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RESEARCH ARTICLE

Barriers Contributing to Loss to Follow-up among HIV-patients in Limpopo Province, South Africa: Patients' and Nurses' Perspectives

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Abstract:

Background:

Antiretroviral therapy is a lifelong commitment that requires patients to adhere to their daily medication dose schedules and make frequent visits to health services for their care. People living with HIV can live healthy long lives when retained on antiretroviral therapy. Retention in care has been identified as the benchmark in the HIV Care Continuum, where most people living with HIV fail. Interventions are urgently needed to address this benchmark to achieve the worldwide 95-95-95 goals. Despite the South African government`s efforts to expand access to antiretroviral therapy services from urban centers to resource-constrained rural communities, there were 140,000 HIV- related deaths in 2014 and 85,796 HIV- related deaths in 2021. Patients have become lost to follow-up, putting their health and that of their communities at risk.

Moreover, the loss of follow-up care among HIV-positive people who are on antiretroviral treatment continues to be a significant problem. The study determined barriers contributing to the Loss of follow-up rates among people living with HIV.

Methods:

A qualitative research study was conducted; Non-probability purposive sampling was used to select eight nurses from clinics with the highest and lowest loss-to-follow-up rates. The probability systematic sampling method was used to select patients from the selected clinics. Data were collected through semi-structured interviews, and content analysis was used to analyse the data.

Results:

Patients' and nurses' perspectives on barriers contributing to the loss of follow-up among people living with HIV included lack of confidentiality, lack of understanding of antiretroviral treatment, patients' self-transfer, and feeling better physically.

Conclusion:

Understanding the reasons for the Loss of follow-up could inform the development of retention in care interventions for Limpopo province. The study can be most beneficial with HIV education, skills building, and outreach programme strategies; this will, in turn, increase the knowledge needed to better attract and retain HIV-positive patients in healthcare settings.

Keywords: Antiretroviral therapy, Loss to follow-up, PLWH, Nurses, Compliance, Barriers.

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1. INTRODUCTION

1.1. Background

Globally, HIV has affected a high proportion of the population, with 38.4 million people living with HIV [1]. South Africa remains the country with the highest prevalence of people living with HIV (PLHIV) worldwide, with 8.45 million people in South Africa living with HIV out of a population of 60.60 million; this means that the estimated overall HIV prevalence rate is approximately 13.7% among the South African population [2]. The total number of PLHIV in South Africa increased from an estimated 3.68 million in 2002 to 8.45 million by 2022 [2].

In response to this overwhelming HIV burden, large-scale programmes to provide antiretroviral treatment (ART) for

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people living with HIV have expanded in Sub-Saharan Africa, with South Africa comprising the largest ART rollout programmes worldwide, with over five million people receiving ART [2]. In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) recommended that countries achieve the 90/90/90 goals to end HIV transmission, meaning that 90% of people living with HIV should know their HIV status, 90% of people who know their HIV status should receive treatment and 90% of people on treatment should achieve viral suppression [3 - 6]. Achieving viral suppression ("undetectable") means that PLWHIV cannot pass on the virus to others (untransmittable) [6]. In December 2020, UNAIDS introduced the new 95-95-95, a five-year plan to replace the previous 90 90 90 targets [7]. This plan aims to ensure that by 2030, 95% of HIV-positive people know their HIV status, 95% of people diagnosed with HIV receive sustained antiretroviral therapy (ART), and 95% of people on ART have viral suppression. Moreover, there seems to be a reduction in the number HIV related deaths in South Africa; an estimated number of HIV -related deaths has declined consistently since 2007 from 274 501 to 79. 420 in 2020, with a slight increase in 2021 at 85.154 and 85.796 in 2022 [8]. Despite this progress, South Africa is yet to meet the 95 95 95 targets.

Noteworthy, people living with HIV can live healthy long lives when retained on antiretroviral therapy [9 - 11]. However, some of the patients living with HIV are lost to follow-up (LTFU) and are therefore at high risk of illness and death due to HIV-related conditions [12 - 14]. For instance, a retrospective cohort study involved the review of 646 records of patients initiated on antiretroviral therapy (ART). The study found that of the 646 patients enrolled, a total of 216 patients (33.4%) were considered LTFU [15]. An Ethiopian study conducted by Alebel *et al.* [16] among adults living with HIV and on ART study also showed that at the end of the study period, 109 (12.9%) participants were considered LTFU.

Furthermore, globally, HIV-positive patients drop out of care for various reasons, including transportation costs, time limitations due to work, long clinic waiting times, stigma and discrimination, long distance to health facilities, fear of disclosure, unsatisfactory treatment by service providers as well as the shortage of medication [17 - 24].

Despite the South African government`s efforts to expand access to antiretroviral therapy services, from urban centers to resource-constrained rural communities, with the vision of zero new infections, and zero HIV- related deaths, loss to follow-up care among HIV-positive people who are on antiretroviral treatment continues to be a significant problem [13]. The rate of LTFU in the Sekhukhune district in Limpopo Province is 23%, which is greater than the South African National LTFU rate of 20% in the financial year 2013/2014 [13]. Therefore, this project focused on this district, and the study provides a better understanding of barriers contributing to LTFU of people living with HIV, at the clinics with the highest and lowest prevalence of LTFU in Sekhukhune District of Limpopo province, South Africa, from patients' and nurses' perspectives.

2. METHODS

2.1. Study Setting

The study was conducted in the Sekhukhune District located in the Limpopo Province, the northernmost part of South Africa. There is an insignificant number of health facilities within the Limpopo province, especially in Sekhukhune district, where on average, there is one clinic for every 17,000 people and approximately 97,500 persons per hospital. In this regard, the district has a total number of 76 clinics, five District hospitals, and two regional Hospitals [25]. All 76 clinics in the district initiate ART, and patients decide to go to whichever clinic is convenient for them. In the age group 25 to 64, the top causes of death for males and females are HIV and TB-related illnesses [25]. Regarding HIV, there are 86. Three hundred thirty-six people were infected with HIV in the district, which constitutes 19.04% and 1.21% of people infected with HIV in Limpopo and South Africa, respectively [25].

2.2. Research Design

The study applied a descriptive qualitative research design to allow patients and nurses to share their perspectives on LTFU in more detail during individual interviews. The descriptive qualitative approach is useful in providing understanding and summarising an area of interest and was appropriately selected for this study.

2.3. Population, Sampling, and Sample

In this study, our target population was all HIV-positive LTFU patients and nurses in clinics with high and low rates of LTFU in the Sekhukhune District. The accessible sample population came from eight clinics in the district. All the nurses and patients were sampled from the same pool of clinics. The district comprises four sub-districts, so two clinics were selected from each sub-district (one clinic with the highest rate and one clinic with the lowest rate in each sub-district). The clinics were sampled because of their high rate of LTFU, while others were sampled because of their low/zero LTFU rate. The district office provided us with a data set we analysed to identify the clinics with low and high rates of LTFU. The sample of patient participants is comprised of 30 HIV-positive people classified as "lost to follow-up". Probability systematic sampling was used to select patients because the study relied on the HIV patients' registers to obtain their contact information. Non-probability purposive sampling was used to sample eight nurses, four from clinics with the highest rates of LTFU and four from clinics with the lowest rates of LTFU. This helped to maximise an equal representation of all the sub-districts in the Sekhukhune district. It also minimised bias and made the results of the study to be generalizable to the whole district. The patient participants included 18 females and only two males; this is because the clinic has more female patients who test for HIV as compared to males. It was established that women were required to test for HIV when they were pregnant, and if one tested positive for HIV, they were put on ART. On the other hand, male patients are fewer in clinics because they do not test for HIV voluntarily unless they are very ill. Loss to follow-up

(LTFU) meant not keeping ART refill appointments for 90 days or longer from the last booked refill appointment date. Only people who are 18 years and older were included in the study because, in South Africa, people 18 years of age and above can give legal consent. The selected patients were traced from their homes with the assistance of Home-Based Carers from the selected clinics. The Home-Based Carers are individuals from the local communities who are employed at the clinic to trace LTFU patients of all chronic illnesses in the communities. To maximize the comfort of the participants, I engaged with the patients in the absence of Home-Based Carers.

2.4. Data Collection

The data was collected from April 2017 to June 2017. The collected data were audio-recorded, and additional information and observations were documented on paper. During data collection, it was observed that patients were comfortable and excited to share their reasons for LTFU with a neutral and unfamiliar individual who is not a nurse and not from their community. The nurses sounded confident that the report from researchers following data analysis will guide them on how they can retain their patients in HIV care. The data was collected through the use of a semi-structured interview guide (refer to Appendix A, B, and C). The semi-structured interview guide questions were derived from the research objectives of the study to address the research questions of the study. It consisted of two sections: Section A gathered participants' demographic information (age, gender, marital status, educational status), and Section B focused the interview on areas that the study sought to explore. The areas of focus included factors contributing to LTFU among HIV-positive patients and strategies to retain HIV-positive patients on ART. The semi-structured interview guide was pretested before the main study to assess if the researcher's questions were answerable and if all the interview questions were clear to the respondents. Pre-testing checked if adaptations to the interview guide were required. For the pre-testing, two HIV-positive patients (LTFU) and two clinic nurses were individually interviewed following the procedures for the actual study. Those three patients and two nurses who participated in the pre-testing of the instrument were not included in the larger study. Pre-testing assisted the researchers to improve the instrument and rephrase some of the questions.

Nurses and patient participants were interviewed in Sepedi to assure comfort during interviews because 83% of the population in the district speak Sepedi as their first language [25]. The data were translated into English by a qualified language translator. Copies of the informed consent form and interview guide were prepared and explained to the participants.

2.5. Data Analysis

The study used content analysis to organise the collected data into themes and sub-themes manually; no qualitative data software was used. During the coding, the researcher was guided by the study research objectives to examine the text for salient categories of information supported by the text from the interviews.

2.6. Ethical Considerations

The Research Ethical Committee of the University of Venda approved the study with project number (Ref: SHS/16/PSYCH/061808). Additionally, the Limpopo Department of Health and the Sekhukhune district health department granted permission to conduct the study. Participants were fully informed about all aspects of the study by reading and translating information into their language in the consent letter before they consented to participate. They were assured that the information shared would not be linked to any of them as pseudonyms would be used. They were informed that they could terminate their participation at any stage of the interview if they became uncomfortable. Participants were further informed that confidentiality and anonymity would be maintained and that their recorded voice equipment and written notes would be kept safe in a locked steel cabinet, and only the primary researchers would have access if needs were.

2.7. Trustworthiness

Trustworthiness is when the study accurately represents how the researcher convinces her audience that the findings are worth taking note of. Trustworthiness can also be considered as the degree of confidence that qualitative researchers have in their data, and it is evaluated using the criteria of credibility, transferability, dependability, and conformability [26]. In this study, credibility was ensured through techniques such as prolonged engagement, quality probing questions, clarification of researcher bias, peer debriefing, and in-member checks. For in-member checks, the researcher went back to the district to seek participants' views on the credibility of the findings and interpretations. The researcher took the data, analysis, interpretations, and conclusions back to the participants, and they judged the accuracy and credibility of the results and interpretations. The researcher had a peer reviewer who went through background information, data collection methods and process, data management, and data analysis. The peer reviewer was a PhD candidate with the researcher at the time of the study, and she asked questions about everything the researcher investigated, including the methods, meanings, and interpretations to verify concepts found in the analysis. Transferability was attained through comprehensive descriptions of the research methodology and the setting of the study. With such detailed information, the readers will be able to transfer the information to other settings and determine whether the findings can be transferred because of shared characteristics. Dependability was achieved through auditing of research processes. Here, an auditor examined documentation of critical incidents in interview notes and products such as research findings, interpretations, and recommendations and confirmed that all these products were supported by data. Conformity was established through the involvement of an expert in qualitative research who reviewed the thematic coding of the data guided by the study questions, the findings, and interpretations to test conformability.

3. RESULTS

This section presents findings inclusive of demographic information of all the patients and nurses who were interviewed individually and their narrative responses on their perspectives on the system and structural barriers contributing to LTFU among HIV- positive patients.

3.1. Demographic Information of the Participants

The patient participants were between ages 25 and 63 and were predominantly female, with 18 females and only two males. Only one patient participant held a grade 12 certificate; the rest of the patients did not complete secondary school.

The majority of the nurses' participants held a nursing diploma; however, one of the nurses held a Baccalaureus Curations (Bcur degree).

4. DETAILED RESULTS

The interviews were conducted with nurses whose clinics have lower rates of LTFU and also with nurses whose clinics have the highest rates of LTFU in their respective sub-districts. HIV-positive LTFU patients were also interviewed individually in their respective homes, and nurses were interviewed in the clinics. Various similarities and differences in the responses were well established during the discussions with the nurses and patients. Two themes that emerged from the study are 1) Patients' perspectives on barriers contributing to LTFU among HIV- positive patients and 2) Nurses' perspectives on barriers contributing to LTFU among HIV- positive patients. Below are all the findings that were incorporated to demonstrate the themes outlined.

4.1. Patients` perspectives on barriers contributing to LTFU among HIV–positive patients

Patients outlined various sub-themes that contributed to their decision to discontinue HIV treatment. The sub-themes included lack of understanding of ART leading to patients' non-retention in care; absence of confidentiality by nurses and HBCs discouraging patients` retention in care; Unwelcoming and rude behaviour by nurses discouraging patients from remaining in care; Patients` fear of disclosing HIV status discourages staying in care; traditional beliefs is patients' barrier to retention in care inhibits patients from staying in care. All these identified sub-themes are detailed below.

4.1.1. Lack of Understanding of ART Leads to Patients' Non-retention in Care

Patients emphasized that the nurses did not clarify that the medication was lifelong. They assumed that when they completed the first dose of medication, there was no need to visit the clinic for a refill. They also thought that there was no need to take HIV medication when feeling well physically. This is supported by these statements from some of the patients:

"I just thought that since I am feeling strong physically and I am also using a condom when engaging in sex, there is no need for me to continue taking medication."

"I don't feel any pains in my body, So I don't need any medication."

"I thought the medication was to protect the baby; after giving birth, I stopped taking the medication; I saw no use of it."

4.1.2. The Absence of Confidentiality by Nurses and HBCs Discourages Patients` Retention in Care

Patients emphasized that they have defaulted from care due to the absence of confidentiality by nurses and home-based carers; they fear being stigmatized if their HIV status was to be exposed to the people around them. Patients pointed out that the home-based carers and the nurses disclosed patients' HIV status to other people in the community. The following statements were highlighted by patients:

"The nurses and home base carers tell other people in the village that I am HIV -positive and that I take HIV medication."

"I can never go to the clinic because the nurses and home-based carers gossip about my HIV status in the village."

"I will never return to this clinic in the village; the HBCs are gossipers; I would rather go to a further located clinic where I have to take a taxi to get there."

4.2. Unwelcoming and Rude Behaviour by Nurses Discourages Patients from Remaining in the Care

Patients mentioned that they have defaulted from care due to rude conduct towards them by nurses. A patient highlighted that nurses are not welcoming and are rude to them during their visits; he cited that one Afrikaans nurse was racist and harsh towards black patients and further emphasized that he could not stand to be spoken to like a child; he stated:

"There is an Afrikaans nurse in the clinic who is rude to most patients; she does not treat me well every time I visit the clinic, especially if I miss one appointment. Therefore, I decided to avoid her by not visiting the clinic anymore".

4.3. Patients' Fear of Disclosing their HIV Status Discourages Staying in Care

Fear of disclosing one 's HIV status was reported to be a barrier by patients. Patients said that the reason they discontinued taking their medication was that they were afraid to disclose that information to their partners. To the patients, demanding condom use automatically meant one should disclose their HIV status to their partner. The partner would demand to know the reasons for sudden condom use. Some of the patients illustrated:

"The father of my baby refuses to use a condom, and I am afraid to disclose my HIV status to him, so I don't see the need to take medication since it won't be effective."

"My partner does not know that I am HIV positive, so he will be surprised if I suddenly request a condom, especially because he wants a baby, so it is useless for me to continue with the medication."

4.4. The Traditional Belief is Patients' Barrier to Retention in HIV Care

The use of traditional medicine was also mentioned as a barrier to retention in care. One participant calmly mentioned that she defaulted on ART medication because she resorted to traditional medication. She sounded hopeful and believed that she could be healed using traditional medicine. The patients said:

"I am using traditional medication to fight what I have in my body; the traditional medicine will clean my blood then I will be HIV-free".

4.4.1. Nurses` Perspectives on Barriers that Contribute to Patients' Loss to Follow-up in Care are Inconvenient

Nurses outlined reasons that they perceive as barriers to HIV patients` LTFU. Emerged sub-themes from nurses included self-transfer causes high LTFU records; fear of lack of confidentiality discourages patients from staying in care; lack of understanding of ART causes patients to default from HIV care; religious/traditional beliefs is patients' barrier to retention in HIV care; patients` fear of disclosure discourages retention in care; inconvenient clinic operating hours restrict patients to stay in care; and disability grant encourages patients to default from HIV treatment. These sub-themes are detailed below.

4.5. Patients' Self-transfer Causes High LTFU Records

The most common reason reported by nurses was patients' self-transfer. The nurses emphasized that patients relocate from the village where the clinic is located without obtaining an official transfer-out letter from the clinic. As a result, those patients are labeled as a loss to follow up in their records. Some of the nurses said:

"Most of our patients are immigrant farm workers; they don't inform us when they are moving to another farm or returning to their home country. Thus, in our system, they are recorded as a loss to follow up".

"Majority of our patients study at the FET College nearby, so when they complete their studies, they self-transfer themselves to the clinics at their homes. They relocate without notifying the clinic; then in our records, they are LTFU".

4.6. Fear of Lack of Confidentiality Discourages Patients from Staying in Care

The nurses with concern confirmed that patients' fear of lack of confidentiality might be the reason for patients` LTFU. The nurses confirmed that most of the nurses and all home-based carers are from the same village as the patients and, therefore, well known to the patients. Subsequently, patients fear that their HIV status will be known to other people in the village if they continue going to the clinic for HIV care. One of the nurses illustrated:

"Our patients default because most of the nurses in our clinic are from this village, so patients feel uncomfortable. They are fearful that we might disclose their HIV status and the fact that they are taking HIV medication to other people in the village".

4.7. A Lack of Understanding of ART Causes Patients to Default from HIV Care

Nurses had the same perspective as the patients, as mentioned above. Looking concerned, nurses highlighted that patients default from care due to a lack of understanding of the importance of ART and feeling strong physically. The nurse said:

"Patients default from care due to a lack of understanding of how ART works, the moment they feel well in their bodies, they stop taking the medication".

4.8. Patients` Fear of Disclosure Discourages Retention in Care

Nurses cited that patients' fear of disclosure to their family members is the reason for default. Nurses mentioned that patients default because they think that if they continue taking the medication at home, family members will be suspicious that they might be HIV-positive since they are taking pills daily. The nurse said:

"Our patients default because they are scared to disclose to their family members; they are afraid that family members will speculate that they might be HIV-positive if they continue taking pills daily."

4.9. Religious/traditional beliefs are patients' barriers to retention in HIV Care

Nurses indicated that some of the patients default from care due to traditional or religious beliefs. The nurses emphasized that some patients default from treatment because they believe that they can be healed by either God or traditional healers. The nurses said:

"Some of the patients tell us that they were instructed by a traditional healer to stop taking their HIV medication and focus only on the traditional medication."

"Despite our efforts explaining to them that the medication is lifelong and there is no cure for HIV, patients still replace ART with holy water, they believe that God can heal all illnesses, they still seek help from pastors."

5. DISCUSSION

This study examined patient and nurse perspectives on barriers contributing to LTFU. While there is widespread literature on patients' perspectives [18, 27 - 29], literature on the nurses' perspectives is not as extensive [30, 31]. Notably, the participants' demographic data collected did not inform the study in any way. Below is a preview of the findings that were incorporated to demonstrate barriers that contributed to patients' loss to follow-up, as well as global relevant literature for each reason [29, 32 - 35]. This discussion will assist in establishing if the literature contradicts or supports the findings of the study. Moreover, the findings presented in this study highlight an urgent need for strategies to address various barriers to ART adherence and less dropout of HIV care.

In the current study, there are various barriers, which were described by nurses and patients as obstacles that hinder patients from retaining HIV care. Patients also feel that some of the obstacles are beyond their ability to overcome. The barriers outlined by patients and nurses included a lack of understanding of ART, lack of confidentiality, traditional/ religious beliefs, disability grants, unsatisfactory treatment by staff, fear of disclosure, inconvenient operating hours, difficulty taking time off from work, and patients' self-transfer.

Some patients felt that they should discontinue taking their medication because they feel strong physically. They believe that a person living with HIV should feel pain, be weak, and be unable to carry on with their daily routine activities. These perceptions are due to a limited understanding of how HIV and ART work [32,36]. Patients in the study further indicated that they were unaware that ART is a lifelong treatment and that a person living with HIV and on HIV treatment can live a normal healthy life like everyone else. Nurses also attested to what patients reported that they believe that patients discontinue taking their medication when they feel strong physically. They also reckon this might be due to misinterpretation of how ART works.

The above-mentioned results are not far off from the findings in some of the studies in Africa [22, 36, 37]. For instance, in some of the studies conducted in East Africa (Uganda, Tanzania, and Kenya), it was found that one of the most common reasons for non-return in care was "felt well and therefore did not see any reason for coming to the clinic" [38 - 41].

Patients also said that their confidentiality was compromised by nurses and home-based carers; hence they dropped out of care. They shared with certainty that the clinic staff disclosed their HIV status and the fact that they were on HIV medication to the other community members in the village. Patients in the current study pointed out that it is easier for home-based carers and nurses to share their confidential information with other people in the village because they reside in the same village as their patients. Nurses in this study stated that patients' speculation that clinic staff discloses patients' HIV status and the fact that they are on HIV treatment is incorrect. The nurses mentioned that patients may assume that since they live in the same village as them, their health issues will be shared with other community members.

There are concurring results in various studies, as in a study conducted in Ethiopia, the lack of confidentiality by healthcare providers was raised as a concern by patients [42]. Consistent findings were found in a Tanzanian study highlighted that they were afraid that health providers would disclose their HIV status, especially of patients known to them [43]. This relates to what one of the patients in the current study said that they prefer to travel to a far distant clinic for their HIV medication to avoid confidentiality issues. The study further established that patients dropped out of care due to negative treatment by nurses. Patients highlighted that nurses are impolite and disrespectful towards them during their regular visits. Therefore, to avoid hostile treatment, patients left care. This finding is similar to the results of South African studies that were conducted by [35,44], which found that the most highly reported perceived barrier was poor service delivery in health facilities. Consistent results in a Kenyan study reported that poor service delivery, including long queues and negative provider attitudes, were prominent barriers to retraining patients in care [21]. More concurring findings from a study conducted in 24 countries in Sub-Saharan Africa also revealed that the majority of the patient participants experienced negative treatment from clinic staff [44]. This was a primary barrier that discouraged them from remaining in HIV care.

Moreover, Patients mentioned that they discontinued taking their medication because they are afraid to disclose their HIV status to their partners. They also assume that if they disclose their HIV status, their partners will end the relationship. The fear of rejection by partners has been reported to be a hindrance to retention in care. For example, a study conducted in Eswatini showed that non-disclosure to partners was found to be a hindrance to retention in care [45]. These are consistent with results from a study that cited fear of disclosure to others, followed by fear of disclosure to their partner as a barrier to non-retention in care [27]. These results are also similar to the results reported in a Ghanaian study which found that fear of HIV status disclosure was a considerable barrier to remaining in care [46].

Furthermore, patients in the study dropped out of care due to the use of traditional medication or faith healing. They believed that they could be cured by a traditional healer using traditional medication or by God. One of the patients in the study confirmed that she opted for traditional medication as an alternative therapy because she strongly believed that she would be healed. This concurs with the results of a study conducted in Malawi to identify patients` reasons for interrupting ART; some of the patients stated traditional medication as the reason for dropping out of care [47]. Similar findings in an American conducted study reported that participants dropped out of care because they believed that Traditional medicine would cure HIV [48]. In a related study in the Caribbean, results showed that some postpartum women believed that God would cure them; as a result, they defaulted on their medication and put their trust in the pastor for remedy [49]. Concurring results in Uganda also reported that they dropped out of care because they believed that God could 'cure HIV' [50].' Contrary to all the above results that have been reported that religious beliefs are barriers to retention in care among HIV-positive individuals, findings in one of the studies conducted in Congo discovered religious beliefs as a facilitator to remaining in care. Many participants sustained the belief that God provided the knowledge to make ARVs; thus, the ARVs would help them feel better and live a long, healthy life. This mindset motivated them to keep adhering to the treatment [51].

Lastly, nurses frequently reported patients' self-transfer as a barrier to retention in care. They mentioned that patients are labeled as LTFU in their records due to self-transfer, but patients did not report this. A study conducted in three Eastern African countries (Uganda, Kenya, and Tanzania) to assess reasons for non-return in care revealed that of 18,081 patients, 10% of the patients self-transferred without obtaining an official letter from the previous clinic [41]. In another Ugandan study, it was found that (36.4%) of those who were classified as LTFU at the facility level had self-transferred to another facility [52]. Similar results in a study conducted in Kenya showed that more than half of the traced patients who are recorded as LFTU had self-transferred to other health facilities [10].

6. RECOMMENDATIONS

The findings of this study have revealed limitations and challenges encountered by both patients and nurses within the district. Some recommendations are therefore suggested to close the gaps identified and improve patients' retention in care. Most importantly, the recommendations are also suggested to help to reach the 95 95 95 targets. The recommendations include responsibilities that should be achieved by the DOH district, the nurses, the clinic managers, and home-based carers to improve patients' retention in care as well as ART adherence.

7. RECOMMENDATIONS FOR NURSES AND DOH

The clinic manager should provide nurses and home-based carers with continuous in-service training on ethics, especially confidentiality and respect for patients.

Nurses should provide patients with health education in an engaging, interactive, and respectful manner.

Nurses should conduct outreach programs to engage and educate the community, especially pastors and traditional healers, on ART and HIV.

Nurses should continuously remind patients to inform the clinic when they decide to continue to care in another clinic to avoid having inaccurate LTFU rates.

The DOH district should provide nurses with training on motivational interviewing to furnish them with skills on how to provide health care engagingly and respectfully.

8. LIMITATIONS OF THE STUDY

Due to the sensitivity of the study topic, patient participants were unable to open up and be comfortable in the beginning. It took some little time, therefore, to build a relationship with the patients for them to be comfortable enough to engage freely in the discussions.

CONCLUSION

The information outlined in the current study demonstrates that achieving adherence to HIV medication is an urgent issue for the public health services in Limpopo to consider for implementation. The findings of this study also point out various important areas of improvement for the future. This study adds to the few studies in South Africa that have explored the barriers faced by HIV-positive people in accessing ART. While the study only focuses on the Sekhukhune district of the Limpopo Province, South Africa, it reveals several findings that should be given attention.

LIST OF ABBREVIATIONS

AIDS = Acquired Immune Deficiency Syndrome
ART = Antiretroviral Therapy
BCUR = Baccalaureus Curationis
CD4 = Cluster of differentiation 4
DOH = Department of Health
HBCs = Home-Based Carers
HIV = Human Immune Virus
LTFU = Loss to follow up
PLHIV = People living with HIV
STATS SA = Statistics South Africa.
UNAIDS = Joint United Nations Programme on HIV/AIDS
WHO = World Health Organization

AUTHORS' CONTRIBUTIONS

MB was involved in writing the project proposal for approval by RPC at UNIVEN, LB was the supervisor of the study, and K was the co-supervisor. MB collected, analysed, and drafted the results. LB and K supervised data collection, analysis, and drafting of the results. MB conceptualised the results, interpretation, and writing of the original draft. MB, LB, and K discussed the final manuscript and approved it for publication.

ETHICS APPROVAL AND CONSENT TO PARTICIPATION

The ethical clearance for this study was granted by the University of Venda Research Ethics Committee (Approval No: SHS/16/PSYCH/061808). The permission to collect data in the healthcare facilities was obtained from the Department of Health, Limpopo Province, and each district by the district executive manager.

HUMAN AND ANIMAL RIGHTS

No animals were used in this research. All human research procedures followed were following the ethical standards of the committee responsible for human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

All patients and nurses participated voluntarily and gave their informed consent.

AVAILABILITY OF DATA AND MATERIALS

The datasets generated and/or analysed during the current study are available from the corresponding author [M.M] upon reasonable request.

FUNDING

None.

STANDARDS OF REPORTING

CORREQ guidelines were followed.

CONFLICT OF INTEREST

The authors declare that they have no competing interests.

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APPENDIX A: Interview guide for patients

Section A: Sociodemographic

Age in years as at last birthday ....

Gender

Female …………………………………………………….

Male …………………………………………………….

Education

1) None

2) Primary

3) Secondary (High School)

4) University

Marital status

1) Single

2) Married/cohabiting

3) Divorced/separated

4) Widowed

The main source of income ....

Monthly income (Rands) ....

Means of transport to clinic ………………………………………………………………………

Time taken to reach the clinic from home (hrs)…………………………………………………….

Cost to get to the clinic (Rands) ....

Do you take time off work to come to the clinic? 0) No 1) Yes

Section B: Personal Perceptions of Health and ART treatment

1. Did you discontinue ART treatment, and if so, when?

2. Please share with me your reasons for discontinuing taking the antiretroviral treatment.

3. Are there any alternative treatments you are using to replace the antiretroviral treatment?

a. Tell me about them (description).

b. When did you start using this alternative treatment?

c. Why did you seek alternative treatment?

d. How much do you spend on alternative treatment?

4. Have you experienced any issues taking both alternative treatment and ART?

5. How do you feel about the alternative treatment you are using compared to the biomedical treatment you were receiving from clinics?

6. Why did you choose to take alternative treatments?

7. Do you currently receive or have you previously received a disability grant?

8. What relationship, if any, does the disability grant have on you dropping out of care?

9. What do you know about the importance of remaining on ART and in care?

10. What do you think can be done to re-engage you and other LTFU patients in care?

11. What do you think can be done to help patients remain in care?

APPENDIX B: Interview guide for nurses whose clinics have high LTFU rate

Section A: Sociodemographic

Gender

Female …………………………………………………….

Male …………………………………………………….

Education

1. Degree

2. Diploma

3. Other ……………………………………………………

Section B: Perceptions about LTFU patients and strategies

In your opinion:

1. Why do HIV-positive patients drop out of care in your clinic?

2. What can be done to re-engage these patients in care?

a. What are you already doing about re-engaging patients in care?

b. What have you tried that did not work?

c. What are you planning to re-engage patients?

3. What can be done to help HIV-positive patients remain in care?

APPENDIX C: Interview guide for nurses whose clinics have low LTFU rate

Section A: Sociodemographic

Age in years as at last birthday ....

Gender

Female …………………………………………………….

Male …………………………………………………….

Education

4. Degree

5. Diploma

6. Other …………………………………………………

Section B: Perceptions about LTFU patients and strategies

1. What do you know about the rate of LTFU in your clinic?

2. Did your clinic experience higher LTFU rates before now?

3. If yes, please share with me what you think contributed to patients' loss to follow up in your clinic then.

4. What efforts did you and your team make to achieve low rates of LTFU today?

5. Do you have patients that have been re-engaged in care?

6. If yes, what did you do to re-engage those patients in care?

7. What tips and advice would you give to clinics that are struggling with high rates of LTFU?

8. What do you think are the top 3 strategies you use to retain or re-engage patients in care?

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