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Barriers to Tuberculosis Care Access Across the Care Cascade in the Democratic Republic of Congo: A Cross-sectional Study

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Abstract

Background

Progress toward TB control depends on timely diagnosis and treatment. Despite global efforts, people with tuberculosis (TB) in high-burden countries such as the Democratic Republic of Congo (DRC) continue to face substantial barriers throughout the TB care cascade. This study assessed barriers to accessing clinical assessment, diagnostic testing, and treatment services among TB patients in the DRC.

Methods

A cross-sectional study was conducted from March to April 2024 among 449 adult patients with pulmonary TB recruited from 37 health facilities in four provinces of the DRC. Participants were selected using a two-stage cluster sampling design and interviewed using a structured electronic questionnaire. Descriptive analyses accounting for the complex sampling design were performed.

Results

Most participants were rural residents (70.0%), male (60.4%), married (67.2%), and of low socioeconomic status (63.6%). Only 42.2% correctly identified bacteria as the cause of TB, while 57.8% held misconceptions. Although 92.3% knew TB treatment was free, only 40.3% were aware that TB screening services were free. The most frequently reported barriers across the care cascade were perceived high service costs (66.5–70.9%), transportation and related expenses (62.6–64.3%), believing symptoms did not require medical attention (62.0–68.7%), lack of information on where to seek care (60.2–65.3%), long travel distances (54.4–57.6%), and fear of stigma (43.3–47.2%). Overall, 27.9% initially sought care outside the formal health system, and approximately 22% delayed seeking care for more than one month after symptom onset.

Conclusion

TB patients in the DRC face important socioeconomic, geographical, informational, and stigma-related barriers that delay access to diagnosis and treatment. Addressing these barriers through patient-centered and community-based interventions is essential to improve timely access to TB services and accelerate progress toward the End TB Strategy.

1. Introduction

Tuberculosis (TB) remains one of the leading infectious causes of morbidity and mortality worldwide and continues to pose a major public health challenge, particularly in low- and middle-income countries (LMICs), where access to quality healthcare services remains limited. The Democratic Republic of Congo (DRC) is among the 30 countries with the highest TB burden globally, where the disease continues to exert a substantial health and socioeconomic impact [1]. In 2022, the country recorded an estimated 291,000 incident TB cases, corresponding to an incidence rate of 311 per 100,000 population, and

approximately 73,000 TB-related deaths, including those occurring among people living with HIV [2]. Although effective diagnostic tools and curative treatment are available, timely access to TB services remains suboptimal because of persistent barriers throughout the TB care cascade, including clinical assessment, diagnostic testing, treatment initiation, and treatment completion. These barriers contribute to delayed diagnosis, delayed treatment initiation, loss to follow-up, and continued disease transmission, thereby compromising progress toward the End TB Strategy [3–5].

Access to healthcare services in LMICs is influenced by multiple structural, socioeconomic, and geographical constraints. In the DRC, geographical accessibility represents a major challenge, with only about 35% of the population living within five kilometers of a health facility [6]. Financial hardship further limits healthcare utilization, as widespread poverty, transportation costs, and out-of-pocket expenditures often prevent individuals from seeking care despite the availability of TB services [5, 7]. These challenges are compounded by the unequal distribution of healthcare resources, particularly between urban and rural settings, leaving rural populations disproportionately affected by limited access to quality TB services [8, 9].

Beyond these general health system constraints, individuals affected by TB experience disease-specific barriers that further delay diagnosis and treatment. Stigma, misconceptions about TB, and inadequate knowledge of available services remain important obstacles to care seeking in the DRC [10]. Fear of social exclusion or being perceived as HIV-positive, poor understanding of TB transmission, and limited awareness that TB diagnosis and treatment are provided free of charge discourage many individuals from seeking timely healthcare [10]. In addition, recurrent shortages of diagnostic tests and anti-TB medicines weaken service delivery, delaying diagnosis and treatment initiation and negatively affecting treatment adherence [11, 12].

Although several studies have documented barriers to TB care in the DRC, recent evidence remains limited and is predominantly qualitative, providing little information on the magnitude and distribution of these barriers across the TB care cascade. Quantitative evidence is needed to better prioritize interventions and inform policies aimed at improving equitable access to TB services. Therefore, this study aimed to assess barriers to accessing TB clinical assessment, diagnostic testing, and treatment services among patients receiving TB care in the DRC. By quantifying the most frequently reported obstacles across different stages of the care cascade, the findings are expected to support the development of evidence-based interventions to strengthen patient-centered TB services and accelerate progress toward TB elimination in the country.

2. Methods

2.1. Study design and setting

We conducted a cross-sectional analytical study to assess barriers to accessing tuberculosis (TB) services among patients diagnosed with pulmonary TB in the Democratic Republic of Congo (DRC). This

study formed part of a larger survey investigating the prevalence of tuberculosis–diabetes comorbidity. Data were collected between March and April 2024 in four of the six provinces covered by the USAID SASA IVI Elimination Project (SIEP), which were purposively selected to capture diverse geographical settings and health service delivery contexts.

The SIEP project was implemented by SANRU Asbl, in collaboration with the National Tuberculosis Program (NTP), with financial support from the United States Agency for International Development (USAID). The project aimed to contribute to national and global efforts to end TB by strengthening TB prevention, early case detection, diagnosis, treatment, community-based interventions, health system capacity, and operational research.

2.2. Study population and participant selection

The study included adult patients (≥ 18 years) receiving TB care in SIEP-supported health facilities. Eligible participants had bacteriologically confirmed pulmonary TB diagnosed by sputum smear microscopy (Ziehl–Neelsen) or Xpert MTB/RIF within the six months preceding the survey in order to minimize recall bias. Patients diagnosed with extrapulmonary TB were excluded because they may experience different pathways and barriers to healthcare access.

2.3. Sampling procedure

A multistage cluster sampling design was employed to obtain a representative sample of adult patients receiving tuberculosis (TB) care in health facilities supported by the USAID SASA IVI Elimination TB Project (SIEP). This sampling approach was selected to ensure adequate geographical representation while accounting for the hierarchical organization of TB services within the study area. In the first stage, four of the six provinces covered by the SIEP project were purposively selected to capture diverse epidemiological, geographical, and health service delivery contexts. Within these provinces, a comprehensive sampling frame of all 390 SIEP-supported health facilities providing TB diagnosis and treatment services was established using the National Tuberculosis Program (NTP) database. Health facilities were then selected using probability proportional to size (PPS) sampling, with the number of adult pulmonary TB patients registered at each facility serving as the measure of size. This approach ensured that facilities with larger patient populations had a greater probability of selection while maintaining representativeness across facilities of different sizes. Overall, 37 health facilities were randomly selected. During the second sampling stage, an updated list of all eligible adult patients with bacteriologically confirmed pulmonary TB was obtained from the TB treatment registers of each selected health facility. Eligibility was verified by reviewing clinical records before participant selection. Patients were included if they were aged 18 years or older and had received a confirmed diagnosis of pulmonary TB by sputum smear microscopy (Ziehl–Neelsen staining) or Xpert MTB/RIF assay within the six months preceding the survey. Restricting inclusion to recently diagnosed patients minimized recall bias regarding their healthcare-seeking experiences. Patients diagnosed with extrapulmonary TB were excluded because their diagnostic pathways and healthcare experiences differ substantially from those of pulmonary TB patients. Simple random sampling was subsequently performed within each selected

facility to recruit approximately 13 eligible participants. Where the number of eligible patients was fewer than the planned sample size, all eligible patients were invited to participate. Using this procedure, 478 patients were initially selected, of whom 449 completed the interview, corresponding to a response rate of 94.0%.

2.4. Data collection

Data collection was conducted between March and April 2024 by a team of trained research assistants with prior experience in TB surveys. Before field implementation, all interviewers participated in standardized training covering the study objectives, eligibility assessment, participant recruitment procedures, administration of the questionnaire, ethical principles, informed consent procedures, confidentiality, and electronic data capture. A pilot exercise was conducted before the survey to ensure consistency in questionnaire administration and to identify operational challenges. Selected participants were primarily recruited during their routine visits to health facilities for directly observed therapy (DOT), scheduled clinical consultations, or medication refills. Patients who did not have scheduled appointments during the data collection period were contacted through healthcare providers or community health workers and, after obtaining their agreement, were interviewed at home. This strategy minimized non-response and ensured inclusion of patients who might otherwise have been missing because of irregular attendance at health facilities. Data were collected using a standardized structured questionnaire programmed in Open Data kits (ODK) and administered electronically on password-protected tablet computers. The use of electronic data captures reduced transcription errors, improved data completeness through automated consistency checks and skip patterns, and enabled secure daily synchronization of collected data. The questionnaire was developed specifically for this study based on the objectives of the research and a review of the literature on barriers to TB care. It comprised six major sections: (i) sociodemographic and socioeconomic characteristics; (ii) knowledge of tuberculosis transmission, symptoms, prevention, and treatment; (iii) awareness of available TB services; (iv) attitudes and perceptions toward TB and TB-related stigma; (v) barriers encountered during clinical assessment, diagnostic testing, and treatment initiation; and (vi) healthcare-seeking practices and treatment adherence. Most questions consisted of predefined response categories, although selected items allowed multiple responses to capture the complexity of barriers experienced by participants. Each interview lasted approximately 30–40 minutes and was conducted in a private setting to ensure confidentiality and encourage honest responses. Interviews were conducted in French or translated into the participant's preferred local language by trained interviewers whenever necessary. At the end of each interview, questionnaires were reviewed for completeness before being uploaded to a secure, password-protected server accessible only to authorized members of the research team. Daily quality-control procedures, including verification of data completeness, consistency, and duplicate records, were performed throughout the data collection period under the supervision of the study coordinators.

2.5. Statistical analysis

Data was analyzed using Stata version 18 (StataCorp, College Station, TX, USA). Analyses accounted for the complex two-stage sampling design by applying sampling weights and adjusting standard errors for

clustering at the health facility level. Complete-case analysis was performed by excluding observations with missing values for variables included in the analyses. Categorical variables are presented as weighted proportions with corresponding standard errors and 95% confidence intervals (95% CI), while continuous variables are summarized using weighted means with standard errors and 95% confidence intervals.

2.6. Ethical considerations

The study protocol was reviewed and approved by the Ethics Committee of the Protestant University of Congo (Reference No. CEUPC 0112). Written informed consent was obtained from all participants before enrolment, and confidentiality and anonymity were ensured throughout data collection, management, and analysis.

3. Results

3.1. Participant characteristics

Among the 1,820 eligible adult patients with pulmonary tuberculosis identified across the 37 selected health facilities, 478 were randomly selected for participation. Of these, 449 consented and completed the interview, yielding an overall response rate of 94.0%. Among the 29 non-respondents, the main reasons for non-participation were death before the interview (n = 16), inability to locate the selected patient (n = 11), and relocation outside the study provinces (n = 2).

The sociodemographic characteristics of the study population are presented in Table 1. Overall, participants were predominantly male (60.4%), lived in rural areas (70.0%), and were married (67.2%). Approximately one-third (32.2%) were aged 50 years or older, while 49.8% had at least secondary education. More than half of participants were unemployed (55.2%), three-quarters reported a monthly household income below US$100 (75.0%), and nearly two-thirds belonged to the low socioeconomic group (63.6%). Household size was generally large, with 84.6% of participants living in households comprising five or more members.

Table 1
Sociodemographic characteristics of the study population

Variables	Frequency, unweighted n = 449	%, weighted	Standard error
Residence			
Rural	274	70.0	4.2
Urban	175	30.0	4.2
Age			
18–29	114	22.6	3.1
30–39	116	27.2	2.6
40–49	95	18.0	2.0
≥ 50	124	32.2	3.4
Sex			
Female	184	39.6	4.0
Male	265	60.4	4.0
Marital status			
Cohabiting	20	5.6	2.5
Single/never married	69	14.2	1.7
Divorced/widow	52	12.9	3.9
Married	308	67.2	5.2
Education level			
Primary or less	225	51.6	4.1
Secondary	189	43.7	3.9
University	23	4.7	2.1
Occupation			
no occupation	249	55.2	6.5
has an occupation	200	44.8	6.5
Income level			
< 100$	341	75.0	4.9
≥ 100$	108	25.0	4.9

Variables	Frequency, unweighted n = 449	%, weighted	Standard error
Socioeconomic status			
Low	312	63.6	8.2
Medium	126	33.4	7.7
High	11	3.0	1.4
Household size			
< 5 personnes	84	15.4	2.6
5–9 personnes	261	58.8	3.4
> 9 personnes	104	25.8	3.4
Religion			
Other	28	7.0	1.9
Catholic	134	27.4	2.4
No religion	20	3.8	1.7
Protestant	109	25.0	5.0
Evangelical	158	36.8	3.9

3.2. Knowledge and attitudes toward tuberculosis

Participants demonstrated variable levels of knowledge regarding tuberculosis (Table 2). Although almost all respondents recognized TB as a curable disease (96.4%), only 42.2% correctly identified bacteria as its causative agent. Misconceptions remained common, with participants attributing TB to smoking (16.4%), alcohol consumption (15.4%), viral infection (10.4%), or other incorrect causes such as poor hygiene, pollution, inherited factors, or exposure to cold air (15.6%). Knowledge of TB transmission was generally high, with 89.9% correctly identifying airborne transmission through coughing. Nevertheless, misconceptions regarding transmission persisted, as many respondents incorrectly believed that TB could be transmitted through sharing food (71.5%), sharing utensils (64.9%), or sexual contact (45.8%). Recognition of TB symptoms was relatively good. Chest or back pain (84.5%) and persistent cough lasting more than two weeks (80.6%) were the most frequently reported symptoms, followed by persistent fever (69.3%), weight loss (67.6%), and night sweats (59.6%). Awareness of available TB services was uneven. While more than nine out of ten participants knew that TB treatment was provided free of charge (92.3%), fewer than half (40.3%) were aware that TB screening services were also free. Regarding attitudes toward TB, 75.4% perceived TB as a very serious disease, 82.5% stated that they would be willing to work with someone successfully treated for TB, and 86.9% agreed that people affected by TB have the same right to healthcare services as other patients. However, 13.9%

reported concealing their diagnosis from relatives or friends, suggesting that stigma remains an important concern.

Table 2
Knowledge of and attitudes towards TB and TB care available in the country

Variables	Frequency, unweighted (n = 449)	%, weighted	Standard error
Causes of TB			
Alcohol	49	15.4	3.7
Smoking	49	16.4	4.8
Germ/bacteria	141	42.2	8.0
Virus	33	10.4	2.7
Others (inherited, bad hygiene, pollution, cold wind, unspecified causes)	53	15.6	4.5
Mode of TB transmission*			
Airway when coughing	407	89.9	2.4
Sharing utensils	282	64.9	5.8
Through food	317	71.5	4.6
Sexual contact	208	45.8	6.3
Symptoms of TB*			
Chest and back pain	391	84.5	3.7
Cough lasting more than 2 weeks	353	80.6	6.6
Persistent fever	315	69.3	6.6
Weight loss	300	67.6	7.3
Night sweats	277	59.6	8.8
How serious is TB?			
Not serious	31	7.9	1.9
Very serious	329	75.4	5.0
Somewhat serious	63	16.7	3.6
Is TB a curable disease?			
Yes	433	96.4	0.8
No	16	3.6	0.8
* Multiple responses were allowed			

Variables	Frequency, unweighted (n = 449)	%, weighted	Standard error
Did you hide your tuberculosis diagnosis from your family members or friends?			
No	369	86.1	3.2
Yes	78	13.9	3.2
Would you be willing to work with someone who has already been treated for tuberculosis?			
No	78	17.5	3.8
Yes	363	82.5	3.8
Agreement with key statements about TB care*			
TB screening is available for free in the DRC	181	40.3	7.6
TB treatment is available for free in the DRC	416	92.3	2.2
People with TB have the right to access healthcare like any other patients	387	86.9	3.1
* Multiple responses were allowed			

3.3. Perceived barriers to accessing TB services

Participants reported multiple barriers affecting access to TB services throughout the care cascade (Table 3). Economic constraints emerged as the predominant obstacle at every stage of care. Before seeking clinical assessment, 70.1% perceived TB services as too expensive, 68.7% believed that their symptoms did not require medical attention, 63.1% lacked financial resources for transportation or other related expenses, and 60.2% reported not knowing where to seek care. More than half also cited long distances to health facilities (57.6%) and perceived discrimination against TB patients within healthcare settings (59.7%). A similar pattern was observed for diagnostic testing. Approximately two-thirds of participants reported financial barriers related to service costs (66.5%) and transportation expenses (62.6%), while 65.3% indicated insufficient knowledge about where to obtain testing. Geographic accessibility remained problematic, with 57.0% reporting excessive distance to health facilities. In addition, 43.3% feared stigma, 41.4% required permission from family or community members before seeking testing, and 38.6% reported that TB testing was unavailable at the health facility. Barriers to treatment initiation and continuation closely resembled those reported during earlier stages of care. The most common obstacles included perceived treatment costs (70.9%), transportation expenses (64.3%), underestimation of symptom severity (62.6%), insufficient information about available services (60.5%), and long travel distances (54.4%). More than half of participants (51.1%) reported self-medication before treatment initiation, while approximately 40% reported concerns about medication availability or lack of

trust in healthcare providers. Across all stages of the care cascade, stigma, concerns regarding confidentiality, and limited social autonomy consistently emerged as important barriers.

Table 3
Perceived and experienced barriers when accessing TB screening, testing, and treatment services

Variables	Frequency, unweighted (n = 449)	%, weighted	Standard error
Participants who agreed with the following statements about TB clinical diagnostic: "Before I seek help for TB symptoms..."*			
I thought the services were too expensive	312	70.1	4.7
I didn't think the symptoms required care or treatment	296	68.7	5.8
I had no money for transportation or other expenses	277	63.1	6.0
I didn't know what to do or where to go	278	60.2	5.6
I thought people with tuberculosis were not welcome in health facilities	252	59.7	6.3
The health center was too far away	247	57.6	5.6
I feared being stigmatized or abandoned by my friends, family, church, or other community members.	200	47.2	7.0
I didn't have time	193	46.7	7.2
I was concerned about the lack of privacy/confidentiality	179	44.3	6.8
I did not trust the healthcare facility/provider	167	41.1	8.0
Participants who agreed with the following statements about TB testing: "Before I got tested for tuberculosis…"*			
I thought the services were too expensive	285	66.5	5.3
I didn't know what to do or where to go	289	65.3	5.5
I had no money for transportation or other expenses	272	62.6	5.1
I didn't think the symptoms required care or treatment	275	62.0	6.0
The health center was too far away	240	57.0	5.7
I didn't have time	189	47.9	7.3
I feared being stigmatized or abandoned by my friends, family, church, or other community members	187	43.3	8.0
I needed permission from family members, friends, religious leaders, or other community members	181	41.4	7.9

* Multiple responses were allowed

Variables	Frequency, unweighted (n = 449)	%, weighted	Standard error
I was concerned about the lack of privacy/confidentiality	174	40.5	7.4
Testing was not available at the health facility	162	38.6	8.5
Participants who agreed about the following statements about TB treatment: "Before starting anti-tuberculosis treatment or during anti-tuberculosis treatment…"*			
I thought the services were too expensive	300	70.9	5.2
I didn't have money for transportation or other expenses	270	64.3	5.7
I didn't think the symptoms required care or treatment	271	62.6	5.6
I didn't know what to do or where to go	275	60.5	5.1
The health center was too far away	228	54.4	6.1
I tried to self-medicate	215	51.1	6.9
I didn't have time	186	46.8	8.0
I feared being stigmatized or abandoned by my friends, family, church, or other community members	195	46.5	7.6
I was concerned about the lack of privacy/confidentiality	174	44.2	7.7
I needed permission from family members, friends, religious leaders, or other community members	177	42.4	8.1
I didn't trust the health facility/provider	160	40.0	8.4
I thought or heard that medications were not available at the health facility	158	39.6	8.6
* Multiple responses were allowed			

3.4. Care-seeking practices and treatment

Healthcare-seeking practices are summarized in Table 4. Following symptom onset, 72.1% of participants sought care directly from a health facility, whereas 27.9% initially relied on alternative sources, including self-medication, traditional healers, or religious leaders.

Timeliness of healthcare seeking varies considerably. Overall, 62.5% sought care immediately or within one week after symptom onset, whereas nearly one-quarter delayed seeking care for more than one month. The most frequently reported reasons for eventually attending a health facility were failure of initial treatments (27.3%), advice from relatives or community members (22.4%), persistence of

symptoms for several weeks (22.0%), and recognition that symptoms might be related to TB (15.9%). Once TB was clinically suspected, access to diagnostic testing was relatively prompt, with 88.8% undergoing testing immediately or within one week following clinical evaluation. Similarly, after laboratory confirmation, 88.3% initiated anti-tuberculosis treatment within one week. Regarding treatment adherence practices, 80.4% reported taking their medications once daily as prescribed, whereas 19.6% reported taking them either less or more frequently than recommended. Medication refill schedules also varied considerably: 43.7% attended health facilities daily or almost daily, 31.8% collected medicines weekly, and approximately one-quarter refilled their medications only once or twice per month or even less frequently. When experiencing health problems during treatment, most participants (80.5%) indicated that they would seek care from a health facility or a community health worker. Reliance on alternative sources of care, including pharmacies, relatives, religious leaders, or traditional healers—was uncommon, with each accounting for fewer than 6% of responses (Table 4).

Table 4
Practices related to tuberculosis care seeking and treatment

Variables	Frequency, unweighted (n = 449)	%, weighted	Standard error
Where did you first go for advice or help when you started developing symptoms of tuberculosis?			
Health facility	328	72.1	4.7
Self-medication from pharmacies or other sources	56	13.6	3.3
Traditional healer	33	7.7	2.4
Religious leader	28	6.2	1.8
Other	1	0.4	0.4
Why did you decide to go to the health facility after you developed the first symptoms of tuberculosis?			
The treatment I was receiving was not working	68	27.3	7.1
I was told to go to the health center	83	22.4	4.2
Symptoms lasted for 3–4 weeks without improving	77	22.0	4.5
I realized that my symtpoms might be linked to tuberculosis	64	15.9	3.3
My health was worsening	35	12.3	2.2
How long after you first started experiencing symptoms of tuberculosis did you go to a health facility for those symptoms?			
Soon after/immediately	145	35.9	6.0
Within a week	110	26.6	3.7
Within a month	75	15.5	2.9
One or two months later	72	13.6	3.2
More than two months later	42	8.4	1.8
When you first saw a provider who thought you might have TB, how soon after did you go to a lab to get tested or provide a saliva sample for testing?			
Soon after/immediately	221	52.2	6.6
Within a week	169	36.6	5.3
Within a month	42	8.0	1.8

Variables	Frequency, unweighted (n = 449)	%, weighted	Standard error
One or two months later	16	2.9	1.1
More than two months later	1	0.4	0.4
How long after being informed that your TB test was positive did you go to the health facility to start TB treatment?			
Soon after/immediately	228	53.0	6.4
Within a week	163	35.3	4.9
Within a month	47	9.2	2.3
One or two months later	10	2.4	1.0
More than two months later	1	0.1	0.1
How often do you go to the health facility to pick up your tuberculosis medications?			
Everyday or almost everyday	164	43.7	6.4
Once per week	140	31.8	5.1
Once or twice per month	138	23.1	5.7
Once every other month	5	1.4	0.9
How often do you take your tuberculosis medications?			
Once per day	379	80.4	6.0
Less frequently than once per day	38	12.6	4.7
More frequently than once per day	29	6.9	1.7
If you had health problems while receiving tuberculosis treatment, where would you seek help?			
Health facility or community health worker	358	80.5	4.3
Friends or family members	27	5.7	2.7
Pharmacy	21	5.4	2.3
Religious leader/church	27	5.3	1.8
Traditional healer	11	2.1	0.8
Internet/media	3	0.9	0.5
Other	1	0.1	0.1

4. Discussion

This study provides comprehensive evidence on barriers affecting access to tuberculosis (TB) services across the care cascade in the Democratic Republic of Congo (DRC). Four principal findings emerged. First, participants demonstrated limited knowledge of TB, with widespread misconceptions regarding its causes and transmission. Second, socioeconomic barriers, including perceived healthcare costs and transportation expenses, were the most frequently reported obstacles at every stage of the TB care cascade. Third, stigma, geographical inaccessibility, and limited awareness of available TB services continue to delay care seeking. Finally, although most patients-initiated diagnosis and treatment rapidly once they entered the healthcare system, a considerable proportion delayed seeking formal healthcare after symptom onset or initially relied on informal sources of care.

The limited knowledge of TB observed in this study is consistent with previous evidence from the DRC showing persistent misconceptions surrounding TB transmission, causes, and treatment [10]. Fewer than half of participants correctly identified bacteria as the cause of TB, while many attributed the disease to smoking, alcohol consumption, or other incorrect causes. Such misconceptions are particularly concerning because they may reduce risk perception, delay healthcare seeking, and contribute to continued community transmission. Encouragingly, most participants recognized TB as a curable disease and understood its airborne transmission, suggesting that previous awareness campaigns have achieved partial success. However, the low level of awareness regarding the availability of free TB screening services indicates that health education efforts should place greater emphasis on improving public understanding of the complete package of TB services available within the National Tuberculosis Program.

Stigma remains another major obstacle to TB care. Nearly half of participants reported fear of stigma and discrimination during healthcare seeking, while a proportion admitted concealing their diagnosis from relatives or friends. These findings support previous observations that TB remains strongly associated with HIV infection and social exclusion in the DRC [10]. Anticipated stigma may discourage individuals from seeking early diagnosis, disclosing symptoms, or adhering to treatment, thereby perpetuating community transmission. Addressing stigma therefore requires interventions beyond the health sector, including community engagement, culturally appropriate communication strategies, and involvement of TB survivors as advocates to normalize discussion of the disease and reduce discrimination. Economic barriers emerged as the dominant challenge throughout the TB care cascade. Although TB diagnosis and treatment are officially provided free of charge, most participants perceived TB services as expensive and reported transportation costs and other indirect expenditures as major barriers. Similar findings have been reported in Ethiopia and other low- and middle-income countries, where transportation expenses, income loss, and other out-of-pocket costs substantially reduce access to TB services [7, 13]. These results emphasize that eliminating user fees alone is insufficient to achieve equitable access. Patient-centered social protection measures, including transportation support, decentralization of TB services, and community-based service delivery, should be considered to reduce the financial burden experienced by affected households. Geographical accessibility also represented an

important barrier. More than half of participants reported long distances to health facilities, reflecting the unequal distribution of healthcare infrastructure previously documented in the DRC [6, 8, 9]. Geographic barriers often interact with poverty, resulting in cumulative disadvantages for rural populations who must travel long distances while simultaneously bearing transportation costs and income losses. Expanding community-based TB services, strengthening referral networks, and integrating TB activities into primary healthcare could substantially improve timely access to diagnosis and treatment. Our findings further demonstrate that these barriers translate into delayed healthcare seeking. Nearly one-third of participants initially sought care outside the formal healthcare system, relying on self-medication, traditional healers, or religious leaders before attending a health facility. Furthermore, approximately one-fifth delayed seeking formal care for more than one month after symptom onset. These observations are consistent with evidence from a systematic review showing substantial patient delays before TB diagnosis across low- and middle-income countries [14]. Such delays increase disease transmission, worsen clinical outcomes, and compromise national TB control efforts. The persistence of delayed care seeking highlights the importance of strengthening community-based interventions. Active case-finding strategies involving community health workers, former TB patients, and community volunteers have demonstrated effectiveness in increasing case detection, improving linkage to care, reducing stigma, and shortening diagnostic delays [1, 14, 15]. In the DRC, expanding these approaches, together with targeted health education campaigns and community support groups, could substantially improve early diagnosis and treatment initiation while addressing the multiple barriers identified in this study. Although most participants initiated treatment rapidly after laboratory confirmation, gaps remained in treatment adherence and medication refill practices. Nearly one-fifth of participants reported taking TB medications either less or more frequently than prescribed, while approximately one-quarter collected medications only monthly or less frequently. These findings suggest that important barriers persist even after treatment initiation. Previous studies have shown that treatment adherence is strongly influenced by educational attainment, socioeconomic conditions, patient-provider relationships, and treatment literacy [16]. Additional research is needed to better understand the determinants of treatment adherence in the DRC and to develop interventions that improve long-term treatment completion. Overall, our findings emphasize that barriers to TB care are multidimensional and interconnected. Financial hardship, geographical inaccessibility, inadequate knowledge, and stigma interact to delay care seeking and reduce timely access to diagnosis and treatment. Consequently, interventions targeting a single barrier are unlikely to achieve substantial improvements. Comprehensive patient-centered strategies combining health education, social protection, decentralization of TB services, community engagement, and health system strengthening are more likely to accelerate progress toward the End TB Strategy.

Strengths and limitations

This study has several strengths. It included a large sample of bacteriologically confirmed TB patients recruited through a probability-based multistage sampling design across multiple provinces, increasing the representativeness of the findings within the study area. Standardized electronic data collection procedures and weighted analyses accounting for the complex sampling design further strengthened the validity of the estimates.

Nevertheless, several limitations should be acknowledged. First, the cross-sectional design precludes causal inference between identified barriers and healthcare-seeking behaviours. Second, participants were limited to patients with recently diagnosed pulmonary TB who had already accessed TB services; therefore, the findings cannot be generalized to individuals who never reached the healthcare system or to patients with extrapulmonary TB. Third, some variables relied on participants' recall of events preceding diagnosis, making recall bias possible despite restricting eligibility to patients diagnosed within the previous six months. Fourth, social desirability bias may have influenced responses concerning knowledge, attitudes, and treatment practices, although confidentiality assurances and standardized interviewing procedures were used to minimize this risk. Finally, because the study was conducted in provinces supported by the SIEP project, the findings may not fully reflect barriers experienced in provinces with different health system capacities or TB program implementation.

Conclusion

This study demonstrates that patients with tuberculosis in the Democratic Republic of Congo continue to face substantial and interconnected barriers throughout the TB care cascade. Limited knowledge of TB, persistent misconceptions, financial hardship, geographical inaccessibility, stigma, and health system constraints collectively contribute to delayed healthcare seeking and hinder timely diagnosis and treatment.

These findings underscore the need for comprehensive, patient-centered interventions that simultaneously address demand- and supply-side barriers. Strengthening community-based health education, expanding active case-finding strategies, reducing the indirect costs of care, improving the geographical accessibility of TB services, and reinforcing health system capacity are essential to promote equitable access to quality TB care. Community engagement initiatives, including the involvement of TB survivors, behavioral change communication, and community feedback mechanisms, may further reduce stigma, improve treatment adherence, and enhance case detection.

Addressing these multiple barriers through coordinated multisectoral action will be critical to improving the performance of the TB care cascade and accelerating progress toward the End TB Strategy in the Democratic Republic of Congo.

Declarations

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Ethics approval and consent to participate

This study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki and national guidelines for research involving human participants in DRC. Ethical approval for the pilot project and the use of programmatic routine data for research purposes was obtained from the Institutional ethics committee of the Université Protestante au Congo (**Réf: CEUPC:0204**). Administrative authorization was granted by the Ministry of Health and the Provincial Health Divisions in the selected provinces. All participants provided informed consent prior to inclusion in the study. Confidentiality and anonymity of participants were strictly ensured throughout the data collection and analysis process.

Consent for publication

Not applicable

Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Authors' contributions

All authors have read and approved the final manuscript. **Conceptualization:** Philippe Lukanu Ngwala (PLN); **Methodology:** PNL, ANN, DB; **Investigation (data collection):** JNT, MMS, NNM, IKK, AKN, ANK, FKM ; **Formal analysis:** ANN, DB; **Resources (funding acquisition, materials):** JLL, PLN; **Data curation:** ANN ; **Writing – original draft:** PNL, ANN, DB; **Writing – review & editing:** All authors; **Visualization (figures/tables):** ANN, PNL, **Supervision:** PLN, JLL, JFN; **Project administration:** PNL

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Competing interests.

The authors declare no competing interests.

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Supplementary Files

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