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RESEARCH ARTICLE **OPEN ACCESS**

Beyond the Clinic: Community Health Workers' Perspectives on Tracing HIV and TB Patients in Rural South Africa

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Abstract:

Introduction: Human immunodeficiency viruses and tuberculosis burden continue to cause major public health concerns in South Africa. Patients who are lost to follow-up impede treatment continuity, contributing to an alarming spread of infections. Community health workers are the main drivers in tracing patients who have defaulted appointments and supporting them in returning to care. However, their perspectives in rural areas have not yet been explored.

Methods: An exploratory study design adopting a qualitative approach was used to explore CHWs' perceptions, challenges, and successes in tracing HIV and TB patients in the North West Province. Seventeen CHWs with at least one year of tracing experience were purposively selected from five primary healthcare clinics with a high number of LTFU patients. In-depth semi-structured face-to-face interviews were conducted in Setswana, audio-recorded, transcribed verbatim, and thematically analysed.

Results: The results revealed five comprehensive themes: (1) CHWs' critical role and economic dissatisfaction; (2) communication and documentation gaps, including poor record-keeping and ineffective down-referrals; (3) social barriers, notably patient non-disclosure and stigma; (4) perceived success in re-engaging patients and associated personal satisfaction; and (5) recommendations for improving patients tracing, During the interview, decentralised medication pick-up points and stronger collaboration with healthcare facilities emerge strongly.

Discussion: CHWs expressed that financial insecurity, inadequate logistical support, and community stigma undermine their effectiveness. Nevertheless, they reported satisfaction when patients returned to care.

Conclusion: Addressing identified challenges through structured remuneration policies, enhanced digital record-keeping, and stigma reduction campaigns could strengthen CHWs' capacity to improve retention in HIV/TB care. These findings have implications for policymakers and programme managers seeking to optimise CHW-led tracing interventions to reduce loss to follow-up and advance progress toward ending HIV/TB by 2030.

Keywords: Antiretroviral therapy, Community healthcare workers, Missed appointments, Outreach team leader, Patient tracing, Stigma.

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1. INTRODUCTION

Human immunodeficiency virus (HIV) and tuberculosis (TB) continue to pose a major public health challenge around the world, despite a significant achievement in low and middle-income countries (LMICs) with high preva-lence rates of co-infections [1, 2]. Compared to HIV, TB remains an utmost global health concern, where the burden of infection is regarded as high [1]. In 2023, it was confirmed that more than 8.2 million people worldwide were infected with TB, compared to 7.5 million in 2022 and 7.1 million in 2019 [1]. TB infections in South Africa are one of the most alarming concerns. Despite efforts to prevent national TB outbreaks, South Africa accounts for 3.3 per cent of the global burden. In 2022, 48 per cent of TB-infected people were co-infected with HIV, making TB infection the main cause of mortality among them in the country [3]. Although access to antiretroviral therapy (ART) has significantly improved, the health outcomes of people with HIV/TB remain a risk of mortality and morbidity [4].

People with HIV/TB co-infection significantly complicate disease management and undermine treatment compliance [5, 6]. Loss to follow-up (LTFU) among HIV/TB co-infection patients disrupts continuity of care, increases the risk of drug resistance, and fuels ongoing transmission [7]. Loss to follow-up refers to a situation where a patient does not return to a scheduled clinic visit for a medication refill within a certain period, usually 90 days or more after the last scheduled appointment in the clinic, and the outcome of the treatment is unknown [8].

The Sustainable Development Goal (SDG) 3 seeks to end the HIV and TB epidemics by 2030 [9], but socio-economic barriers, health system limitations, and stigma continue to undermine retention in care [10, 11]. Stigma and persistent socio-economic barriers, such as food instability, transportation costs, and unemployment, combine to weaken the effectiveness of community health workers (CHWs) [12]. It also has a significant impact on the effectiveness of patients' adherence to treatment, especially in HIV/TB care and other chronic diseases [13]. Studies have shown that stigmatisation caused by fear of disclosure, discrimination, and social exclusion limits the ability of CHWs to openly engage patients and provide home care [14, 15]. Patients suffering from social exclusion often dodge visits by CHWs, and fail to adhere to treatment plans [14, 15]. Coupled with other barriers, CHWs also find it difficult to fulfil the duties in a limited resource environment, with insufficient remuneration, and a lack of social acknowledgement [16, 17].

CHWs in South Africa are the pillar of patient tracing, thereby serving as a bridge for healthcare facilities and communities [14, 18, 19]. simply appears as an important-approach to reintegrate patients who were LTFU, to promote treatment retention in care [20]. CHWs conduct home visits, identify patients who have missed appointments, address barriers to adherence, and facilitate re-entry into care. While this approach has shown promise, success rates vary across contexts due to stigma, inadequate resources, migration, and inconsistent record-keeping [21-23].

In Moretele sub-district, North West Province, CHWs, among other activities, are also tasked with tracing HIV and TB patients flagged as LTFU through the national electronic register (TIER.Net) and other referral mechanisms. TIER.Net is a centralised digital health information system improves patient management, monitoring and evaluation, and supports data-driven decision making in South Africa's public health system [24]. Its effective implementation will contribute to improving the continuity of care, program performance, and achievement of public health objectives in the management of HIV and tuberculosis [25]. The system automatically generates summary reports on key programme indicators such as care retention and monitoring the defaulters. Healthcare providers can use TIER.Net to track patient appointments, identify missed appointments, and generate follow-up default lists. However, TIER.Net is largely an independent system at the facility level and limits the integration of other electronic health information systems, such as the District Health Information System, in real time [26].

Despite considerable investments in patient retention strategies, South Africa continues to experience high LTFU rates in HIV and TB care [27]. Several studies indicate that while CHWs successfully re-engage approximately 51 per cent of traced patients, up to 15 per cent remain lost to follow-up [28, 29]. Factors such as stigma, patient mobility, poor communication between healthcare facilities and CHWs, and limited operational resources undermine tracing effectiveness [30-34].

In the Moretele sub-district, the true realities affecting rural healthcare delivery, including poverty, limited transport infrastructure, and high unemployment, exacerbate these challenges. Furthermore, gaps in insufficient and incomplete recording, inconsistent referral systems, inadequate training,+ and lack of support impede optimal achievements of CHWs. Although CHWs are strategically placed to tackle both medical and social determinants of health in the community, limited qualitative studies i limited qualitative studies exploring their lived experiences in tracing HIV and TB patients where the study was conducted.

Therefore, this qualitative study explored CHWs perceptions, barriers, and achievements in tracking HIV and TB patients in a targeted environment (rural Moretele subdistrict, South Africa). The results of the study can be used to inform local and national health policies to promote CHW-led interventions, promote communications systems, and reduce stigma. Moreover, the results might have a practical effect to improve training and financial support and promote links between the healthcare facilities and the communities at large. By strengthening the voices of CHWs, this study might also contribute to the global discussion of community-based health programmes and alignswith the global goal to put an end to the HIV and tuberculosis epidemic by 2030. Finally, these perceptions can help to enhance patient tracking models in similar resource-limited environments.

2. MATERIALS AND METHODS

2.1. Study Design

The qualitative design was adopted to explore the perceptions and experiences of CHWs working to track patients living with HIV and/or infected with TB in the community. Qualitative approach is appropriate to examine a lived experience and contextual factors in unstudied areas, allowing a rich and sophisticated understanding beyond what the quantitative methods can gather [35].

2.2. Study Setting

The study was conducted in the Moretele local municipality of Bojanala Platinum District, North West Province, South Africa. Moretele local municipality does not have a provincial or district hospital. It is served by two community health centers and a total of twenty-one clinics, six of which operate 24 hours a day. While residents rely primarily on these clinics and community health centers for routine healthcare. Access to specialised care requires travel to hospitals located outside the municipality or in nearby districts.

Although the population bears a high burden of HIV and TB, with many patients defaulting on treatment due to socio-economic challenges, transport barriers, and stigma, five facilities were purposively selected for this study based on their high loss-to-follow-up (LTFU) rates as reported in weekly clinic records.

2.3. Study Population

The study population was CHWs from Moretele sub-district who were directly involved in tracing HIV and TB patients. The allocation of CHWs is in line with ward-based distribution models. The composition of Ward-Based Primary Healthcare Outreach Teams (WBPHCOTs) ideally consists of six to ten CHWs (Schneider, Sanders & Besada, 2018). Clinics are allocated several CHWs based on the population served by their attached Primary Healthcare (PHC) facilities. Clinics serving larger populations are supported by more teams and, consequently, by a greater number of CHWs.

In total, 310 CHWs are distributed across twenty-one clinics, with each facility receiving several CHWs proportional to the size of its catchment population, ranging from five to thirty per facility. The exact number of CHWs assigned to each clinic is not publicly available, as these data are managed at the district level and may fluctuate according to population trends.

2.3.1. Inclusion Criteria

- Linked to one of the selected clinics.
- At least one year of experience tracing HIV and TB patients.

2.3.2. Exclusion Criteria

- CHWs not involved in patient tracing HIV and TB patients.
- Less than one year of tracing experience.

2.4. Sampling and Recruitment

Purposive sampling was employed to select participants from the pool of eligible CHWs. This is a phenomenological study aimed to interview between 20 and 30 participants to allow deep exploration, targeting approximately five to six CHWs per facility. At each facility, the names of all eligible CHWs were placed in a bowl, and the operational manager assisted in randomly drawing ten participants. The operational manager then approached the selected CHWs to explain the reason for their selection. Once they agreed to participate, the researcher engaged each of them individually to provide detailed information about the study and to schedule an interview appointment.

However, only seventeen participants were involved due to data saturation.

2.5. Data Collection Instrument and Procedure

A semi-structured interview guide was used for the interviews. The guide comprised three sections:

- **Section A:** Demographic details.
- **Section B:** Challenges experienced during patient tracing

Can you describe the main challenges you experience when tracing HIV and TB patients who have missed their clinic appointments, and how these challenges affect your work?

- **Section C: Perceived Success and Recommendations**

From your experience, what has been most successful in helping patients return to care after tracing, and what recommendations would you suggest to improve the tracing process?

Data were collected through face-to-face, in-depth, semi-structured interviews. The interview guide was structured in English, informed by the study objective and literature review of similar studies. Setswana is the dominant language spoken in the study setting, hence the interview guide was translated into that language to ensure that data is accurately collected and to promote open discussions. The translation was done by an external professional language expert. With participants' consent, all interviews were audio-recorded, and each session lasted approximately 40 to 45 minutes. Field notes were taken to supplement the data. Data were collected over two months (February to March 2024), during which two participants from each clinic were interviewed per week

Prior to the main data collection, a pilot test was conducted with two CHWs to refine the interview questions, and the pilot data were excluded from the final analysis.

2.6. Data Analysis

All audio-recorded interviews were transcribed verbatim and then back-translated into English by the primary researcher and later reviewed and edited by the professional language editor appointed for this study.to ensure the accuracy of meaning [36]. A thematic analysis approach was employed, following the steps of familiarisation with the data, initial coding, theme development, refinement, and interpretation [37-39]. Cross-validation of coding was conducted to ensure consistency and reliability of data analysis. Both the researchers independently coded a sample of five transcripts using the preliminary codebook. The coded data were then compared, and discrepancies were discussed until consensus was reached. Then the final coding framework was developed and applied to all the remaining transcripts. Regular peer debriefing sessions after every five transcripts were done to maintain analytical rigour.

Descriptive codes reflecting CHWs' experiences, challenges, and successes were organised into broader categories and overarching themes. To preserve meaning, translated transcripts were carefully compared with the original audio recordings. Finally, the themes were critically reviewed in relation to existing literature and the study objectives to enhance the credibility and analytic rigour of the findings.

After the manual data analysis, codes, themes, quotes, and the verification of transcripts, data were imported into NVivo version 15 software for organisation and management. This allows for efficient retrieval and comparison of data segments of data among the researchers. It has also increased transparency and coherence by maintaining audit trails of all code activities and notes made by both researchers [40].

2.7. Trustworthiness

Trustworthiness in qualitative research reflects the credibility and reliability of both the researcher and the study findings, and is established through four key strategies: credibility, transferability, dependability, and confirmability [41]. Credibility was ensured through prolonged engagement with participants for over a period of two months, triangulation of data sources, and peer debriefing among the research team. Transferability was ensured by providing giving detailed description of the study processes, such as data collection procedures, study setting, and participants characteristics. Purposive sampling of participants was used to ensure diversity of the experiences. It allows other researchers to judge the applicability of the findings to similar contexts. Dependability was strengthened by maintaining consistency in the interview process, using the same questions for all participants, recording responses, and transcribing audio while preserving meaning. An audit trail was kept. The researchers conducted cross-validation of coding, and discrepancies were discussed until a consensus was reached.

Lastly, confirmability was achieved through audio recordings, field notes, and a clear outline of data collection, analysis, and interpretation, with an audit trail kept, allowing future verification of the findings. The themes were supported by the participant's quotations. Audio recordings and transcripts were securely stored in Google Cloud, protected with an encrypted password accessible only to the primary researcher.

2.8. Ethical Considerations

Ethical approval was granted by the Sefako Makgatho University Research Ethics Committee (**SMUREC/H/390/2022:PG**) and the North West Department of Health. Written informed consent was obtained from all participants, who were informed about the study aims, procedures, potential risks, and their right to withdraw at any time without penalty. Interviews were conducted in private spaces within health facilities to protect confidentiality and minimise social desirability bias. Participants were assigned numbers, and identifying details were removed from transcripts. Data were stored securely in password-protected files and locked cabinets accessible only to the research team. Given the sensitivity of HIV and TB status, additional measures were taken to safeguard participants from stigma and unintended disclosure.

3. RESULTS

3.1. Participant Characteristics

Seventeen CHWs from the three selected clinics participated in the study. The ages ranged from 22 to 54 years, with most participants over 40 years. The majority were female, single, and had completed secondary education (Table 1). Setswana was the predominant home language.

3.2. Emerging Themes

Five major themes and twelve subthemes were identified through thematic analysis (Table 2).

Table 1. Profile of the participants.

Participants	Age	Gender	Marital Status	Highest Grade	Home Language
CHW1	44	Female	Married	Matric	Tswana
CHW2	51	Female	Single	Matric	Tswana
CHW3	23	Male	Single	Matric	Tswana
CHW4	54	Female	Single	Matric	Tswana
CHW5	32	Female	Single	Matric	Sepedi
CHW6	37	Female	Single	Matric	Tswana
CHW7	49	Female	Single	Grade 11	Tswana
CHW8	50	Female	Married	Matric	Sepedi

Participants	Age	Gender	Marital Status	Highest Grade	Home Language
CHW9	52	Female	Single	Matric	Sepedi
CHW10	45	Female	Single	Level 4 ABET	Tswana
CHW11	46	Female	Single	Matric	Tswana
CHW12	37	Female	Married	Matric	Tswana
CHW13	41	Female	Single	Matric	Tsonga
CHW14	35	Female	Single	Grade 11	Tswana
CHW15	45	Female	Single	Grade11	Tswana
CHW16	53	Female	Married	Grade 11	Tswana
CHW17	47	Female	Married	Grade 10	Tswana

Note: *ABET = Adult Basic Education and Training.

Table 2. Themes and Sub-themes.

Themes	Sub-themes
1. CHWs’ role and economic dissatisfaction	1.1 Perceived as providing a crucial role in community health. 1.2 Dissatisfaction with the monthly stipend.
2. Communication and documentation challenges	2.1 Communication with facility-based healthcare providers. 2.2 Poor documentation of clinic visits. 2.3 Ineffective down-referral feedback.
3. Social barrier inpatient tracing	3.1 Non-disclosure of HIV/TB status to family. 3.2 Stigma attached to their role and self. 3.3 Denied access to households.
4. Perceived success of CHWs in tracing HIV and TB patients	4.1 Successful re-engagement in care. 4.2 Personal satisfaction.
5. CHWs’ recommendations	5.1 Medication pick-up points. 5.2 Collaboration with clinic staff members.

3.2.1. Theme 1: CHWs’ Role and Economic Dissatisfaction

Community health workers (CHWs) are key to bridging the gap between hospitals and rural communities, tracking patients lost to follow-up and supporting the continuity of care. They recognise the importance of their role, but many express dissatisfactions with lack of financial incentives, limited resources, and poor working conditions. These economic strains not only affect their motivations but also affect the efficiency of their daily work.

3.2.1.1. Perceived Crucial Role in Community Health

Participants described themselves as an extension of the Department of Health (DoH) within their communities, providing a range of services beyond tracing. This included household registration, health education, screening for chronic conditions, medication delivery, and postnatal follow-up.

“We work in the community doing household registration, tracing patients who miss their appointments, and conducting campaigns. When patients have social problems, we refer them to social workers.” CHW 13

“I teach people about health matters and support those on chronic medication so they can live longer. We also deliver medicines to those registered on CCMDD. In addition, we trace patients with abnormal results and those who miss their appointments.” CHW 11

“I work in the community where we trace patients, educate people about health conditions, and support and encourage those on chronic medication to continue taking their treatment.” CHW 1

“I do household registration, screening, and tracing of patients who miss their appointments. I also check children under five to ensure their Road-to-Health booklets are up to date. We conduct postnatal checks from the day after being discharged up to six weeks. Overall, we provide health services to the community.” CHW 4

3.2.1.2. Dissatisfaction with the Monthly Stipend

Although participants valued their work, they expressed deep dissatisfaction with the stipend. They reported stagnant pay despite increasing workloads, no benefits, and out-of-pocket expenses for transport, food, and stationery.

“Our stipend is depressing. With the little money we receive, we still have to travel to the clinic every week and buy lunch, yet we are not given any lunch allowance.” CHW 3

“Aish! We are struggling... a travel allowance would be much better to cover our travelling .” CHW 15

“Yoo! We have too much workload, but our stipend remains unchanged even though we are expected to reach the houses that are far and pay for our own transport.” CHW 9

“Our salary is not pleasing... Sometimes we are expected to cover photocopies payments. It is difficult for me as a single parent to use my little stipend to cover all those costs.” CHW 4

“There is a shortage of stationery; as a result, we opt to use our own money to buy stationery and make copies. This causes an overstretch to our salary.” CHW 14

3.2.2. Theme 2: Communication and Documentation Challenges

Proper communication and reliable record keeping are essential for effective patient tracking, but CHW often encounters incomplete addresses, outdated information, and poorly maintained documentation systems. These limitations cause inefficiency, and CHWs spend time attempting unsuccessful tracking or duplicating attempts. The weak integration of facilities records and community monitoring further undermines their ability to connect patients to care.

3.2.2.1. Communication with Facility-based Healthcare Providers

Most CHWs described effective communication with healthcare facility staff members only when receiving tracing lists, often generated after three unsuccessful telephone contact attempts. However, they noted that HIV patients were less frequently referred than TB patients.

"At the clinic, there is someone responsible for tracing. She gives us a list of patients who have missed their appointments and need to be traced physically." CHW 2

"Every Monday, we go to the clinic to collect the tracing list. Each CHW then selects patients according to their designated work area." CHW 6

"It is a problem now… We used to use phones with the mHealth app. It was simple because we could receive the information without going to the clinic." CHW 11

On the contrary, CHWs stated that the main communication problem is the lack of structured, timely, and two-way communication between them and healthcare professionals (nurses), which leads to poor coordination, inefficiencies, and gaps in patient monitoring.

3.2.2.2. Poor Documentation of Clinic Visits

CHWs reported that missed appointments were sometimes due to incomplete record-keeping, with nurses failing to update patient files despite visits being made. This led to unnecessary tracing of patients who were still in care.

"The challenge is that we are allocated patients for tracing, but when we arrive, we find that the patient already has their treatment and next appointment date." CHW 6

"The clinic gives us a tracing list, but sometimes we discover that the patient actually visited the clinic a few days earlier." CHW 7

"Sometimes nurses do not record information in the patient's file, and the patient then appears on the tracing list as if they missed an appointment." CHW 12

Participants persistently report the gaps with incomplete back-referral forms, which impede accurate reporting and result in fragmentation of care.

"We are struggling…we are receiving incomplete referral forms from nurses to patients we should track. We have lost many patients because we cannot follow up with them." CHW 17

CHW 9 also shares the same view, indicating that, although successful patient tracing has been achieved, nurses have not completed the down referral form, which simply means that patients do not return to CHW for further engagement.

3.2.3. Theme 3: Social Barriers in Patient Tracing

The tracing for patients is determined by various social realities, such as stigma, domestic conflict, immigration, and community resistance. CHW often finds patients hiding information to avoid contacting them or fearing discrimination. These obstacles emphasize the role of broader social dynamics in the shape of health-seeking behaviour and influence the success of tracking initiatives.

3.2.3.1. Non-disclosure of HIV/TB Status to Family

Patients who had not disclosed their status often reacted with anger or hostility toward CHWs.

"Aish… some patients do not disclose their HIV status to their family members." CHW 10

"When tracing patients who have not disclosed their status, we are also afraid to leave a message with the family." CHW7

3.2.3.2. Stigma Attached to their Role and Self

Community members often assumed CHWs only visited HIV/TB patients, perpetuating stigma and resistance.

"There is a lot of stigma attached to us… People have labelled the CHW programme as an HIV programme." CHW3

"They are not happy because they think CHWs only trace HIV patients." CHW5

3.2.3.3. Denied Access to Households

Some patients avoided interaction by hiding or locking gates.

"Sometimes family members tell us the patient is not home while he or she is actually hiding." CHW 13

*"Some patients lock their doors and do not want to talk to us."*CHW14

3.2.4. Theme 4: Perceived Success in Tracing HIV and TB Patients

Despite persistent challenges, CHWs identify cases where their efforts result in a successful patient re-engagement in HIV and tuberculosis care. Success is often attributed to persistence, familiarity with local communities, and supporting collaboration with clinic staff. These positive results give CHW a feeling of satisfaction and strengthen the value of their contribution.

3.2.4.1. Successful Re-engagement in Care

Many CHWs reported that traced patients returned to care and adhered to treatment after receiving education and support.

"I can say I am a lucky woman… they have gained weight, and some are back to work." CHW 4

"Since I started with tracing… patients that I traced are back in care." CHW 16

3.2.4.2. Personal Satisfaction

Re-engaging patients was a source of pride and motivation.

" I feel so excited since I have saved many lives in my community." CHW 3

"Wow, the patients are taking our effort seriously." CHW 4

3.2.5. Theme 5: CHWs' Recommendations

CHWs emphasised the need for systemic improvements to strengthen patient surveillance, including better training, adequate wages, improved record systems, and support monitoring. Its recommendations emphasise its position as both the first-line implementer and the key informant for program improvement. By integrating their insights, you can improve patient retention strategies and improve health outcomes in rural communities.

3.2.5.1. Medication Pick-up Points

Participants recommended decentralising medication collection to reduce clinic visits, suggesting community collection points and pharmacy-based models.

"Patients like the CCMDD… we collect on their behalf if they are registered." (CHW 3)

"My suggestion is to have dedicated areas in the community where all patients living with chronic conditions can go to collect their pre-packed medicine." CHW 4

3.2.5.2. Collaboration with Clinic Staff

CHWs demand regular participation in clinic meetings to discuss challenges and share their views and solutions.

"*Clinic staff should consider inviting us to be part of their monthly meetings so that we can raise our concerns and resolve our challenges."* CHW 10

"Although the meetings that are supposed to happen monthly are not regularly, I still feel that they are crucial to address issues, and it must be prioritised." CHW 8

4. DISCUSSION

This study explored CHWs' perceptions of their roles, challenges, and successes in tracing HIV and TB patients in the Moretele sub-district, North West Province. The findings reaffirm CHWs' critical function in linking communities with the health system while highlighting structural, operational, and social barriers that affect tracing effectiveness.

4.1. Economic Dissatisfaction and Financial Constraints

Although CHWs found their work with patients deeply rewarding and expressed an intense sense of professional fulfilment, they also highlighted significant dissatisfaction with the financial compensation and remuneration associated with their roles. The stipend of approximately R3,500 per month has remained stagnant despite increasing workloads and expanding community coverage. Participants also frequently incurred personal costs for transport, food, and stationery, which contributed to financial strain and, in some cases, reduced field efficiency.

Similar concerns are documented in other South African studies, where inadequate remuneration and absence of benefits contribute to burnout, attrition, and reduced motivation among CHWs [42-45]. Financial insecurity has been associated with poor job performance and weakened service delivery, especially in limited resource settings [46]. Strengthening remuneration policies, particularly travel allowances and resource support, is therefore essential to sustaining the CHW workforce and improving patient re-engagement.

These financial challenges highlight the wide-ranging structural problem of community health programs and the persistence of undervaluation of front-line health workers. Although CHW plays a key role in South Africa's primary health care restructuring strategy, their salaries and working conditions do not reflect the complexity and importance of their responsibilities. This deficiency undermines the sustainability of tracking programs, as ongoing financial insecurity leads to discouragement, reduced retention, and reduced productivity. At the system level, inadequate investment in CHWs reflects a broader health financing gap and competing resource priorities, limiting progress towards the national targets of HIV/AIDS management. Therefore, compensation is not just a welfare issue, but a basic requirement to strengthen the performance of the health system at the community level.

4.2. Communication and Documentation Gaps

Effective patient tracing depends on accurate and timely communication from health facilities. While CHWs reported positive relationships with clinic staff, documentation errors and incomplete patient records, and poor feedback on down-referrals often resulted in unnecessary tracing of patients who remain active in care. These challenges mirror findings from other sub-Saharan contexts where poor record-keeping, reliance on manual systems, and limited digital integration hinder tracing efficiency [47, 48]. The shift from mHealth platforms to paper-based systems in the study setting was perceived as a setback, echoing global evidence that digital health tools improve accuracy, speed, and efficiency in patient follow-up [47]. Reinstating and scaling up mHealth systems could reduce administrative errors and strengthen communication.

These communication challenges illustrate the more profound weaknesses in health information governance. Relying on manual and fragmented systems suggests that data quality, responsibility, and interoperability are still underdeveloped. The lack of documentation is not only an operational problem, but also a symptom of a systemic imbalance between services based on facilities and communities. When the CHW relies on incorrect or outdated information, the tracking becomes inefficient and undermines the trust between patients and the health system. In addition, the abolition of digital tools such as mHealth applications is an opportunity missed to modernise patient management in rural environments. This regression hampered the expansion of national programmes to improve the continuity of care through digital transformation.

4.3. Stigma and Social Barriers

Social stigma emerged as a prominent barrier to effective tracing. Patients who have not revealed their HIV and or TB status often refuse to access CHWs or react defensively. This strengthens the false belief that CHWs work exclusively with HIV/TB patients and strengthens the suspicion of the community. This stigma has reduced the acceptance of CHWs visits and prevented reintegration into care.

The influence of stigma on treatment adherence and care engagement is well established [49]. CHWs who themselves face stigma bear additional emotional burdens that may reduce their effectiveness. Community sensitisation and CHW training in stigma-reduction and sensitive communication are therefore essential. Evidence shows that when community attitudes shift positively, treatment uptake and retention improve [50].

The stigma experienced by both CHWs and patients reflects deep-rooted social dynamics formed by historical inequalities, cultural norms, and persistent misconceptions about HIV and TB. However, the results suggest that the social environment may enable or constrain CHW interventions. Stigma does not only function at the individual level, but is also considered a structural obstacle to disclosure, influencing health-seeking behaviour and the perception of the community. These dynamics demonstrate that clinical interventions alone are not sufficient; meaningful improvements in tracking of patients require social interventions that address power relations, community beliefs, and visibility of the role of CHWs.

4.4. Successes in Tracing and Reintegration

Despite all barriers encountered, CHWs reported considerable success in re-engaging patients in care, often through personalised education and support during home visits. Such interventions not only facilitated treatment adherence but also improved patients' physical and emotional well-being.

These findings are consistent with evidence from patient tracing initiatives in other low-resource settings, where CHW involvement has led to substantial improvements in ART adherence, TB treatment completion, and viral load suppression [6]. The sense of personal satisfaction expressed by CHWs underscores the intrinsic motivation that can be leveraged in program strengthening. These successes highlight an important mechanism within the Community Health Programme's relations of trust. CHW's ability to re-engage patients is not only rooted in clinical messages, but also in the social integration, cultural knowledge, and sustained presence of the community.

This related dimension is often neglected in policy frameworks, which tend to emphasise biomedical outcome and facility-based indicators that health-seeking behavioural outcomes. Strengthening tracking programmes will require recognition that demonstrates community trust and personalised support as a core element of CHW practices, which will be supported by appropriate supervision and skills development.

4.5. Recommendations from CHWs

CHWs suggested practical strategies to improve tracing efficiency and patient retention, notably decentralising medication collection points to reduce clinic congestion and stigma. Similar differentiated service delivery (DSD) models, including community pharmacies and adherence clubs, have demonstrated positive outcomes in retention and patient satisfaction [18, 51, 52].

Additionally, CHWs called for consistent inclusion in clinic staff meetings to improve coordination and address operational issues. Collaborative problem-solving between CHWs and facility staff is known to enhance mutual understanding, streamline workflows, and improve patient outcomes [53, 54].

The recommendations proposed by CHW show a critical point of view. Frontline workers possess contextual knowledge, which is essential for the development of realistic and sustainable health interventions. Their proposals are consistent with the evidence of the global quality of service delivery, but also reflect local differences such as transport barriers, community perceptions, and infrastructure limitations. This shows the need for a participatory planning process in which the CHW not only implements but also contributes to programme design.

5. STRENGTHS AND LIMITATIONS

Despite the limitations observed in this study, the results provided in detail the understanding of structural and bottlenecks affecting CHW performance. The study pointed out how structural issues such as financial constraints, incoherent data systems, and stigmatisation at the community level affect the service delivery by CHWs. These perspectives show the importance of contextualised research in the healthcare system by obtaining the first-line viewpoints and bringing out the obstacles that can be captured not only by quantitative variables.

Some limitations and biases were observed in our study in study. The study was confined to five primary health facilities and may affect the transferability of the results to other settings. There may be a bias in responses, as the CHWs may provide a socially desirable response, especially when it comes to discussing their roles, relationships with healthcare providers, and tracing outcomes. Adding to social desirability bias, participant checking to verify our findings was not covered. Furthermore, the interpretations of results were based on self-reported data and may be affected by the recall biases and face-to-face interview process.

Unlike a qualitative research approach alone, this study would have benefited more if a mixed-method approach had been considered. Adding to this, community-led participatory research is also recommended to capture broader contextual variations and to deepen understanding of how structural and system-level factors influence CHWs' performance. Community-led participatory research can ensure decision-making, provide a more comprehensive understanding of tracing effectiveness and contextual challenges, and provide an opportunity for direct observation of tracing activities to improve community well-being and bring about social change.

6. STUDY RECOMMENDATIONS

Based on the study findings, the following measures are proposed to strengthen CHW-led tracing of HIV and TB patients in rural South African settings:

6.1. Improve Financial Incentives and Job Security

Implement structured remuneration policies that include annual increments, performance-based bonuses, and travel allowances.

Strengthening CHW compensation is not only about morality and retention, but also about a broader system of health equity. The appropriate remuneration recognises the professional value of community-level care, mitigates labour shortages, and improves the sustainability of patient tracking programmes.

6.2. Enhance Digital Health Systems and Record-keeping

Reintroduce mHealth applications for patient tracking to reduce administrative errors and avoid unnecessary tracing of patients already in care. Improved digital systems go beyond operational efficiency and enable timely decision-making, strengthening accountability and integration between community and facility care. This might provide evidence-informed interventions and a real-time insight to inform policy and resource allocation.

6.3. Address Stigma through Targeted Community Engagement

Conduct ongoing community awareness campaigns to clarify CHWs' broad health mandate and reduce misconceptions that they serve only HIV/TB patients. Community engagement offers CHWs training opportunities in the techniques of communication aimed at reducing stigma and handling information in a sensitive way.

The fight against stigma requires both community-level and structural interventions. To address social norms, misinterpretations, and discrimination, the health system needs to create an environment that enables the functioning of CHWs to be effective and in patients can participate fully in the care.

6.4. Expand Differentiated Service Delivery (DSD) Models

Establish community-based medication pick-up points, adherence clubs, or pharmacy partnerships to reduce clinic congestion and patient travel costs.

Prioritise household delivery for stable patients to minimise stigma associated with clinic attendance. By decentralising care and using community resources, the DSD model might reduce structural barriers, improve treatment compliance, and strengthen the autonomy of the patient.

6.5. Strengthen Clinic–Community Collaboration

Institutionalise regular joint meetings between CHWs and clinic staff to discuss tracing challenges, review patient outcomes, and develop shared solutions. Assign dedicated facility-based liaison officers to streamline referral and back-referral processes.

Strengthening the links between the community and the healthcare system contributes to integrated primary health care and more resilient health systems capable of responding to the challenges of HIV/TB.

CONCLUSION

Community health workers play a key role players for HIV and TB patients tracing in rural South African communities. They play a significant role in re-integrating patients who are lost to follow-up or have defaulted on treatment and ensure an ongoing adherence process to support long-term treatment. The study shows that CHWs have the enthusiasm to achieve a remarkable success in bringing patients back to care despite serious financial constraints, documentation gaps, and persistent stigma. Their personal commitment, knowledge of the community, and the ability to provide tailored support to patients in the community are the core of positive tracing outcomes.

Resolving fundamental challenges such as insufficient remuneration, inconsistency in communication between healthcare nurses and CHWs, and social stigmatisation is important to optimise the impact of tracing programs. Improvements to digital record systems, the expansion of differential service delivery models, and the strengthening of clinical-community collaboration can further improve the patients' linkage to care. Based on these conclusions, policymakers and healthcare managers can strengthen the role of CHWs in the healthcare system to minimise treatment interruptions among patients living with HIV and TB. This innovation can facilitate expedited progress towards achieving the national and global objectives of ending the HIV/AIDS epidemic by 2030.

AUTHORS' CONTRIBUTIONS

This study was derived from the master's dissertation of the first author (DSM), under the supervision of MPL. Both authors confirm their contributions to the paper. DSM was responsible for the study conception, design, data collection, and analysis. All authors reviewed the findings, contributed to drafting the manuscript, and approved the last version.

LIST OF ABBREVIATIONS

ART = Antiretroviral Therapy
CHWs = Community Health Workers

DSD = Differentiated service delivery
HIV = Human Immunodeficiency Virus
LTFU = Loss to follow-up
SDG = Sustainable Development Goal
TB = Tuberculosis
WBPHCOTS = Ward-Based Primary Healthcare Outreach Teams

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was granted by the Sefako Makgatho University, South Africa Research Ethics Committee (SMUREC/H/390/2022:PG).

HUMAN AND ANIMAL RIGHTS

All procedures performed in studies involving human participants were in accordance with the ethical standards of institutional and/or research committee and with the 1975 declaration of Helsinki, as revised in 2013.

CONSENT FOR PUBLICATION

Participants were informed about the dissemination of the study findings during data collection and provided informed consent for their information to be published.

STANDARDS OF REPORTING

COREQ guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

The authors confirm that the data supporting the findings of this research are available within the article.

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None.

CONFLICT OF INTEREST

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

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AI DISCLOSURE STATEMENT

Some parts of this manuscript have been edited for grammar and vocabulary using artificial intelligence (AI).

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