The Open Public Health Journal

DOI: 10.2174/0118749445433456251210195121, 2026, 19, e18749445433456

ISSN: 1874-9445

RESEARCH ARTICLE **OPEN ACCESS**

“Why Patients drift away”: A Qualitative Study to Explore Factors associated with Loss to Follow-up of Patients Living with HIV in the DIMAMO Surveillance Area in Limpopo Province

Tsakani Millicent Maluleke[1], Mxolisi Welcome Ngwenya[1,*], Nkateko Linneth Mabila[2] and Livhuwani Muthelo[1]

[1] *Department of Nursing Science, University of Limpopo, Mankweng 0727, South Africa*
[2] *Department of Pharmacy, University of Limpopo, Mankweng 0727, South Africa*

Abstract:

Introduction: Loss to follow-up (LTFU) has been reported as a recurrent challenge affecting the success of antiretroviral treatment among HIV-infected patients in low- and middle-income countries. Additionally, loss of follow-up is a significant problem associated with increased treatment failure, which can be presented through clinical, immunological, and virological failure. Lastly, LTFU exacerbates the rates of morbidity, mortality, and drug resistance among people living with HIV.The study explores factors associated with loss to follow-up among patients living with HIV in selected public clinics under the DIMAMO surveillance area in the Capricorn district of Limpopo province.

Material and Methods: A qualitative research approach, particularly Phenomenology, was adopted to explore and understand the experiences of registered nurses and community health workers who work with patients on antiretroviral treatment at the selected public clinics. Twenty-eight (28) participants were purposively selected. Furthermore, data were collected using semi-structured interviews. Lastly, data was analysed using Delve narrative analysis as guided by Delve and Limpaecher.

Results: Following the process of data analysis, the study revealed that patients living with HIV often face diverse internal conflicts and significant barriers leading to loss of follow-up. The following themes emerged: 1.) Patient-related factors identified in a form of denial related to perceptions of HIV, perceptions of being healed or healthy, and lastly, not accepting responsibility for HIV health status. 2.) Significant barriers associated with disengagement from HIV care among patients were identified in the form of non-disclosure of HIV status to significant others, fear of stigmatisation, perceived breach of confidentiality, and lastly, resistance to or non-use of community healthcare interventions.

Discussion: In summary, the study identified the key challenges affecting HIV care, including internal conflicts, which manifested in the form of denial, and misconceptions about health status as reported by the participants. Thus, the significant barriers to care disengagement included non-disclosure of HIV status, fear of stigma, perceived breaches of confidentiality, and resistance to community healthcare interventions.

Conclusion: Furthermore, these findings highlight the need for targeted interventions to improve patient retention rates. Notably, a comprehensive training program and information guide for healthcare providers can enhance their ability to support antiretroviral patients and improve treatment adherence and health outcomes.

Keywords: Loss to Follow-Up of Patients, Antiretroviral Treatment, HIV, Care disengagement, HIV care, People Living With HIV, Opportunistic infection, Community Health Workers.

*Address correspondence to this author at the Department of Nursing Science, University of Limpopo, Mankweng 0727, South Africa; Tel: +2715 268 4652; E-mail: mxolisi.ngwenya@ul.ac.za

Cite as: Maluleke T, Ngwenya M, Mabila N, Muthelo L. “Why Patients drift away”: A Qualitative Study to Explore Factors associated with Loss to Follow-up of Patients Living with HIV in the DIMAMO Surveillance Area in Limpopo Province. Open Public Health J, 2026; 19: e18749445433456. http://dx.doi.org/10.2174/0118749445433456251210195121

Received: August 07, 2025
Revised: October 30, 2025
Accepted: November 05, 2025
Published: March 31, 2026

1. INTRODUCTION

One of the main challenges in effectively managing Human Immunodeficiency Virus (HIV) patient care and treatment is the loss to follow-up (LTFU) from antiretroviral therapy (ART) [1]. Undeniably, loss to follow-up (LTFU) is a significant public health concern, despite the rapid expansion of ART services [2]. Furthermore, the United Nations AIDS Organisations identified that the HIV treatment works best when taken as prescribed [3]. Therefore, patient loss to follow-up in the context of HIV care presents a significant issue, particularly in settings with limited resources [4]· Remarkably, Loss to follow-up has been previously reported to contribute to higher rates of treatment failures, including clinical, immunological, and virological issues, which ultimately increase morbidity, mortality, and drug resistance [5]. Subsequently, loss to follow-up has been reported as the leading cause of morbidity, mortality, hospitalisation, treatment failure, high burden of opportunistic infections (OIs), the emergence of drug resistance to HIV, and transmission of the virus to uninfected sexual partners among patients with HIV/AIDS [6].

Moreover, Telayneh *et al.* also expressed concerns that LTFU could escalate treatment failures, such as clinical, immunological, and virological [7]. However, the Joint United Nations Programme on HIV/AIDS (UNAIDS) [8] and the World Health Organisation (WHO) [9] outlined that the United Nations has set ambitious targets to end the HIV/AIDS epidemic by 2030, called the 95-95-95 targets [8, 9]. Furthermore, these targets would ensure that 95% of people know their status, and 95% of people who know their status are receiving treatment; further, 95% of people on HIV treatment have a suppressed viral load.

According to the World Health Organization, global data indicated that approximately 40.8 million people were living with HIV at the end of 2024 [9]. Furthermore, when examining the first target of the 95-95-95 initiative, which stipulates that 95% of individuals should be aware of their HIV status, it was found that only 88% of adults living with HIV were aware of their condition in 2024. Additionally, regarding the second target, only 78% of adults were receiving antiretroviral therapy by the end of that year. This report clearly underscores the need for enhanced efforts to meet the established targets. Notably, the National Strategic Plan for HIV/TB and STIs initiative for 2023-2024 highlighted that although we have made considerable progress in certain areas, such as HIV testing, we are still trailing behind in retaining infected people on ART [10]. Furthermore, a recent report by Hilton indicated the threat of the implications of the United States' withdrawal from the World Health Organization (WHO), which has served as a significant source of funding for HIV programmes [11]. Moreover, on this issue, Global health experts have further raised concerns that this withdrawal could undermine decades of progress in the fight against diseases and increase the risks associated with pandemics. Hence, this study was conducted to understand why ART patients drift away from care to prevent future occurrences of LTFU.

Additionally· Tweya *et al.* reflected that a global health sector strategy on HIV, a comprehensive plan to reduce HIV infections and deaths, is a significant initiative in the field [12]. Drawing back from the previously highlighted percentages, as noted previously, it suggests that healthcare workers must understand how and why people drop out of ART programmes, because retaining people on ART and ensuring treatment adherence are critical determinants of successful long-term outcomes [8].

Moreover, it has been reported that globally, HIV-positive patients drop out of care for various reasons, including transportation costs, time constraints due to work, long clinic waiting times, stigma and discrimination, long distances to health facilities, fear of disclosure, unsatisfactory treatment by service providers, and a shortage of medication [13]. However, in Sub-Saharan Africa (SSA), significant loss to follow-up among people living with HIV (PLHIV) has been noted. However, the risk factors for this loss to follow-up are not well understood [5]. Furthermore, in SSA, loss to follow-up is predicted to be between 20% and 40%. In contrast, in low-income countries such as Asia, the risk of loss to follow-up is 4.1%, while it is 21.8% in Western Africa. In Ethiopia, the cumulative prevalence of loss to follow-up was 7.7%, 8%, and 16.6% at 6, 12, and 24 months, respectively [5]. Additionally, System Research Council surveys the US Centers for Disease Control and Prevention (CDC) *et al.* highlighted that Limpopo achieved targets regarding the 95-95-95 goals of 88.6%, 90.5%, and 90.9%, respectively, across various demographic characteristics [14]. Therefore, these identified targets demonstrate that Limpopo is still falling short of the national average and is lagging in reaching the UNAIDS 95-95-95 targets [14].

Notably, patients' loss to follow-up at different stages of the HIV cascade may lead to increased HIV transmission, mortality, and morbidity rates, as well as hinder efforts to control the HIV epidemic [15]. Hence, the current study highlights the critical need for targeted interventions to improve retention rates by addressing the key issues and challenges faced by ART patients.

Moreover, the Capricorn District Monitoring Report has highlighted a pressing issue-stockouts and shortages of essential medications, including antiretroviral (ARV) drugs, tuberculosis (TB) medicines, and contraceptives [13]. These disruptions lead to increased costs and seriously threaten treatment adherence. Urgent measures are required to address these shortages, especially in instances where clients are sent home empty-handed [13].

Following the earlier reports noted in this study, the purpose of the current study was to conduct an analysis of factors associated with loss to follow-up in patients on antiretroviral therapy at selected public clinics in the DIMA area under the Capricorn district of Limpopo province. The study underscores the urgent need for targeted interventions to enhance retention rates. This serves as a call to action for all stakeholders, including registered nurses (RNs), Community Health Workers (CHWs), and the Department of Health, to identify and address the key issues and challenges that ART patients face, thereby reducing loss to follow-up and improving the treatment adherence indicator at the end of each month as required by the Department of Health.

2. METHODOLOGY

2.1. Study Setting

The study was conducted in the 07 selected public clinics under the DIMAMO surveillance area, a region within the Capricorn district of Limpopo province that is under health monitoring, in the Capricorn district of Limpopo province. In addition, the DIMAMO area consists of rural and semi-rural areas within the Health and Demographic Surveillance Site (HDSS), consisting of 51 villages and approximately 100,000 population. People in this area are mostly Northern-Sotho speaking, although other languages are also spoken in this area, and the population is mostly African. Furthermore, DIMAMO Population Health Research Centre indicated that DIMAMO is one of the 03 HDSS founding nodes hosted by the Medical Research Council / Wits Rural Public Health and Health Transitions Research unit, and it is under the University of Limpopo, which is located in Limpopo province [16, 17].

2.2. Study Design

The study adopted a phenomenological, descriptive, and contextual design to gain an in-depth understanding of and circumstances that contribute to LFTU through the lived experiences of registered nurses (RNs) working in the ART section and community health workers (CHWs) who trace and support the patients in the community. Furthermore, the study was guided by the positivist paradigm to describe and understand the hidden factors, *e.g*, contextual, social, and system factors associated with LTFU [18]. Additionally, the interpretivism paradigm was also applied to explore the meaning attached, creating awareness and guiding towards the development of a training programme and information guide [18].

2.3. Population and Sampling

The population consisted of twenty-eight (28) Registered Nurses (RNs) and thirty-five (35) Community Health Workers (CHWs) who worked with ART patients at the selected public clinics in the Capricorn district of Limpopo province. Purposive sampling was used to select fourteen (14) RNs and fourteen (14) CHWs who have knowledge about the phenomenon under study, as they worked with those patients and had lived experiences of what could have mostly led to LTFU status. The sample size was determined by data saturation, where there was no new information that emerged from participant number twelve (12) in both groups, and the interview session continued until participant number fourteen (14).

2.4. Data Collection

The current study gathered data through semi-structured individual interviews, during which the narratives of Registered Nurses (RNs) and Community Health Workers (CHWs) were audio recorded, and accompanying field notes were taken. As highlighted in the previous statement, these professionals work at ART service points across selected clinics. Each interview lasted up to 20 minutes or continued until data saturation was reached. Furthermore, data was collected by the primary researcher. The study interviewed a total of 28 participants because data saturation was achieved among the fourteen (14) participants from both groups. As mentioned earlier, during the data collection process, semi-structured interviews were conducted to collect data, and the central question asked was: “What do you think are the factors that are associated with LTFU in the selected public clinics under the DIMAMO surveillance area?” Thereafter, the central question was followed by probing questions to allow the collection of sufficient data. Data collection took place over three months (01/12/2023 to 28/02/2024), accommodating participants' busy schedules and aligning with pre-scheduled interview dates. The interview guide was developed and validated by the supervisor. Furthermore, before conducting the main study, the instrument was pilot tested at a clinic within the DIMAMO area, and the results were not included in the main study.

Quality assurance and data managements was ensured through audio recording of the interview proceedings and member checking, which was done after the data was transcribed verbatim to enhance the credibility of the data. Furthermore, the recordings were sent to the independent coder for verification of the themes and subthemes, there after a meeting was held to reach conse-nsus agreement. Data protection was done by creating a password-protected soft copy and also sharing it with the research team for storage. Anonymity was maintained by using numbers instead of the names of the participants and the selected primary health care facilities.

2.5. Data Analysis

The study utilised thematic analysis, as guided by Cresswell *et al.*, to understand how research participants described their in-depth understanding and lived experiences regarding factors associated with LTFU in the selected clinics [17]. Firstly, data was transcribed by listening to the audio recordings and noting the transcripts verbatim. Thereafter, transcripts were read and re-read to understand the interviews and familiarise the researcher with the data. Subsequently, each verbatim transcript was systematically selected based on the order of participant interviews, and they were analysed one by one. Thereafter, data with similar ideas or topics were coded, and similar topics were grouped into categories. Several themes and subthemes emerged from each category. Validation of the final themes and sub-themes was done by the research team and the independent coder through sending data (voice recorder and field notes), who is an experienced qualitative researcher. Thereafter, the meeting was arranged with the research team and the independent coder to agree on the final themes and sub-themes.

2.6. Trustworthiness

According to Statistics Solution, this concept encompasses the systematic strategies employed in qualitative research to uphold a research study's quality, rigour, and credibility [19]. It involves meticulous design, execution, and articulation of the research process to ensure valid and reliable outcomes.

The study employed several strategies, such as credibility, confirmability, triangulation, clarifying research bias, and member checks, to ensure trustworthiness as guided by Lincoln and Guba [20]. Credibility was ensured through several strategies, including prolonged engagement, visiting the study site more than once to establish rapport and set an appointment for an interview, peer debriefing (to clarify the study’s objective), and clarification of potential research biases. Furthermore, member checking was performed after data collection to verify if what was obtained was actually what members meant. Conformability was ensured using a voice recorder to confirm that the collected narratives could be verified. Furthermore, all transcripts and field notes were kept, enabling the supervisor to verify that the study was conducted as planned [20]. Triangulation was ensured through the use of various data collection methods, such as interviews, field notes, audio recording, peer debriefing, and independent coders, to review and enrich the findings. To ensure transferability, the study thoroughly described the data collection process, which included interviews and the methods used, and encouraged participants to share their experiences until data saturation was reached.

To guarantee dependability, the study noted that the findings related to factors linked to Loss to Follow-up (LTFU) could be insightful for future researchers, depending on the methods used and the context of the investigation.

2.7. Ethical Considerations

The study has obtained ethical clearance from the Nursing Department under the School of Health Care Sciences (FHDC2023/1), Turfloop Research and Ethics Committee (TREC/100/2023: PG), the Limpopo provincial government (LP_202308-016), and the Capricorn Sub-district Manager (S.5/3/1/2) lastly, consent was obtained through signing a consent form by participants. Additionally, participants were reassured of the confidentiality of information collected from them. The study adhered to ethical guidelines as stipulated by the Department of Health ethical guidelines, which states that the risk-to-benefit ratio should be favourable when conducting research [21]. Hence, the study ensured complete transparency, and all information, including potential benefits and risks, was clearly explained to participants. Lastly, the study ensured by all means that it would not pose a risk but would benefit the participants or the community.

3. RESULTS

3.1. Discussion of Demographics of Participants

Both groups in the study exhibited similar demographic characteristics. A notable aspect was the higher number of female participants compared to males, primarily attributable to the predominance of women among Community Health Workers (CHWs) and Registered Nurses (RNs). Furthermore, the study found that most participants were older nurses and community health workers, while younger nurses were under-represented. Of the 28 participants, the majority—thirteen (13)—completed high school. However, only one (1) completed primary education. Additionally, nine (9) participants graduated from college, while only five (5) pursued further university education. Table **1** depicts the demographic data of the participants.

Table 1. Demographic characteristics of participants.

Gender	Age	Occupation	Highest Level of Education	Duration of Employment
Females: 25	18-28: 3	CHW: 14	College: 9	Under 1 year: 1
Males: 3	29-38: 1 39-48: 4 49-58: 19 59 and above:1	RN: 14	University: 5 High school:13 Primary: 1	1-5 years: 3 6-10 years: 5 11-15 years: 15 16-20years: 3 Over 20years: 1

Table 2. Themes and Sub-themes as identified by participants.

1. Internal conflicts and misconceptions about HIV	1.1. Denial related to perceptions of HIV
	1.2. Perceptions of being healed or healthy
	1.3. Not accepting responsibility for HIV health status
2. Significant barriers associated with the disengagement of HIV care among patients	2.1. Non-disclosure of HIV status to significant others
	2.2. Fear of stigmatisation
	2.3. Perceived breach of confidentiality
	2.4. Resistance to or non-use of community healthcare interventions

Following the data analysis process, two themes and seven sub-themes emerged. The themes and sub-themes are presented in Table **2**.

3.1.1. Theme 1: Internal Conflicts and Misconceptions About HIV

Patients' reactions to positive test results can influence their chances of becoming lost to follow-up (LFTU). Community Health Workers (CHWs) and Registered Nurses (RNs) have shared various experiences with patients that often lead to this outcome. The study identified two distinct issues within this theme. Firstly, participants reported internal conflicts and misconceptions about HIV among patients, as illustrated by the subthemes below.

3.1.1.1. Sub-theme 1.1. Denial Related to the Perception of HIV

Participants identified several factors contributing to loss to follow-up (LFTU), with cultural and religious beliefs playing a significant role in the denial of HIV status. Many expressed that patients frequently turned to traditional healers and local pastors, who created a perception that they were not suffering from an illness but were instead affected by ancestral issues or witchcraft. This study was conducted in a rural area where cultural and religious factors contributed to the refusal to accept HIV test results. Furthermore, Nigusso and Mavhandu-Mudzusi emphasised that while the link between religion and development in Africa is complex, religious beliefs still have a substantial impact on many communities [22]. Both Community Health Worker (CHW) and Registered Nurse (RN) participants largely agreed that denial is a contributing factor to loss to follow-up (LTFU). Below are some quotes taken from the transcripts.

Participant RN1 said, “Okay, I will say most of them are because they have not accepted their status yet; they were newly diagnosed. You see, the thing is, they have to accept their status first. It is then that they will take their medications.”

While another participant said:

Participant RN7: It is mainly caused by unacceptance of one’s status, so they move to the next clinic to counter-test if they are really positive. It is a result of denial.”

The second group of participants said that what Community Health Workers said was:

Participant CHW2: “It's just that they, as patients, are full of denial.”

Participant CHW4: *Said*, ***“****Because nowadays these clients hide and say they are suffering from ancestors attack and they need to go to traditional healers to do what we call to ‘’Go thoma bjalo ka ngaka ya setšo or go thwasa” and (become a traditional healer) too whereas they are sick (Indicating this to be a matter of concern by raising hand her hands up and parting them sideways with raised shoulders and opening her eyes wide)”.*

3.1.1.2. Sub-theme 1.2 Perceptions of Being Healed or Healthy

Registered nurses and community health workers (CHWs) have observed that patients’ perceptions of their health and healing play a crucial role in their adherence to treatment. In their investigations of patients who have dropped out of care (LTFU), they found that some individuals stopped their antiretroviral therapy (ART) because they believed they were healed through the intervention of a pastor. Unfortunately, these patients remain unaware of the importance of continuing their treatment to sustain their health and extend their lives. Below are some of the quotes as drawn from the data transcripts of registered nurses and community health workers that highlight these key insights.

Participant RN4: Said**,** *“Because these people, once they take treatment and their condition improves, they think they are healed, and they stop taking treatment.”*

The other participants narrated that:

Participant RN11:*“ Another thing… is the person will say I have tested at clinic A, and pastor so and so prayed for me and gave me anointed oil or tea, now I am healed, I am HIV negative. Yes, you might have tested negative now, but that doesn’t mean you don’t have the virus. Then the person will say That’s why I left my medication, and they become lost to follow-up.”*

While the other group of participants said that:

Participant **CHW4***: “I am saying so because you will find that when you trace and ask them why they are no longer coming to collect their medication, they will say it is because they are not sick. And if you ask them, if they are not sick, they will say I have never been to the clinic, you never saw me, they have sent you to the wrong person”.*

Participant CHW14: “These people might be turning out to be lost to follow-up because they feel strong and think that they are no longer sick and can stop taking ART. They feel that now that they have taken ART and feel strong, it means that treatment is a cure; they can now stop taking ART. They no longer believe that the condition can change, and they become sick again. They don't know that it is a chronic treatment."

3.1.1.3. Sub-theme 1.3. Not accepting Responsibility for the HIV Health Status

Not accepting responsibility for HIV health status seemed to be a dominant factor that was identified during this study. Participants have observed that HIV-positive patients frequently become lost to follow-up (LTFU) due to their difficulty in accepting responsibility for their health. For individuals to truly take charge of their HIV status, they must first accept their condition and have the courage to disclose it. Below are impactful quotes from the participants.

Participant RN2: Said **"**We cannot force them to come and collect medication, imagine last week I did counselling to a lady who came here for CTOP. She told me she does not want to hear anything about HIV "(Indicating a sign of disappointment, waving hand on the side)

Participant RN 14*also revealed this***:***"And some of them don't have reasons. I just don't know if they don't know the importance of taking medication or what. We do emphasise it, but they choose to stay at home, so we don't know."*

Participant CHW9: Said, ***"****Most of the things that we come across are that when we get there and tell a person that they need to come to the clinic, they will say I will go. But they never come. Sometimes, after several visits or tracings is then that a person will say I don't want to go there".*

While the other participant narrated that;

Participant CHW11: "Other patients will say okay, I will go and collect, but they end up not coming".

Secondly, the study has identified that patient-related factors were further influenced by certain significant barriers associated with LTFU. Participants have narrated that they have observed some of the factors that were occurring as a result of the patient's inability to disclose their status. This was also related to fear of stigmatisation, as patients were reportedly afraid that their significant others might stigmatise them if they knew about their status. Furthermore, some have not disclosed because they assumed that they were healthy or healed and did not need to take ART any longer. The study has also revealed that one of the reasons why patients became LTFU was that they refused to use community health care interventions, which resulted in ART patients being LTFU. Below are some of the subthemes' quotes as extracted from the narratives:

3.1.2. Theme 2: Significant barriers associated with the disengagement of HIV care among patients

Under this theme, it became clear that several significant barriers identified by participants influence patients' likelihood of becoming lost to follow-up (LFTU). Participants shared various experiences, with non-disclosure emerging as a notable factor. Furthermore, fear of stigmatisation was reportedly linked to non-disclosure. Other significant barriers included perceived breaches of confidentiality, as well as resistance to and non-utilisation of community health interventions. These identified sub-themes are elaborated upon in the sub-themes below.

3.1.2.1. Sub-theme 2.1. Non-disclosure of HIV status to significant others

Study findings revealed a significant gap in disclosing HIV status to significant others, which negatively affects adherence to ART and contributes to clients being classified as LTFU. Participants indicated that non-disclosure often stems from the denial of their test results as identified under patient–related factors, which were influenced by internal conflicts. The study further identified that there was a great consensus between not accepting their status and non-disclosure, which in turn leads to ART defaults. Both registered nurses (RNs) and community health workers (CHWs) have identified this issue. Below are some of the quotes.

The first group of participants said:

Participant RN7: "Because if you can hear most of the patients telling you about their reasons for becoming lost to follow-up, they will tell you that my partner doesn't know, and I cannot take that treatment in my partner's presence. They end up telling the truth that I cannot take this treatment because my partner doesn't know."

Participant RN2: also reported that **"**Some is because they have found a new sexual partner and they are afraid to tell that partner their status, so they hide their treatment, and that makes them forget to take their treatment. Imagine how you can take your medication while you are hiding."

While the second group narrated that:

Participant CHW5: "You know what, my sister (leaning forward in an attempt to voice her opinion), some of these patients are afraid of people, and some are because of non-disclosure at home. Because imagine if a family member or a partner is unaware that they are taking treatment, they are afraid to come for treatment collection, with the reason that what if so and so sees them in the clinic collecting treatment on the ARV site, they won't come. Especially now it's December holidays, and their partners are at home for festive leave, most tend not to come if it's their return date and they did not disclose, mainly because they are afraid their partners and family will see them here at the clinic collecting treatment".

The same participant further said:

Participant CHW5: "Yes, it was the other day we traced a man who did not disclose to his wife, and the wife ended up dying of HIV while they were saying she had been bewitched, the wife then married another woman to take care of him and the kids. He was hiding the ARVs in a small plastic bag at the back of the pit toilet. He went there every time at 20hoo to drink his treatment, and one day his 17-year-old daughter went there to check what was hidden there because she noticed that the man went to the same spot every night at 20hoo. She saw a small hole with a container inside the plastic, and she heard strange sounds from those tablets because they make noise when shaken. She then took a picture of the container and searched on Google. Only to find out that those were ARVs, and then she realised it meant Daddy is using treatment for HIV. Then she told her stepmom to be careful because her mother died, and she saw 1-2-3- at the back of the toilet. You know what my sister (elaborating further), that is where I saw that these HIV patients hide their status".

3.1.2.2. Sub-theme 2.2. Fear of Stigmatisation

Fear of stigma emerged as a factor contributing to loss to follow-up (LTFU) in this study. During the interviews, participants identified fear of stigma as a significant reason for LTFU. Many patients who were previously traced by RNs and CHWs mentioned that they stopped treatment because they did not want others to see them collecting antiretroviral therapy (ART), fearing that they would be stigmatised. Below are some comments extracted from the verbatim transcripts.

Participant RN4: Said **"**You see, under patient-related, you find that a person comes here at Mamabolo J and they are from Mankweng or far places just because they don't want to be seen by people who know them at their local clinic. Or you find that a staff member is the one who is diagnosed with HIV, then they decide to go to a far clinic just because they protect their reputation and don't want people to know."

Participant RN6 also said, "With loss to follow-up, the majority is because of stigma. They are afraid to come back for treatment collection."

The second group of participants, who were Community Health Workers, narrated that:

Participant CHW7:" Imagine if they gossip about me and say she is HIV positive and is taking treatment from a certain clinic, it's painful if the person who does not know about HIV, like you and me. So that thing is destroying HIV patients a lot, and they decide to stop taking treatment so that they can deny and say no, I am not on any treatment, to convince people that they are not sick."

Participant CHW13: Also said, **"**I remember this December I was talking to someone who was reported as lost to follow-up, and she is residing here at Mamotshwa, but then she said I am collecting treatment at A. Mamabolo, I am no longer going there. I asked her how possible that is, can you really leave the nearest clinic and go very far, and she said that side nobody knows me, but here almost everybody knows me, and they will talk about me."

3.1.2.3. Sub-theme 2.3 Perceived Breach of Confidentiality

Participants have voiced out that a perceived breach of confidentiality was more likely to be a factor associated with LTFU. Where patients just had a feeling that health care workers were disclosing their status, they decided to stop taking treatment. These are some of the quotes as reported by participants.

Participant RN1: "Even if they try to send home-based care personnel while saving money for transport…so they are afraid, especially when they think that they will disclose their status."

The other participant narrated that:

Participant RN10: "But because of the stigma that is attached to it, we have problems because it is one of the reasons why people give us incorrect addresses, so that we cannot find them. The minute they know, they move to other clinics to collect medication, not knowing that there is confidentiality, and it is a shared confidentiality because if you are in the clinic, everybody is going to work with you. The data capture must work with you, and the lay counsellors must work with you. They don't understand that it is a shared confidentiality".

From the second group of participants, they narrated that:

Participant CHW1: "And one other thing that happens is that we will be given a client with a certain surname, and when I get to that place, I find 5 houses with the same surname, and I don't know where the person exactly is staying. So will get to the 1st house, and they say they don't know that person. They will go to the 2nd house, and they say they don't know that person, then the 3rd house maybe they know the person and say that person is staying at the 5th house so- so - so – so, when you finally find the person and assist with re-arrangement to ART Service, then that person somehow hears that you were looking for them from those 1st houses then they will say you were talking about them and their condition. They get angry at you for thinking you talked about them or their condition, and then leave or stop taking treatment again."

Participant CHW10 said, **"**If somehow you trace a person successfully, and the person asks you, but they didn't say anything to you? (Acting frightened or curious to know what it is that you have heard). And I will say no, they didn't tell me a thing. It is up to you and your nurses; you will go and hear it from them because it is your secret…The challenge is that they want to dig and find out from you that, before you were sent to them, is there something that you know about them, or what?"

3.1.2.4. Sub-theme 2.4 Resistance to or non-use of community healthcare interventions

During the study, it became clear that patients lost to follow-up (LTFU) resisted or did not engage with community health interventions. The community health worker (CHW) participants specifically identified this issue. Additionally, the CHWs reported that some patients resist assistance when they offer help with medication collection, which is essential for ensuring patients continue to take their antiretroviral therapy (ART). Below are some quotes that support the subtheme extracted from the data transcripts.

***Participant* CHW1:** Said, *“Eish! My sister, it is not easy, as I have already told you, and we encounter more challenges. I remember this other client seeing me approaching her house, and she locked the gate and the house and kept quiet in there. I ended up taking a picture of myself at the gate to serve as proof I went there, and I didn’t ask anyone because they would change the story.”*

While the other participant narrated as follows:

Participant CHW11: “You will find that they will tell us that we don’t want you to follow up. Don’t come around hanging out at my place, I don’t want to see you in my house. Do you understand such comments?”

4. DISCUSSION

The study aimed to explore factors associated with loss to follow-up of patients living with HIV in the DIMAMO Surveillance Area. In addition, the study was carried out because the United Nations AIDS Organization requires that by 2030, 95% of the population needs to be aware of their HIV status [3]. Additionally, of those who know their status, 95% need to be on treatment. Lastly, of those who are on treatment, 95% need to be virally suppressed. Notably, the deputy minister of health in the National Strategic Plan (NSP) for HIV/TB and STIs initiative for (2023-2028) [10], highlighted that although we have made considerable progress in certain areas, such as HIV testing, we are still lagging in retaining infected people on ART. Hence, the current study explored and described the factors associated with the loss to follow-up of patients living with HIV, aiming to assist healthcare facilities in achieving a retention rate of 95% by 2030. Additionally, the study paved the way for understanding why patients drift away from HIV care and ART. Inevitably, the current study revealed two major themes associated with loss to follow-up (LTFU), which are noted as: 1) internal conflicts and misconceptions about HIV, and 2) significant barriers related to disengagement from HIV care among patients.

To describe the themes that emerged as highlighted earlier, the study identified three sub-themes, which were linked to this main theme, namely: Denial related to perceptions of HIV, perceptions of being healed or healthy, and a lack of acceptance of responsibility for HIV health status. Furthermore, the study revealed that these internal conflicts, such as denial related to perceptions of HIV, were primarily influenced by religious and cultural beliefs. Additionally, many participants narrated that patients who were previously traced as LTFU cases mentioned that they did not believe their HIV positive results. This was further aggravated by the false reassurance that they received when consulting traditional healers or prophets. Where they highlighted that, after consulting pastors or traditional healers, spiritually they believed that they were either not infected with HIV or had have been healed, which made them to discontinue their treatment, to participate in church or traditional rituals such as *“Go Thoma bjalo ka ngaka ya setšo”* (To emerge as a traditional healer), which was popularly reported as *“ukuthwasa”* by most participants. Notably, Nigusso and Mavhandu-Mudzusi also highlighted a similar finding, where it was evident that their cultural and religious belief mainly influences South African medical-seeking behaviour [22]. In addition, these cultural beliefs were so prevalent in the church community that associating HIV and AIDS with witchcraft is primarily influenced by the side effects experienced by People Living with HIV (PLWHIV) when taking ART. The current study has been conducted in a rural area of the Capricorn District where cultural values and norms still shape community behaviour. Furthermore, this study revealed that many community members maintain their cultural and religious practices, influencing their use of ART. Lastly, on internal conflicts and misconceptions about HIV as an identified factor, the study revealed that patients lack information, which highlights the importance of complying with ART medication. However, it was noted in the National ART Clinical Guideline that ART literacy education empowers clients to adhere to treatment and positively influences clinical outcomes [23]. Undeniably, as discussed previously, the first theme highlights that ART patients still lack this education somehow. In addition, developing a basic training programme and information guides will ensure continuous ART education. Furthermore, it is crucial to equip registered nurses and Community Health Workers (CHWs) with the necessary knowledge and training to effectively disseminate information to ART patients.

Concerning the second theme, significant barriers related to disengagement from HIV care among patients are identified. The study revealed four sub-themes which were linked to this central theme, namely: non-disclosure of HIV status to significant others, fear of stigmatisation, perception of being healed and healthy, and resistance to and non-use of community health interventions. Additionally, participants narrated that patients living with HIV (PLWHIV) voiced out that the reasons which led to their discontinuation of ART medication included being afraid to disclose information about their HIV positive results to their significant others. As a result, one participant narrated a scenario where patients were reportedly hiding their ARVs at the back of the toilet because they were afraid of disclosing to their partners. Based on the previously mentioned scenario, the study highlighted that there was potential non-compliance with ART. Because it was not easy to take ART at the same time every day while they were hiding, this identified factor may lead to poor viral suppression, one of the problems the department is currently trying to control or address. Previously, a challenge of Fear of disclosure was highlighted in a study conducted at the Sekhukhune district by Modipane *et al.*, where patients were reported to be afraid to disclose to their sexual partners [6]. Based on these findings, the study highlights that there should be ways to ensure continued disclosure of HIV status to significant others to promote retention of patients living with HIV on ART. The current study has also identified that ART patients can comply well with treatment and stay on treatment if they are not hiding it from anyone. The department currently has Standard Operating Procedures

(SOPs), such as the National ART Clinical Guideline, which encourages individuals to disclose their HIV status to sexual partners and significant others [23]. However, Gardner and Khan revealed that there are no specific laws in South Africa that explicitly make it an offence to withhold, transmit, or reveal HIV status to a consenting adult partner during sexual activity or in any other context [24]. This situation is complicated further by the fact that criminalising non-disclosure would violate human rights, as outlined [24]. Therefore, it would be great to create some clear laws to ensure that no one can unfairly withhold a positive status from their significant others. This way, everyone can enjoy more transparency and fairness in their relationships.

For argument's sake, a recent report by Hilton indicated the threat of the implications of the United States' withdrawal from the World Health Organisation (WHO), which has served as a significant source of funding for HIV programmes [11]. Moreover, on this issue as a threat, Global health experts have further raised concerns that this withdrawal could undermine decades of progress in the fight against diseases and increase the risks associated with pandemics [11]. Therefore, the study serves as a possible significant way to create further awareness of factors associated with LTFU. So that health officials can be knowledgeable about these factors, to help prevent the re-emergence of the HIV pandemic and keep it under control.

In summary of this discussion, the study identifies key factors that lead to loss to follow-up (LTFU) amongst patients living with HIV, in selected public clinics under the DIMAMO surveillance area. One of the major issues is that many patients living with HIV face internal conflicts about the perception of HIV status and certain significant barriers that contribute to the LTFU outcome. Additionally, the study has identified that health education and further awareness about HIV and ART are crucial to ensure that patients remain on treatment. As previously highlighted, it would be beneficial for health facilities to provide continuous education and awareness about the condition to achieve the zero target on LTFU by 2030 as stipulated by the UNAIDS 2030 targets.

5. LIMITATIONS OF THE STUDY

The study yielded positive results; however, certain limitations must be recognised. It was conducted exclusively in selected clinics within the DIMAMO Surveillance area of Limpopo Province. The original objective was to include loss-to-follow-up (LTFU) patients, registered nurses (RNs), and community health workers (CHWs) as participants. Unfortunately, this plan did not materialise, as the pilot study faced significant challenges locating most LTFU patients. Contributing factors included unreachable contact numbers and the relocation of some individuals to unreported areas.

CONCLUSION

In conclusion, the study highlights the critical need for targeted interventions to improve retention rates by identifying the key issues and challenges ART patients face. In addition, this includes patient-related factors, which were linked to internal conflicts and misconceptions about HIV, such as denial, perception of being healed or healthy, and not accepting responsibility for HIV positive health status. Additionally, loss to follow-up among ART patients is significantly influenced by specific barriers related to disengagement from HIV care. These barriers include non-disclosure of HIV-positive status, fear of stigmatisation, perceived breaches of confidentiality, and, lastly, resistance to or lack of utilisation of community healthcare interventions. Finally, the findings provide a foundation for developing a comprehensive training programme and information guide aimed at healthcare providers and community health workers. This training programme will enhance their capacity to support antiretroviral patients effectively, ultimately contributing to better treatment adherence and health outcomes depending on the context and population under study.

AUTHORS’ CONTRIBUTIONS

The authors confirm their contribution to the paper as follows: T.M.M.: Study conception and design; M.W.N., N.L.M. and L.M.: Writing-Reviewing and Editing. All authors reviewed the results and approved the final version of the manuscript.

LIST OF ABBREVIATIONS

ART	=	Antiretroviral Treatment
CHW’S	=	Community Health Workers
CTOP	=	Choice on Termination of Pregnancy
DIMAMO	=	Dikgale Mamabolo and Mothiba
HDSS	=	Health and Demographic Surveillance Site
HIV	=	Human Immunodeficiency Virus
LTFU	=	Loss to Follow-Up
PLHIV	=	People Living With Hiv
TB	=	Tuberculosis
UNAIDS	=	The Joint United Nations Programme on HIV/ AIDS

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The study has obtained ethical clearance from the Nursing Department under the School of Health Care Sciences (FHDC2023/1), Turfloop Research and Ethics Committee (TREC/100/2023: PG), the Limpopo provincial government (LP_202308-016), and the Capricorn Sub-district Manager, South Africa (S.5/3/1/2).

HUMAN AND ANIMAL RIGHTS

All human research procedures followed the ethical guidelines as stipulated by the Department of Health ethical guidelines and with the 1975 Declaration of Helsinki, as revised in 2013.

CONSENT FOR PUBLICATION

Consent to publish from the participants was obtained through detailed written consent.

STANDARDS OF REPORTING

COREQ guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

The dataset used in this study is available upon reasonable request from the first author [T.M].

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENTS

The authors thank all the participants in the study. Additionally, the authors acknowledge DIMAMO surveillance for support offered during the study.

REFERENCES

[1] Anulo A, Girma A, Tesfaye G, Asefa F, Cheru A, Losanko AA. Incidence and predictors of loss to follow-up among adult patients receiving antiretroviral therapy in Central Ethiopia: a multi-centre retrospective cohort study. Front Public Health 2024; 12: 1374515. http://dx.doi.org/10.3389/fpubh.2024.1374515

[2] Birhanu MY, Leshargie CT, Alebel A, *et al.* Incidence and predictors of loss to follow-up among HIV-positive adults in northwest Ethiopia: A retrospective cohort study. Trop Med Health 2020; 48: 78. http://dx.doi.org/10.1186/s41182-020-00266-z

[3] United Nations AIDS Organisation. HIV Treatment. 2022. Available from: https://www.unaids.org/en/topic/treatment#:~:text=HIV%20treatment%20works%20best%20when%20taken%20as%20prescribed.,allow%20HIV%20to%20multiply%20and%20progress%20to%20disease

[4] Endebu T, Taye G, Deressa W. Rate and predictors of loss to follow-up in HIV care in a low-resource setting: Analyzing critical risk periods. BMC Infect Dis 2024; 24(1): 1176. http://dx.doi.org/10.1186/s12879-024-10089-6 PMID: 39425041

[5] Kebede HF, Mwanri L, Ward P, Gesesew HA. Predictors of lost to follow up from antiretroviral therapy among adults in sub-Saharan Africa: A systematic review and meta-analysis. Infect Dis Poverty 2021; 20: 33. http://dx.doi.org/10.1186/s40249-021-00822-7

[6] Modipane M, Khoza LB, Ingersoll K. Barriers contributing to loss to follow-up among HIV-patients in Limpopo Province, South Africa: patients' and nurses' perspectives. Open Public Health J 2023; 16(1)e187494452307070 http://dx.doi.org/10.2174/18749445-v16-230815-2023-71

[7] Telayneh AT, Tesfa M, Woyraw W, *et al.* Time to lost to follow-up and its predictors among adult patients receiving antiretroviral therapy retrospective follow-up study Amhara Northwest Ethiopia. Sci Rep 2022; 12(1): 2916. http://dx.doi.org/10.1038/s41598-022-07049-y PMID: 35190629

[8] The Joint United Nations Programme on HIV/AIDS. Approaching 95-95-95 HIV/AIDS goals for focusing on patients. 2020. Available from:https://www.unaids.org/en/resources/documents/2020/unaids-data

[9] World Health Organization (WHO). Information sheet, HIV statistics, globally and by region. 2025. Available from: https://cdn.who.int/media/docs/default-source/hq-hiv-hepatitis-and-stis-library/who-ias-hiv-statistics_2025-new.pdf

[10] National Strategic Plan (NSP) for HIV/TB and STIs initiative for (2023-2028). 2024. Available from: https://sanac.org.za/wp-content/uploads/2023/05/SANAC-NSP-2023-2028-Web-Version.pdf

[11] Hilton A. World Health Organization announces cost-cutting after the US withdraws funding 2025. Available from: https://www.abc.net.au/news/2025-01-25/donald-trump-executive-order-us-withdrawal-who/104850406

[12] Tweya H, Oboho IK, Gugsa ST, *et al.* Loss to follow-up before and after initiation of antiretroviral therapy in HIV facilities in Lilongwe, Malawi. PLoS One 2018; 13(1)e0188488 http://dx.doi.org/10.1371/journal.pone.0188488 PMID: 29373574

[13] Capricorn District Monitoring Report. 2020. ARV Collection. 2020. Available from:https://www.bing.com/search?q=Capricorn+District+Monitoring+Report%2C+2020.+ARV+Collection+and+Access&form=WSBEDG&qs=SW&cvid=b25b0b9be5c0473fb6b7a83516d7faa7&pq=Capricorn+District+Monitoring+Report%2C+2020.+ARV+Collection+and+Access&cc=ZA&setlang=enUS&nclid=3025002549AB57648AC4572939A88272&ts=1760795535567&PC=WSBQUF

[14] The Health System Research Council surveys the US Centres for Disease Control and Prevention (CDC), the South African Medical Research Council (SAMRC), the University of Cape Town (UCT), and the National Institute for Communicable Diseases (NICD).. Limpopo sees a decline in HIV prevalence, but gaps remain in treatment and prevention. 2024. Available from: https://hsrc.ac.za/press-releases/public-health-societies-and-belonging-phsb/limpopo-sees-a-decline-in-hiv-prevalence-but-gaps-remain-in-treatment-and-prevention/

[15] Fuente-Soro L, Varela EL, Augusto O, *et al.* Loss to follow-up and opportunities for reengagement in HIV care in rural Mozambique: A prospective cohort study. Medicine 2020; 99(20): e20236. http://dx.doi.org/10.1097/MD.0000000000020236

[16] DIMAMO Population Health Research Centre.South African Population Research Infrastructure Network (SAPRIN). 2025. Available from: https://saprin.mrc.ac.za/dimamo.html#:~:text=DIMAMO%20Population%20Health%20Research%20Centre%20%28PHRC%29%20operates%20as,of%20Capricorn%20District%20in%20Limpopo%20Province%2C%20South%20Africa

[17] Creswell JW. Research Design: Qualitative, Quantitative & Mixed Methods Approaches. (5th ed.), Thousand Oaks: Sage Publications 2018.

[18] Kivunja C, Kuyini AB. Understanding and applying Research paradigms in Educational contexts. Int J High Educ 2017; 6(5): 26. http://dx.doi.org/10.5430/ijhe.v6n5p26

[19] Frey BB. Statistics Solution. Measurements evaluation: The SAGE Encyclopedia of Educational Research. SAGE Publications, Inc 2022.

[20] Lincoln YS, Guba EG. Naturalistic Inquiry. Thousand Oaks: SAGE 1985. http://dx.doi.org/10.1016/0147-1767(85)90062-8

[21] Department of Health. Ethics in Health Research: principles, process, and structures. DoH Printers 2015.

[22] Nigusso FT, Mavhandu-Mudzusi AH. Health-related quality of life of people living with HIV/AIDS: The role of social inequalities and disease-related factors. Health Qual Life Outcomes 2021; 19(1): 63. http://dx.doi.org/10.1186/s12955-021-01702-2.

[23] National ART Clinical Guideline. ART clinical guidelines for the management of HIV in adults, pregnancy, and breastfeeding, adolescents, children, infants, and neonates. 2023. Available from: https://www.scribd.com/document/665374405/National-ART-Clinical-Guideline-2023-04-28-signed

[24] Gardner JB, Khan S. Recent South African court rulings on failing to disclose HIV status to sexual partners. S Afr Fam Pract (2004) 2024; 66(1): e1-4. http://dx.doi.org/10.4102/safp.v66i1.6014