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From Awareness to Access: Community, Family-centred and Health System Approaches to Strengthening Antiretroviral Adherence in the Northwest Province, South Africa

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Abstract

Human immunodeficiency virus (HIV) remains one of the most serious Public Health threats of the 21st century. An estimated 40.8 million People are living with HIV (PLHIV) globally, and the number continues to rise despite progress in prevention, testing, and treatment, particularly the expansion of Antiretroviral (ARV) treatment. These figures highlight the urgent need to strengthen efforts to mitigate increasing infection and death rates. This study explored community-, family-centred, and health system approaches to enhance ARV treatment adherence among PLHIV in the Northwest Province, South Africa. A qualitative phenomenological design was employed with 12 purposively selected PLHIV aged 18–40 years who had defaulted from ARV treatment for 30–90 days and were traced back to the clinic. Data was collected using semi-structured, individual in-depth interviews guided by an interview guide, and analysed using Tesch's framework, which generated key themes from participants' narratives. Trustworthiness measures were applied, and the study adhered to ethical considerations throughout the research process. Findings reveal that adherence to ARV treatment is influenced by personal and systemic factors. Stigma, lack of community awareness, and emotional isolation hinder consistent treatment, while distant clinics, transportation challenges, medication shortages, and overworked health workers add complexity to care. Potential solutions include improved family and peer support, greater community education, home-based ARV distribution, and enhanced counselling. A comprehensive strategy addressing these interconnected issues can create a more supportive environment, ensuring treatment is accessible, comprehensible, and socially endorsed.

Keywords: antiretroviral adherence, community, family-centred, and health system.

1. Introduction

1.1 HIV Overview

HIV continues to pose a significant health risk today due to the fatalities caused by illnesses related to the virus (Fauci & Lane, 2020). In 2024, it was estimated that over 40 million people globally were living with HIV(Payagala & Pozniak, 2024). Africa is reported to be leading in the number of people living with HIV, with recent statistics showing that Africa accounts for the majority of the global HIV burden, with sub-Saharan Africa in the lead (Payagala & Pozniak, 2024). According to Del Rio (2017), the sub-Saharan Africa region holds 71% of the global population of PLHIV and 72% of all AIDS-related deaths, highlighting the severe impact of this disease in this part of the continent. Statistics indicate that South Africa has the largest number of PLHIV in both Africa and globally (Ugwu & Ncayiyana, 2022). As of 2024, approximately 8 million people in the country are living with HIV (Zhang & Saruchera, 2025).

Although a cure for HIV has not yet been discovered, the prognosis for those living with the virus has significantly improved over the years, thanks to the discovery and widespread availability of antiretroviral (ARV) drugs. Introduced in the late 1980s, ARVs are standard anti-HIV medications that have dramatically altered the course of HIV infection, turning it from a potentially fatal infection into a manageable chronic condition (Allergy & Diseases, 2018). These drugs inhibit viral replication in the body, reducing the patient’s viral load, increasing CD4 counts, lowering the risk of opportunistic infections and hospitalizations, enhancing the patient’s quality of life, and decreasing mortality (Allergy & Diseases, 2018).

The World Health Organization (WHO), a specialized agency of the United Nations (UN) responsible for international public health, recommends that ARVs be made accessible to all PLHIV, regardless of their clinical stage and CD4 cell count, at no cost in all public health facilities (Ford et al., 2018). WHO further recommends that initiation should be offered on the same day to those ready to start or within seven days of HIV diagnosis (Ford et al., 2018).). Payagala and Pozniak (2014) state that, in response to WHO recommendations, many countries have adopted guidelines for universal access to ARVs. Approximately 31.6 million PLHIV globally accessed ARV treatment in 2024, up from 28.7 million in 2021, according to Payagala and Pozniak (2014). In Africa, as of 2024, approximately 25.5 million PLHIV were receiving ARV medication (Payagala & Pozniak, 2024). South Africa was among the first African countries to adopt the policy of 'universal' access to ARVs, with an estimated 6.3 million PLHIV accessing treatment in 2024, an increase from 5.5 million in 2021 (Myburgh et al., 2021).

Consistent adherence to ARV drugs is crucial for effectively managing HIV. Marzaei-Alavijeh (2025) points out that by following a medication regimen, PLHIV can achieve sustained viral suppression. This not only improves individual health outcomes but also reduces the risk of transmission and strengthens epidemic control as a public health strategy (Mehdi Mirzaei-Alavijeh et al., 2025). Viral suppression increases survival rates, enhances quality of life, and reduces the likelihood of hospitalization, Oguntibeju (2012) adds. Viral suppression increases survival rates, enhances quality of life, and reduces the likelihood of hospitalization, as Oguntibeju (2012) adds. Conversely, poor adherence weakens treatment effectiveness, leading to disease progression, the emergence of drug-resistant HIV strains, and increased strain on healthcare systems due to frequent hospitalizations and higher treatment costs (Oguntibeju, 2012).

Despite the clear benefits and significant progress in expanding access to HIV treatment, many PLHIV still struggle to maintain consistent adherence. The challenges affecting effective adherence to ARVs are complex and stem from factors at the individual, community, health system, and treatment-related levels (Azia et al., 2016). These interconnected barriers highlight the need for a comprehensive understanding of the underlying causes to inform targeted interventions that strengthen adherence, improve treatment outcomes, and sustain the hard-won gains in HIV care and epidemic control.

1.2 Determinants of ARV Adherence

1.2.1 Social Support as Determinants of Adherence

A lack of social support is one of the key factors that make it difficult for PLHIV to consistently take their ARV treatment (Basha et al., 2021). Bouabida et al. (2023), assert that living with HIV often comes with emotional, social, and practical challenges that can be overwhelming, especially when faced alone. Without the backing of family, friends, or peers, many individuals experience deep feelings of isolation and stigma, which can weaken their motivation to undergo regular treatment (Bouabida et al., 2023). On the other hand, those with a strong and understanding support system make a significant difference, Bouabida et al. (2023) add. Encouragement from loved ones can lift one's spirits, help manage the emotional weight of the illness, and reinforce a sense of hope (Bouabida et al., 2023). Acts such as reminders to take medication, accompanying someone to a clinic visit, or offering words of reassurance can go a long way in helping those diagnosed with HIV stay on treatment (Brotherton, 2024). This resonates with a study conducted in Witbank, South Africa, which found that people who feel supported are more likely to stay engaged in care, achieve viral suppression, and enjoy a better quality of life (Habte et al., 2020). In essence, social support is not just emotional comfort; it is a vital part of successful HIV management. In essence, social support is not just emotional comfort; it is a vital part of successful HIV management.

Beyond individual and household dynamics, communities can also play a significant role in shaping patterns of treatment adherence among PLHIV(Green et al., 2020). In many settings, community attitudes and perceptions of HIV are deeply influenced by misinformation, fear, and persistent stigma(Green et al., 2020). These factors can create an environment that discourages individuals from openly seeking care or remaining engaged in treatment processes. Asrina et al. (2023) argue that a lack of accurate information about HIV often fuels misconceptions, such as the belief that HIV is a result of personal failure or moral wrongdoing, which reinforces stigma and discrimination. In such contexts, individuals may face subtle or overt rejection from their communities, including friends, colleagues, neighbours, and even faith-based groups (Asrina et al., 2023). This rejection can take many forms, from social isolation and gossip to exclusion from community activities. The fear of being judged or treated differently often forces individuals to conceal their HIV status, making it difficult for them to attend clinic appointments, participate in support programs, or take medication consistently(Hutchinson & Dhairyawan, 2018). Over time, this emotional burden can erode confidence, heighten feelings of shame, and contribute to disengagement from treatment. Moreover, when communities fail to provide inclusive and non-judgmental spaces, they inadvertently create barriers that undermine treatment efforts. Instead of being a source of strength, the community environment becomes a place of fear and vulnerability, ultimately contributing to poor adherence and poorer health outcomes for those living with HIV.

Therefore, strengthening social support through family education, community involvement, and the inclusion of peer networks in HIV programs is essential for helping people stay committed to their treatment regimens. When families understand the importance of ARV adherence, communities become more supportive, and peers share their experiences, individuals living with HIV feel less alone and more encouraged to continue their medication. Building these supportive connections not only improves adherence but also fosters dignity, hope, and long-term health among those affected.

1.2.2 Health as Determinants of Adherence

While social factors are widely recognized as important, the health system’s role as a structural determinant of adherence is equally important. The health system shapes the context in which individuals access treatment, interact with providers, and experience care (Lonnie et al., 2021). Van Heerden et al. (2002) emphasizes that when the health system functions effectively, it facilitates consistent treatment uptake, supports retention of care, and builds patient trust. However, when fragmented, it can create multiple barriers that hinder PLHIV from adhering to their prescribed regimens(M. Mirzaei-Alavijeh et al., 2025). These determinants are multifaceted and interconnected, encompassing service accessibility, medication availability, health worker attitudes and capacity, clinic processes and efficiency, confidentiality, and privacy.

Accessibility of health services plays a crucial role in influencing adherence patterns. In many resource-limited and rural settings, challenges such as long distances to health facilities, high transportation costs, and inconvenient clinic operating hours persist (Golestani et al., 2025). Individuals who have to travel long distances often experience fatigue, financial strain, and competing priorities, such as work or caregiving responsibilities, which can result in missed appointments or delayed medication refills (Golestani et al., 2025; Trevor & Jane). Long waiting times and rigid service hours only worsen these challenges, making it difficult for patients to consistently engage in care (Trevor & Jane). Studies from Ghana and Ethiopia have shown that patients facing logistical barriers are less likely to keep up with regular clinic visits, impacting their ability to adhere to ARV therapy and maintain viral suppression(Addo et al., 2022; Chachu & Maboe, 2025). Therefore, improving accessibility involves more than just physical infrastructure; it requires health systems to provide patient-centred, flexible, and responsive services that consider real-world constraints.

Closely linked to accessibility is the availability of medications and other vital health resources, which significantly impacts the continuity of treatment. Even when patients succeed in reaching healthcare facilities, shortages of ARV drugs can erode their trust in the healthcare system (Graham et al., 2015). McNeil et al. (2017) and Pietersen at al. (2023), point out that interruptions in the supply of medications may result in missed doses, treatment fatigue, or even complete discontinuation, thereby heightening the risk of drug resistance and adverse health outcomes. Additionally, the lack of supportive resources, such as viral load testing, drugs for managing side effects, and laboratory supplies, can hinder clinical decision-making and diminish patient involvement (McNeil et al., 2017; Pietersen et al., 2023).

In addition, healthcare workers' attitudes significantly impact adherence outcomes. The manner in which healthcare providers treat patients can either foster a sense of dignity and trust or perpetuate stigma and fear (Phelan et al., 2023). Patients who perceive health workers as respectful, supportive, and empathetic are more likely to attend appointments, share adherence challenges, and seek assistance when necessary (Phelan et al., 2023). Similarly, negative attitudes, judgmental comments, and unprofessional behaviour can discourage patients from seeking further care (Phelan et al., 2023). Studies conducted in South Africa and Ghana have shown that patients who experience discrimination in healthcare facilities often delay clinic visits, avoid discussing difficulties, or discontinue care (Bogart et al., 2013; Kwame & Petrucka, 2024).

Linked to attitude is health worker capacity, which includes technical competence and workload management. Healthcare providers with sufficient training are more prepared to offer high-quality adherence counselling, manage side effects, and provide clear information that empowers patients to make informed decisions about their care (Ticha et al., 2024). However, in many public health facilities, especially in rural areas, staff shortages and heavy workloads restrict the time and attention that health workers should devote to each patient, which compromises the quality and provision of a friendly environment and care (Milesky et al., 2025). Milesky et al. (2025) further allude that being short staffed also result into burnout, combined with inadequate training, diminishes healthcare workers' ability to provide patient-centred care. This highlights the need for more insourcing, continuous training, and accountability measures to ensure that there are enough health workers who uphold professional standards to support patient adherence.
Moreover, confidentiality and privacy issues have been reported to contribute to poor adherence to treatment. According to Evangeli and Wroe (2017), many patients fear that their HIV status may be unintentionally disclosed, especially in small or close-knit communities. When consultation rooms lack privacy or when health workers are perceived as being careless with confidential information, patients may avoid seeking care, travel long distances to remain anonymous, or hide their adherence difficulties (Tegegne et al., 2022; Trevor & Jane). This not only impacts health outcomes but also weakens the patient-provider relationship.

Lee et al. (2020) argue that clinic processes and operational efficiency also have far-reaching implications for treatment adherence among PLHIV. According to Lee et al. (2020), inefficient appointment systems, long queues, rigid clinic hours, and lack of service integration make accessing care unnecessarily burdensome. Patients who spend several hours at the clinic or make frequent visits, even when clinically stable, may become discouraged or financially strained, leading to treatment interruptions (Lee et al., 2020). A study conducted by Alturbag found that patient dissatisfaction with clinic efficiency was significantly associated with missed appointments and lower adherence rates (Alturbag, 2024).

The health system plays a pivotal role as a structural determinant of adherence to HIV treatment. Elements such as the accessibility of services, reliable medication supply, health worker attitudes and capacity, efficiency of clinic processes, and protection of confidentiality collectively shape the patient's treatment experience. When these factors are weak, they create barriers that undermine adherence to and retention in care. Equally, a strong, patient-centred health system can foster trust, reduce structural obstacles, and make it easier for individuals to remain engaged in lifelong treatment. Sustainable adherence and improved health outcomes for PLHIV depend on health systems that are responsive, well-resourced, and committed to supporting patients at every step of their care journey.

2. Methods

A qualitative research approach was used to gain a deep understanding of human behaviour, attitudes and lived experiences in real-life settings (Tenny et al., 2022). This methodological choice was especially suitable for uncovering how individuals living with HIV think about effective strategies that can be implemented to improve adherence to ARV treatment. By focusing on participants' subjective realities, this study aimed to move beyond statistics and explore the personal and social meanings attached to their treatment journeys (O'Keeffe et al., 2022).

To accomplish this, a phenomenological research design was implemented, allowing for a detailed and nuanced exploration of participants' stories. This design provided a platform for PLHIV to share their personal experiences and insights into the various factors that impact treatment adherence, and suggest approaches that can be implemented to improve adherence (Alzahrani & Almarwani, 2024). Special emphasis was placed on family-centred support systems, community-based interventions, and the influence of health systems on adherence behaviours. From this perspective, this study sought to showcase the challenges and opportunities present within these interconnected levels of support.

2.1 Study site

The study was conducted at the CHC in Madibeng sub-district municipality, which is part of the Bojanala district municipality in Northwest Province. This CHC serves a population of over 100,000 from areas including Lethlabile, Fafung, Vaalbosch, Rooiwal, Mmopudung, Jericho, Madinyane, Maboloka, Rabokala, Centreville, and Moshaya. Each month, the facility provides healthcare services to an average of 10,000 individuals, among whom approximately 1 000 are living with HIV and receiving ARV treatment at the health facility. Additionally, the facility manages an average of 900 individuals living with HIV who default on their ARV treatment each month and need to be traced back to the facility (unpublished report).

2.2 Selection Sample

The study population consisted of PLHIV between the ages of 18 and 40 years who were registered to receive ARV treatment at the CHC but had previously defaulted on treatment for a period of 30–90 days before being brought back into care. This age range was chosen based on data from South Africa's Department of Health Tier.net system, which showed that the highest rates of treatment interruption occurred in this group of patients.

Purposive sampling was used to select participants with relevant characteristics according to the inclusion and exclusion criteria outlined in Table 1. Campbell et al. (2020) define purposive sampling as a non-probability method that allows researchers to intentionally choose individuals with specific characteristics relevant to the study, who are more likely to provide detailed and meaningful data. This method was ideal for this study because individuals who defaulted on treatment could not easily be identified through random sampling. During the recruitment process, the researcher worked closely with Department of Health officials at the CHC, who were responsible for patient follow-up and retention in care. These officials provided access to a database of patients who had missed appointments by 30–90 days but had been successfully brought back to the facility. The 30 to 90-day timeframe was chosen based on common definitions in the literature, which classify patients who miss appointments within this period as "defaulters," while those who exceed 90 days are considered "lost to follow-up"(Chi et al., 2011).

The following steps were followed to recruit participants for this study:

- For confidentiality reasons, the researcher provided full details of the study and his contact information to the Department of Health officials at the CHC who interact directly with patients on ARV treatment to inform and recruit prospective participants.
- After sharing the study purpose with prospective participants, Department of Health officials informed them that if they were interested in taking part in the study, they should confirm by signing an informed consent document or by sending the researcher a free “call-back” message.
- All participants who took part in the study opted for the callback option.
- Upon receiving confirmation from prospective participants, the researcher arranged individual meetings at a place convenient to them to determine whether they met the inclusion criteria.

Table No. 1: Inclusion and Exclusion criteria

Inclusion Criteria	Exclusion Criteria
• Participants aged 18–40 years living with HIV.	• Participants aged 18–40 years on ARV treatment, but who have not previously defaulted on treatment.
• Participants who had previously defaulted on ARV treatment for 30–90 days were traced back to the clinic.	• Participants aged 18–40 years on ARV treatment, but who had defaulted for less than 30 days.
• Participants able to communicate in Setswana or English.	• Participants aged 18–40 years on ARV treatment who had defaulted for more than 90 days (considered lost to follow-up and removed from the tracing list).
• Participants registered for ARV treatment collection at the CHC.	• Participants aged 18–40 years who defaulted for 30–90 days but could not communicate in Setswana or English.
	• Participants who did not meet the age criteria (under 18 or over 40 years).
	• Participants aged 18–40 years who had defaulted from ARV treatment but were not registered to collect their treatment at the CHC.

2.3 Sample size

The sample size was determined by data saturation, a method used to ensure that sufficient high-quality data are collected to support a study (Hennink & Kaiser, 2022). It was anticipated that at least 12 participants would be required (Hennink & Kaiser, 2022). In this study, data saturation was achieved with a sample of 12 PLHIV, comprising three men and nine women.

2.4 Ethical considerations

Before the study began, ethical clearance was obtained from the Institutional Research Ethics Committee (number # Rec-215/2023). Subsequently, permission was sought from the Department of Health in Gauteng to sample participants from their health facility and to request assistance from the Department of Health official for participant recruitment, both of which were granted. Ethical clearance was obtained from the relevant institutional ethics committee and authorities. Key ethical principles adhered to throughout the study process included informed consent, confidentiality, anonymity, beneficence, debriefing, and avoidance of harm. This ensured that the study was conducted in accordance with established ethical standards and research governance procedures.

2.5 Data Collection

Data collection for this study involved conducting semi-structured, face-to-face interviews guided by a pre-developed interview guide aimed at eliciting rich, in-depth narratives (DeJonckheere & Vaughn, 2019). All participants received an information sheet outlining the study's purpose, which was explained thoroughly, along with a reminder of their rights, such as voluntary participation and the ability to withdraw at any point, without consequence. To cater to participants with varying literacy levels, the study information was presented in Setswana and English, as needed. Written informed consent was obtained before participation (Manti & Licari, 2018). Interviews were held at locations chosen for convenience, privacy, safety, and comfort, with most participants opting to be interviewed at their homes.

Before commencing data collection, the interview guide was reviewed by an experienced qualitative researcher (a professor at the University of South Africa) to enhance its clarity and logical flow (Herber et al., 2020). Language in several questions was simplified, and the sequence of questions was adjusted to ensure a natural progression of conversation. A pilot phase involving five participants who met the inclusion criteria was conducted to assess the clarity, relevance, and appropriateness of the interview tools (Alhejaili et al., 2022). As the questions were well understood and capable of generating meaningful data, no further refinements were required, and the pilot data was excluded from the main report. To support the participants' emotional well-being, pro bono counselling services from a registered private social worker was arranged in advance; however, no participant required these services. With the participants' consent, all interviews were audio-recorded to ensure the accuracy and completeness of data capture and later transcribed verbatim (Rutakumwa et al., 2020). This method allowed participants to express their lived experiences freely while enabling the researcher to maintain consistency across interviews and probe emerging themes in greater depth.

2.6 Data Analysis

This research utilized Tesch's qualitative data analysis approach, as outlined by Creswell (Dawadi, 2020; Xaba, 2024). The procedure involved thoroughly reviewing all transcripts to gain an overall understanding of the data, pinpointing key statements, creating codes, organizing these codes into themes and subthemes, and refining them to ensure they accurately represented the participants' experiences (Dawadi, 2020).

2.7 Trustworthiness

Qualitative researchers employ a range of methods to bolster the credibility or rigour of their studies, aimed at enhancing the study's trustworthiness (Ahmed, 2024). To ensure the trustworthiness of this study, credibility, dependability, transferability, and confirmability were established (Ahmed, 2024). Credibility was achieved by ensuring that the findings accurately reflected the participants' perspectives, which involved minimizing bias and employing triangulation. Triangulation was accomplished through peer debriefing, also known as analytical triangulation (Noble & Heale, 2019). An expert in the research field who was not directly involved in the study provided alternative insights and interpretations of the data. Additionally, the researchers engaged in regular discussions during the data collection and analysis phases of this study. Dependability was ensured by maintaining an audit trail of all study processes. Keeping detailed records was crucial because it provided a clear and auditable decision trail, ensuring consistent and transparent data interpretations. To achieve transferability, comprehensive descriptions of all aspects of the study were provided, allowing users to determine whether the findings were applicable to their situations (Munthe-Kaas et al., 2020). Confirmability was ensured by verifying with participants that the study's findings aligned with their experiences and ideas, rather than being influenced by the researchers' characteristics and preferences (Amin et al., 2020).

3. Results

Interviews were conducted with 12 PLHIV, and data saturation was achieved. The majority of those interviewed were women (n=9). The participants' ages ranged from 27 to 40 years. Most were single (n=10), unemployed (n=6), and lived with their families, including their parents and siblings (Table 1). The majority chose to be interviewed in Setswana, their native language.

Table No. 2: Participants' Characteristics

Variable	**Category**	**Number of Participants**
Gender	Male	3
	Female	9
Language Preference	Setswana	1
	English	3
	Both	8
Marital Status	Single	10
	Married	1
	Separated	1
Employment Status	Employed	4
	Unemployed	6
	Self-employed	1
Living Situation	Alone	1
	With spouse	1
	With family	7
	With partner	3

Table No. 3: Summary of themes and sub-themes

Theme	Sub-theme
1. Enhancing Community Awareness and Education	1.1 Conducting community awareness campaigns on HIV
2. Strengthening Social and Family Support Systems	2.1 Seeking support from family members
3. Enhance Health system service	3.1 Introducing ARV home delivery programmes 3.2 Strengthening adherence counselling

4. Enhancing Community Awareness and Education

4.1 Conducting community awareness campaigns on HIV

Most participants emphasized the importance of the Department of Health taking a more active role in raising community awareness about HIV. They expressed that a key reason for defaulting on their treatment was the fear of being stigmatized or discriminated against by those around them. Participants explained that when community members associate ARV treatment with being HIV-positive, they often avoid going to the clinic to collect their medication out of fear of being identified. This fear, they noted, is largely rooted in the community's lack of accurate knowledge about HIV. Many people still hold misconceptions about the illness, which leads to avoidance and social distancing from those who are known or perceived to be living with HIV. Participants believed that well-structured, community-focused awareness campaigns could help address these misconceptions, reduce stigma, and support better treatment adherence.

> *"I think campaigns regarding HIV and ARVs must be done in our communities so that people can have more knowledge. That is the only thing they can do to reduce people not going to the clinic and not taking their treatment because of discrimination and all that. If they provided education on HIV, the importance of PHIV taking treatment, and the need for acceptance and support by community members, it would change a lot of things because it is hard for us who are living with this disease. People need to be educated, that's it."* (P2)

5. Strengthening Social and Family Support Systems

5.1 Seeking support from family members

Most participants highlighted that family support plays a critical role in improving adherence to HIV treatment. They shared that some of the main reasons they defaulted on treatment included lack of money for transport to the clinic, the emotional burden of nondisclosure, and occasionally forgetting to take their medication. Participants emphasized that family members could provide practical assistance, such as financial support for transport, reminders to take or collect medications, and accompanying them to the clinic. Beyond practical help, they also viewed their family as an important source of emotional and social support, offering a safe space to share challenges and receive encouragement from family members. Participants believed that this kind of support could strengthen their ability to remain consistent with treatment and better cope with living with HIV.

> *"You know, most of us people living with HIV fail to survive and give up because of a lack of support from family members. I know people who died of HIV because they were not receiving treatment; they had not disclosed their status to their families. If your family knows that you are living with HIV, they can be a source of support; they will make you strong to accept your status, and if you accept your status and your family knows, adhering to treatment will be easy. Our family can help remind us of the date of treatment collection, so family is an important source of support."* (P10).
> *"If our family knows that you are on HIV treatment, they can help you with maybe money to go to the clinic and sometimes go with you because it is not easy to go alone; you feel like everyone knows that you are there to take treatment. So, if you are with someone, it is better because they will think you are coming for birth control pills".* (P11)

6. Enhance Health system service

6.1 Introducing ARV home delivery programmes

Participants reported that one of the key factors contributing to defaulting from ARV treatment was the distance between their place of residence and the clinic, compounded by a lack of financial resources for transportation, as most of the participants were unemployed. They suggested that home delivery of ARV medication could serve as a potential strategy to enhance adherence and facilitate consistent treatment uptake.

> *"I have a friend from Mmakau who receives her treatment from Mmakau clinic, where they introduced a system of delivering medication to your home to help with the long queues at the clinic. It started during COVID-19 times due to social distancing, so it made it easier for them to get their medication, especially if you are unemployed and do not have money to go to the clinic. The CHC should introduce that to help us stop defaulting on medication".* (P5)

6.2 Strengthening adherence counselling

Participants identified limited knowledge of HIV as another factor contributing to defaulting from ARV treatment. They recommended that individuals who test HIV-positive and those who do not adhere to treatment should receive comprehensive adherence counselling on the importance and benefits of adhering to their treatment regimen to support consistent uptake.

> *"First, let me start with the clinic: after a person has been tested and given treatment, they should be informed of the benefits of taking their treatment. I think that should be the*

> *first point to be addressed before we even look at issues that have to do with the community".* (P8)

7. Discussion

The findings of this study indicate that limited knowledge of HIV among community members contributes significantly to defaulting on ARV treatment. Participants emphasized that community-targeted awareness campaigns could play a critical role in improving treatment adherence. As highlighted by Fauk et al. (2021), lack of understanding of HIV often leads to stigma and discrimination, compelling PLHIV to conceal their status and avoid visiting clinics for treatment. This is consistent with the findings of Ndlovu et al. (2025). According to the study, stigma is pervasive in many communities and is more pronounced among older, less educated men with limited HIV knowledge and more traditional cultural beliefs. The same study recommended that interventions aimed at increasing HIV knowledge within communities could reduce stigmatizing attitudes, thereby improving support for PLHIV and potentially enhancing treatment adherence.

Another key finding was the importance of family support in promoting adherence to ARV treatment. Participants reported that challenges such as lack of transport money, forgetting to take medication, and the emotional burden of managing HIV alone often led to treatment defaulting. Family members were identified as critical sources of practical and emotional support, including assistance with transportation, reminders to take medications, and guidance on coping with the psychological challenges of living with HIV. Similar findings were reported in Yunnan, China, showing that family support significantly enhanced treatment adherence, provided assistance in the disclosure process, and offered psychological and financial support to PLHIV.(Li et al., 2006). This highlights the value of including families in interventions designed to improve ARV adherence.

Participants further recommended implementing a home delivery program for ARVs to address financial and logistical barriers to clinic access. Unemployment and transportation costs were cited as major obstacles to consistent treatment uptake. A community-based, client-centred model of ARV home delivery has been shown to facilitate uninterrupted treatment and improve the quality of life of PLHIV by removing structural barriers to adherence. Evidence from India highlights transport costs as a significant factor contributing to treatment default, with some PLHIV resorting to selling their personal belongings to maintain treatment adherence. (Kumarasamy et al., 2005). Moreover, during the COVID-19 pandemic, home delivery of ARVs in countries including Indonesia, Laos, Nepal, and Nigeria proved to be an effective strategy for sustaining treatment when clinic access was restricted (Hoke et al., 2021). Locally, a chronic medication home delivery project by Aurum Institute in the Ekurhuleni Metropolitan Municipality and Northwest Province successfully retained patients in care during the pandemic restrictions, although its continuation was hindered by resource limitations (Mboweni, 2024). These findings collectively suggest that, where resources permit, home delivery could serve as a viable and sustainable strategy for enhancing ARV adherence in resource-limited settings.

The study also revealed that some PLHIV discontinued treatment because they did not experience symptoms or feel ill, reflecting gaps in patient education about HIV and the necessity of consistent ARV use. Participants highlighted the need to strengthen adherence counselling at the clinic, ensuring that newly diagnosed individuals receive comprehensive education on the nature of HIV, the importance of daily treatment, and the potential consequences of non-adherence. Adherence counselling serves as a critical mechanism for bridging knowledge gaps, fostering an understanding of ARV efficacy, and supporting informed self-management among PLHIV (Musayón-Oblitas et al., 2019).

These findings highlight the interplay between knowledge, social support, and structural barriers in shaping adherence to ARV treatment. Interventions that combine community awareness campaigns, family engagement, enhanced adherence counselling, and innovative service delivery models, such as home delivery of ARVs, have the potential to significantly improve treatment outcomes for PLHIV. These results highlight the need for multifaceted strategies that address both individual and systemic determinants of adherence within the South African context.

8. Conclusion

This study highlights that adherence to ARV treatment among PLHIV in South Africa’s Northwest Province is shaped by factors beyond individual determination. The experiences shared by participants revealed how stigma, limited community awareness, and emotional isolation continue to undermine consistent treatment, even when life-saving medications are available. Simultaneously, structural challenges, including distant clinics, transport barriers, medication shortages, and overburdened healthcare workers, further complicate individuals’ ability to remain engaged in care. Despite these obstacles, the findings suggest promising avenues for intervention. Strengthening support from family and peers, increasing community education, and exploring innovative approaches, such as home-based ARV delivery and enhanced counselling services, could create a more enabling environment for sustained adherence. These strategies recognize that supporting PLHIV requires addressing both personal and systemic factors to ensure that treatment is accessible, comprehensible, and socially supported. Improving health outcomes for PLHIV calls for a holistic approach, one that sees beyond the statistics to the lived experiences of individuals and seeks to build communities and health systems that empower people to maintain lifelong engagement in care.

9. Recommendations

a. *Recommendations for Practice*

- Introduce home-based ARV delivery programs to reduce logistical barriers and improve access for patients in remote areas.
- Foster confidentiality and privacy in healthcare settings to build trust and encourage continued engagement in care.
- Make clinic services more patient-friendly by simplifying appointment scheduling, cutting down on long waits, and offering hours that accommodate people's work and family commitments.

- Ensure consistent availability of ARV medications and supportive resources, such as viral load testing and side-effect management drugs.

b. *Recommendations for Policy Makers*

- Develop and fund integrated HIV care models that include community outreach, home-based services, and peer-support networks.
- Allocate resources for continuous training and recruitment of healthcare workers to address staff shortages and burnout.
- Implement policies that enforce confidentiality standards and protect patient privacy in all healthcare facilities.
- Support infrastructure development in rural areas to improve physical access to healthcare services.
- Mandate regular monitoring and evaluation of ARV supply chains to prevent stock-outs and treatment interruptions.

c. *Recommendations for Community Leaders*

- Collaborate with local health facilities to identify and support individuals at risk of defaulting on treatment.
- Champion community awareness campaigns to dispel myths and reduce stigma surrounding HIV and ARV treatment.
- Encourage inclusive dialogue within faith-based and cultural groups to promote acceptance and support for PLHIV.
- Promote family education initiatives to help relatives understand the importance of ARV adherence and how to support their loved ones.

d. *Recommendations for Future Research*

- Conduct comparative studies across provinces to identify regional variations in adherence challenges and solutions.
- Explore the effectiveness of community-based stigma reduction interventions on treatment retention.
- Assess the influence of gender dynamics and socioeconomic status on ARV adherence patterns among PLHIV.
- Explore the long-term impact of home-based ARV delivery on adherence and viral suppression rates.

10. Limitations

The majority of the study participants were women, as fewer men reached out to the researcher to participate. This research is confined to the specific clinic where participants were recruited, and since other government clinics also offer HIV services, the findings may only be relevant to the context in which the study was conducted. Given the sensitivity of the HIV topic, identifying participants posed a challenge, requiring additional time to encourage them to volunteer, with more women than men expressing interest in participating. The study sample was limited to PLHIV who spoke only Setswana and/or English. Employing language translators could have allowed for the inclusion of speakers of other languages. Due to the sensitive nature of the topic, participants might have felt uneasy and withheld information regarding their reasons for defaulting on ARV treatment. However, the researcher fostered an environment that promoted openness and honesty among participants.

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12. Author Contributions

Masevhege MT was responsible for conceiving and designing the study, collecting data, analysing data, and drafting the manuscript. The author reviewed and approved the final version of the manuscript.

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14. Conflict of interest

None

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