:

Results and Discussion of Findings

Three themes emerged from the findings in the study, and there were no differences between males and females; a table below represents the themes and subthemes (Table 1).

Theme 1: Dominant tales of perceived family support for HIV positive relative resulting in feelings of despair and those of being accepted.

The study findings revealed that there are dominant stories which the participants’ perceived family support related to their HIV positive relative, resulting in feelings of despair, and also feelings of being accepted by family members. Seven sub-themes emerged during data analysis under this main theme. The following are the tales that emerged under this theme:

- Account of negative treatment experienced from family members.
- Rejection of HIV positive relative leading to feelings of despair.
- HIV test resulted in divorce and separation.
- Acceptance of HIV positive test results by relatives.
- Provision of support by relatives.
- Difficulties experienced to access ART.
- ART clinic a clean environment for a speedy recovery.

The tales are discussed below in the sub-themes of this main theme.

| THEMES | SUB-THEMES |
|--|---|
| 1. Dominant tales of perceived family support for HIV positive relative resulting in feelings of despair and those of being accepted | 1.1 An account of negative treatment experienced from family members 1.2 Rejection of HIV positive relative leading to feelings of despair 1.3 HIV positive test resulted in divorce and separation 1.4 Acceptance of HIV positive status by relatives 1.5 Provision of support by relatives 1.6 Difficulties experienced to access ARTs 1.7 ART clinic a clean environment conducive for speedy recovery |
| 2. Stigma and discrimination related to HIV positive diagnosis | 2.1 HIV positive stigma and discrimination by family members 2.2 HIV positive Stigma and discrimination by community members 2.3 Self-stigma and discrimination |
| 3. Disclosure of HIV positive status | 3.1 Lack of disclosure to relatives and community members 3.2 Fear related to disclosing HIV positive status 3.3 Lack of disclosure to sexual partners 3.4 Benefits of disclosure and belonging to a support group |

Table 1: Themes and sub-themes.

An account of negative treatment experienced from family members

The data portrayed an account of negative treatment experienced by the participants from their family members. Participants verbalized negative experiences they had from their family member.

Most of these negative experiences were from their distant family members, usually the in-laws. Data revealed that some participants reported negative experiences from their immediate family members. These experiences was described by the participant who said,

“They did not want to care for my baby, they did not touch him, touch my utensils when I was ill”

Another participant explained in the manner in which care was poorly given to them by the family. The family linked caring for the HIV positive patients on ARV treatment to them being at a high risk of being infected. Mostly, poor care emanated from ignorance on how HIV is being spread, fear of infection and family did not want to be seen or associated with a person taking ARV treatment

A mother with a twelve month baby recalled well how her mother and sisters in-law after seeing that she was ill and taking ARV treatment. *They were afraid to care for the baby or help to prepare food for her because they did not want to touch her eating utensils.*

“They said she is ill and we do not know the illness, we are unable to take care of her”.

Another male participant showed how his cousins and aunt did not want to be seen or associated with him, they just come to his room and put food and left not minding how he is doing.

- *“They put food and water in the house and went away without even talking to me”.*

Sick people are comforted by being in their own homes and communities with family and friends around them [8]. However, HIV positive patients who are on antiretroviral treatment find that at times they receive poor care from their family members.

People living with HIV/AIDS on ARV showed to be in great need of family support and failure thereof bring negative impact on their health [8]. The researcher in this study has seen very ill, HIV positive patients on ARV treatment coming to the clinic alone without support. Nghifika [19] states that those people living with HIV are being shunned by family, and thus, can negatively affect treatment. Evidence has shown that people living with HIV/AIDS on ARV treatment experience poor care from family due to fear of the family to get infected [20].

The results of this study also revealed that families are ignorant of the mode of spread of HIV, despite all efforts of the talks being done they remain with an attitude. The researcher agrees with the above research that poor care will results in negative impact in HIV positive patients On ARV treatment.

In this study, some clients have shown how they lacked support from family, and this led them to have poor compliance. One participant shows how her mother expelled her from home after she discovered that she is HIV positive and on antiretroviral treatment.

- *“My mother did not want to do anything with me and she expelled me from home, spending some of the days without food and without taking treatment”.*

Rejection of HIV positive relative leading to feelings of despair

The findings indicated that the participants experienced rejection immediately, after they are known to be HIV positive, which results in experiencing feelings of despair this was confirmed by the participants, who said

“They did not want to do anything with me or my baby even if I was sick.

The woman showed her feelings of despair, when she explained to the researcher, sadness showed all over her face. This was also confirmed when she said,

“I felt like it better to die once because I have no one to care for me.

In the study done by Mlobeli [21], it was found that HIV positive patients experienced negative perceptions and enablers from the family, as they mentioned that the family members who were supposed to take care of them when they are sick were the ones who were discriminating and rejecting them. Furthermore, Mlobeli [21] described that some of the participants remarked that rejection suffered at home could launch an individual on a path on instability, insecurity, immense distress and some instances suicide. In this study, the researcher found similar experiences as some of the participant were thinking of suicide.

HIV positive test resulted in divorce and separation

The study findings found out that in married couple, an HIV positive result of one partner may result in a decision to neither divorce nor separation. The following statement gave evidence of the fact that the participant was divorced due to being HIV positive; this was outlined by participant, who indicated that

“My wife has just had a baby and I was about to start treatment. My wife had tested negative several times and on learning that I am positive she decided to go back to her home and finally divorced me”.

Knowledge of HIV itself may lead to divorce, as there are indications that rural people are coming to see divorce, as a means to protect themselves against being infected by an unfaithful spouse. In a study done by Cloete et al. [22], it was stated that women who disclose to their spouse could face divorce, being ejected from their home or even subjected to violence. A similar study by Fedor et al. [23] revealed that spouses usually divorce each other, after realizing that one is infected with HIV, especially rural Malawian women. In this study, most participants, usually females did not disclose to their partners and those who disclose did not experience any problem as their partners were also positive before them.

Acceptance of HIV positive status by relatives

From the findings, it became evident that there are some of the relatives of the HIV positive participants who accepted their status. Participants related how their immediate family members accepted them and supported them throughout, when they were taking treatment. A quotation from participants which supported the fact that the relatives accept their status

“Yes my relatives were able to give me support; my mother even told me that I am not the first to have this sickness”.

Another participant was fast to tell that she was accepted by her family.

“They also accepted my status and that they take me as like any other people”.

In a study done in Thailand, it was found women who were taking treatment were mostly supported by their immediate family members [24]. This study found out those HIV positive patients on ARV are supported by their immediate family more than the extended ones.

Idolor [25] conclude that the family is the only primary environment identified to curtail and preventing the spread of HIV, and its effects on those who infected and affected by HIV. It has further been stated that family support to those with HIV promote strong adherence.

Provision of support by relatives

Reality resulted from the fact that relatives of the HIV positive clients do provide them with support. Provision of support was indicated with the following quotations,

A middle aged woman who disclosed only to her children has this to say;

“When I am sick my children care for me very well”

Some of the participants preferred their children as their supporters, and they had these to say about them

“My firstborn is the only one who knows that I am taking treatment, she consoled me and said, mama you are not the only one”.

“My daughter will tell me, mom you are not the first and you are not going to die, you only have to accept the disease and take your medications”.

According to Fredriksen-Goldsen et al. [26], members with HIV were supported by their family members who always reminded them that they are valuable as persons, supported them financially for transport health matters and medications reminded them on follow up care visits and setting alarms for time to take treatment, prepare their food for them and motivate and encouraged them.

Based on the findings of this study, participants felt relaxed and free after they were reassured and encouraged by their family members. Participants in this study came to identify how valuable they are after they were diagnosed HIV positive, and were about to take treatment. One woman who was staying in an extended family with her mother explained like this:

“My mother would spoil me by giving things even if I have not asked. I could see how valuable to her I was and she was afraid of losing me”.

One participant commented:

“My sister would call me and say hey, it is 8 o'clock now, take your treatment.

Another participant proudly displayed how her child supports her taking care to maintain her privacy:-

- Even if there are visitors around at home, my child will come and say, mama it is 8 o'clock.”

In a study done in Thailand, it was found women who were taking treatment were mostly supported by their immediate family members [24]. This study found out that HIV positive patients on ARV are supported by their immediate family more than the extended ones. Idolor [25] conclude that the family is the only primary environment identified to curtail and preventing the spread of HIV and its effects on those who infected and affected by HIV. It has further been stated that family support to those with HIV promote strong adherence. Support by family members has shown to benefit HIV positive patients on

antiretroviral treatment. In a study done in Yunnan province, China [27] has showed how the family support their HIV positive patients by starting on disclosure processes, medical health care, financial, psychological and support for daily activities.

Difficulties experienced to access ARTs

Confusion resulted from the fact that HIV positive client experienced difficulties to access the ARTs in the ART clinics because sometimes healthcare providers indicate that they are not available. This was confirmed by the following statements,

“I went to Gauteng to start antiretroviral, but the line was too long and the queue was cut just before me. Even on the next day, I found out that there are many people already in the line. These made me to leave trying to seek treatment, until one day I say to myself, let me go back home to Limpopo.”

Participants also face difficulties concerning money for food and transport because they are unemployed

“I do not receive any grant but I volunteer and get only R650-00, sometimes it is difficult to get money for food and transport, but my mother always helps me”.

However, one participant in this study had problems because the time he migrated to this country and he had to miss some doses because they were still opening a file and checking his blood first before he could be given treatment.

- *“I came here with some ARV but I had to miss some doses because they said they first process opening of a file and do blood tests.”*

The researcher's opinion is that the participant waited and presented himself when the medication was about to finish. This study reveal the similar experience found out by Yoder et al. [28], where they state that a number of participants in their study confirmed they stopped taking their pills when they move away far from home in search for a job or to live with other family member.

ART clinic a clean environment conducive for speedy recovery

Positive remarks were stated by the participants in relation to the cleanliness maintained by healthcare providers at the ART clinic. A participant confirmed that by saying:

“The rooms were clean, they were not dirty.”

Another participant when asked was quick to say,

- *“It was always clean, chairs dusted all the time.”*

The participants in this study showed how the counseling rooms, pharmacy were clean.

“I always find that the wellness care clinic is clean.”

It is of crucial importance that the health facilities be kept clean for the health of the HIV positive patients on ARV treatment. According to standard operating procedure (SOP), HIV counseling rooms should ensure privacy; people outside the room should not be able to hear the voices inside the room, the rooms should be closed.

The room should be free from dirt, smoke or any other things like water, spilling now and then from the basins.

Theme 2: Stigma and discrimination in relation to HIV positive diagnosis

Participants in this study experienced some forms of stigma and

discriminations related to them being HIV positive. There are tales by participants of being shunned by family or community, given none or poor care, their relatives uttering statements that lead to psychological damage, which affect their HIV prevention, treatment and care. The following subthemes will be discussed subsequently underneath:

- HIV positive stigma and discrimination by family members
- HIV positive stigma and discrimination by community members
- Self stigma and discriminations

HIV positive stigma and discrimination by family members

The findings of this study show that HIV positive patients are being stigmatized and discriminated against by their family members. Some participants revealed rejection, isolation due to of stigma and discrimination. In a Venda culture, the birth of a baby is considered a gift to be celebrated for, especially by the elders in the family. In this study, one participant showed how her mother-in-law did not want to care for and her baby.

- *"They did not want to care for my baby, they did not touch him, touch my utensils when I was ill". "They said she is ill and we do not know the illness, we are unable to take care of her".*

According to Mlobeli [21], families usually evict their loved ones with HIV, and mostly it is young women who are rejected by parents blaming them of promiscuity.

The family may attach stigma and discriminate an HIV positive patient, who is on ARV because of ignorance of the disease and fear of infection. The following female client stated how her mother evicted her from her home with her baby twins and she had no place to stay until she was helped by neighbors.

"My mother removed all my belongings from the house and ordered me to go away with my illness as I brought this on myself because I did not listen".

Another participant has this to say about how his food eating utensils were treated,

- *"My plates and food were placed away separately from where others put theirs".*

Stigma and discrimination have fuelled the transmission of HIV, and has greatly increased the negative impact of the epidemic. Once rejected, the HIV positive patient has problems complying to treatment well or accepting themselves [29].

In this study, some clients have shown how they lacked support from family, and this led them to have poor compliance. One participant shows how her mother expelled her from home after she discovered that she is HIV positive and on antiretroviral treatment.

- *"My mother did not want to do anything with me and she expelled me from home, spending some of the days without food and without taking treatment".*

According to UNAIDS [30], stigma and discrimination associated with HIV infection is based on lack of understanding of the illness, lack of awareness and knowledge of stigma, fear of acquiring HIV through contact due to misconception about the spread of the disease and linking people with HIV with immoral behavior. The participant had this to say, "My mother will not want me to stay in the house because I was HIV positive".

HIV positive stigma and discrimination by community members

HIV positive patients who are on ARV suffer alienation and isolation due to the acts of stigma and discrimination. Alienation is the state or experience of being isolated from a group or an activity to which one should belong, or in which one should be involved. The findings of this study revealed that participants felt that they were at times alienated by people living with them in the community. This is confirmed by the statements below:

A woman expressed her pains when she explained that her child told her that another child said she should play with her carefully, as she a daughter a person who is HIV positive.

- *"In my area the people told their children to take care when playing with my children because I am HIV positive".*

Aggleton et al. [29] explain that stigma and discrimination occurs at various level, the one occurring in community settings involves discrimination, in which individuals act deliberately or by omission so as to harm or deny others of their rights or entitlements, examples of enacted stigma and discrimination are shunning or avoiding everyday contact, accusations, physical violence, verbal discrediting and blaming, gossiping, verbal harassment and denial of traditional funeral rites. This is illustrated by the quotation below:

"When there is a funeral and the women are gathered helping to cook for burial ceremony, people will not want you to cut vegetables for fear you will infect them when you accidentally cut yourself".

A discouraged unemployed man explains with feelings of despair how community members around him planned about his small business, *"They refrain to buy at my spaza because they say I am HIV positive".*

A mother had this to say about her experiences, while seeking for an employment, in order to can support her children;-

"One woman said, I need a domestic worker but she should have been tested HIV negative".

Manila [31] describes how HIV positive patients are still alienated by the health staff, church members and community members. Furthermore, the researcher showed how this patient isolated himself from other people as a result of acts of alienation.

In this study, participants showed how they were alienated at work, in social gatherings by community member.

When a person is alienated by friends, family and community, he becomes isolated from them. This study reveals how participant felt isolated from the family. when they were alienated by them. In this study, some clients have shown how they lacked support from family and this led them to have poor compliance. One participant shows how her mother expelled her from home after she discovered that she is HIV positive and on antiretroviral treatment.

A woman with a baby said she felt isolated from her family and the community, and this is what she said:

"They did not want to touch my baby even when I was ill. They said because she is sick and we do not know what the sickness is all about".

The finding of this study confirms what previous researchers [29] found in that it was also identified that the community still alienate and isolate HIV positive patients at times.

Self-stigmas and discrimination

Self stigma is likely to make an individual more sensitive to both actual and anticipated rejection and stigmatization by others, which negatively affect the way the individual feels. Disclosure of a person's HIV status when one is taking treatment may bring positive or negative consequence on the self.

In this study, some participants showed how they also experience negative perception of self and self discrimination after realizing that now there are people who know about their HIV status. The following quotation illustrate the feelings of a participant;-

"I felt very bad, people will look at me when I walk and I knew they know that I am HIV positive."

The following quotations show how a participant discriminate himself without anybody telling him to isolate his utensils,

"I will take care not to wash myself using my mother's and child's washing basin for fear of infecting them"

Aggleton et al. [29] explained self stigma and discrimination or internalized stigmatization is when people living with HIV may internalize the negative responses and reactions of others, and as results attach stigma and discriminate themselves. This type of stigma and discrimination is described as 'felt', as it primarily affects an individual's or affected community's sense of pride and worth. For people living with HIV, this may be manifested in feelings of shame, self-blame and worthlessness, which combined with feelings of being isolated from society, can lead to depression, self-imposed withdrawal and even suicidal feelings.

"I have to sleep alone in my room even when I was very ill, go to the clinic alone without help even if was very ill for my family felt embarrassed to be seen with me as they will be associated with HIV/AIDS".

This study confirms similar findings with previous researchers, revealing that there is still stigma and discrimination against HIV positive patients even when they are on treatment.

Theme: 3 Disclosure of HIV positive status

Participants in this study had diverse feelings about disclosing their status to their family, friends or members of their community; some did not even tell anyone. The following subthemes emerged under this theme:

- Lack of disclosure to relatives and community members
- Fear related to disclosing HIV status
- Lack of disclosure to sexual partners
- Benefits of disclosure and belonging to a support group

The tales of the participants will be discussed in full in the subsequent subthemes below.

Lack of disclosure to relatives and community members

Out of ten participants two did not tell anyone, and of those who disclose they did so to their next of kin, like children or parents. However, some participants did not tell their next of kin in an attempt to protect them from worry and shame. One participant said,

- *"I did not tell my child but I could see that he knows something about my illness."*

Disclosure is a very important factor in the context of prevention

and adherence to ARV [22]. Furthermore, Cloete et al. [22] revealed that AIDS related stigma is associated with difficulty of disclosure of an HIV status for fear of rejection.

This is also true in this research where all participants had issues with disclosure of their status. They revealed issues, such as non-disclosure, fear of disclosure, stigma and discrimination post disclosure. This is confirmed by the following narratives of the participants:

"I did not tell anybody, I told myself that as long as I know myself and I am taking treatment is ok".

- "I am afraid if I tell other people they will say things about me"

As it can be seen from above statements, participants lived in fear of being rejected, and were not free to disclose their status to the family and the community.

Fear related to disclosing HIV status

HIV positive status still carries a lot of stigma, in such a way that participants were afraid to disclose for fear of being stigmatized and discriminated against. Some of the participants had the following reasons for not disclosing-

- *"People like to look down upon somebody because of her being ill"*.

Another participant decided to disclose to a stranger, and was confident that as long as she is taking treatment, there is no need of people who know her to know about her HIV status.

- *"I did not tell anybody, I told myself that as long as I know myself and I am taking treatment is ok"*.

According to Moratiao [32] patients who fear rejection and isolation do not reveal their HIV status to their family, health workers for fear of being stigmatized. According to Cloete et al. [22], HIV positive patients are still afraid to disclose their status, reluctance and anxiety to disclose HIV positive status and fears of being discriminated against are evidence of the persistent nature of AIDS related stigma. Furthermore Cloete et al. [22] state that these AIDS related stigma remains the barrier to curb the spread of HIV/AIDS among who know their status.

Lack of disclosure to sexual partners

In this study, it was found that stigma and discrimination is still prevalent as some of the participants did not disclosed to their partners to avoid rejection, stigma and discrimination. One participant had this to say about disclosing;

- "I did not want to tell my wife for fear she will leave me."

Divorce is the final termination of marriage of a marital union before death of either party. HIV status aware couples, with at least one HIV positive partner, are, however, characterized by high separation or divorce rates with its implications for the spread of HIV. According to Nsimba et al. [33] state that disclosure to partners by HIV positive patients has following potential risks, loss of economic support, blame, abandonment physical and emotional abuse, discrimination, disruption of family relationship. Lack of disclosure to partner due to fear of stigma and discrimination is tied to fear of being accused of infidelity rejection and violence [33]. In this study, the participants revealed incidents of being rejected by the partner due positive HIV status.

Benefits of disclosure and belonging to a support group

Participants in this study shows how they benefited while attending these support groups. One participant had this to say, *“The nurses introduced me to other patients who were sick, at first I was depressed seeing those very thin patients, but when others shared their experiences I felt relieved”*.

One participant looked happy as she explained how being in a support group revived her hopes for the future.

“I learned a lot from other patients who had experiences, thus building my hopes that I will also see the future”

The other participant felt a sense of belonging and warmth by being a member of the support group.

“In a support group we live like a family, I felt love unconditionally even though I have HIV”.

According to Moskowitz [7] in Ndala-Magoro [34], support groups prepares HIV positive patients for acceptance of their status, treatment adherence and endower them on adjustment with positive lifestyle living.

According to Liamputtong et al. [35] in the study done in Thailand, it was found that support groups for people living with HIV provides emotional support to many and the members of the group learned more from others. Learning from their peers made these people living with HIV stronger and felt they are not alone. Furthermore, Liamputtong et al. [35] identified that support group gave these people living with HIV a sense of belonging.

In another study done, Heyer et al. [36] showed that the participants in their research revealed how support groups has benefited them emotionally by having freedom to share their experiences with others, having a sense of belonging and developing friendship that progressed beyond the support group. In the study by Ndala-Magoro [34], it was identified that participant saw support groups as a means to impact on their behaviour on lifestyle changes and a platform to share [34].

This study has found out that the participants show similar findings of seeing a support group as a place for learning, sharing and a place for belonging.

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