Investigating Barriers and Challenges to Tuberculosis Service Delivery in Hard-to-Reach Riverine Areas: A Mixed-Methods Study in the Niger Delta Region of Nigeria

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Abstract

Background Little is known about the challenges and barriers to tuberculosis (TB) service delivery in hard-to-reach riverine populations in Nigeria. The missing TB cases in such key populations need to be found if the End TB targets are to be met. This study explored perceptions and attitudes related to TB, as well as the level of diagnostic and treatment delays in communities of the riverine Niger Delta.

Methods This was an exploratory mixed-methods study carried out in two states (Bayelsa and Delta) situated in the Niger Delta region in Nigeria. It consisted of quantitative surveys of community members and TB patients, FGDs with community members and KIIs with health care workers.

Results The questionnaire survey was completed by 597 community members (51.6% female) and 51 TB patients (56.9% female); 73 community members and 15 HCWs participated in FGDs and interviews respectively. Community members' mean [SD] knowledge and attitude scores were 6.1/10 [2.2] and 4.8/12 [1.9] respectively. Older age (>40y) (p=0.04) and regular income (p<0.001) were independent predictors of TB knowledge. Good TB knowledge (aOR 2.5; 95% C.I. 1.5 – 4.4) and formal education (aOR 5.8; 95% C.I. 1.3 – 25.6) were associated with positive TB attitudes. Patients' TB knowledge was similar at 6.8/8 [1.5]. Most (98.8%) respondents took >1 hour to access the nearest diagnostic centre. Mean patient-related and health system-related diagnostic delays were 16.3 and 3.7 weeks respectively. Mean treatment delay was found to be 0.5 weeks. Patient-related, financial, cultural and structural barriers were found to delay TB diagnosis and treatment in this environment. Belief in faith healing and herbal remedies, transport barriers, and negative HCW attitudes were prominent themes in FGDs. Problems transporting sputum samples and tracing mobile communities were primary HCW complaints.

Conclusions A number of barriers affect TB service delivery in hard-to-reach riverine communities in Nigeria. Our study suggests that an appropriately designed community intervention can improve TB service delivery in these communities. The main focus will be to address information asymmetry between service providers and the community, empower affected communities to find cases, engage informal providers such as patent medicine vendors, and strengthen the health system.

Background

Improving tuberculosis (TB) case detection has remained a global challenge. An estimated 10.4 million persons developed TB in 2017, however only 6.7 million new cases of TB were notified (1). India, Indonesia and Nigeria accounted for almost half (46%) of the total gap between TB incidence and reported cases worldwide (1). Therefore, there is a need to improve TB case detection in these and other high burden countries. The World Health Organization (WHO) and Stop TB Partnership have called for a paradigm shift on how TB services are organised, moving from passive to active case finding – particularly in key populations facing higher risk of TB (2-5). Furthermore, both agencies specify that TB testing and treatment services must reach at least 90% of these key populations by 2020 (5-7). Addressing barriers to TB service delivery among key populations is therefore critical to the overall goal of

ending the TB epidemic (2-5). TB key populations vary by country and include people with increased exposure to TB due to where they live or work, people with limited access to services due to social, economic or legal barriers, and people with increased risk of TB because of biological or behavioural factors (2-5).

Nigeria is also among 14 countries with high burden of TB, TB/HIV and multidrug-resistant TB (MDR-TB) [1]. In 2017, only about 24% of the estimated incident cases of TB in the country were notified [1]. To address this, a number of systematic TB screening strategies have been carried out in Nigeria targeting the general population, TB contacts, persons living with HIV (PLHIV), children, urban and mobile populations (6-10). In Nigeria's riverine areas, limited land mass leads to uneven distribution of health facilities in the area and residents require costly marine transport – where a return trip may cost up to US$30 to access appropriate health services (11). As such, people living in riverine areas have limited access to quality TB services and many are highly mobile (fisher folk and traders) further complicating TB diagnosis. The most common occupation in riverine areas is fishing and these rural areas are served by itinerant traders who trade with the fisher folks (12).

In 2015, Nigeria's case notification rate (CNR) was 54 per 100 000 population. In the riverine populations of the Niger Delta, the CNR was 9 per 100 000. Previous studies in Brazil and Nigeria have also shown very low TB case detection rates in riverine compared to inland areas (13, 14). A study conducted in 2016 has shown poor knowledge of TB among women living in the Atlantic coastline of Nigeria (15). Studies conducted in rural and coastal regions of Nigeria have found that financial constraints, distance and poor knowledge are major barriers to accessing TB services (16-18). Lack of accessibility to services, and poor knowledge of TB may contribute to the high rate of Nigeria's missing TB cases. Furthermore, low case detection rates, high mortality rates and stigma may also be contributing factors. Previous studies in Nigeria have illustrated challenges faced by TB patients, however little is known about TB in the communities of the Niger delta. There is also a lack of accurate data of the TB burden in these populations.

In 2017, GLRA received a TB REACH Wave 5 grant to implement a community-driven, output-based approach to intensified TB case finding in 6 Local Government Areas (LGAs) in the Niger Delta. The project sought to use existing community structures to raise awareness about TB and improve access to TB diagnostic, treatment and preventive services. The first part of the project was to gain a baseline understanding of the barriers to accessing TB diagnosis and care hence this study.

The aim of the study was to explore the understanding, perceptions and attitudes related to TB, as well as assess level of diagnostic and treatment delays in communities of the riverine Niger Delta. Understanding the barriers to TB service delivery in the intervention communities was important in designing interventions to increase case detection rates as well as generate local evidence for further policy making by the National TB Control Programme in Nigeria.

Study population and sampling

To achieve 50% prevalence of good knowledge, 95% confidence level and a precision of 5%, we estimated a minimum sample size of 384 for the community member survey. To ensure higher precision, we interviewed 600 community members (100 per LGA). This number was based on feasibility of data collection. As all LGAs have approximately the same population, equal number of community members were sought from each LGA.

The semi-structured questionnaire interviews were carried-out among community members and TB patients who were receiving treatment in the study area. The community survey utilised simple random sampling to select households based on the census enumeration area for each LGA. In each selected household, the head of the household (or next eligible person) was recruited until the desired sample size was reached. Community members who participated in this survey were different from those who participated in the FGD.

To avoid intervention bias, only patients who were receiving/have received treatment in all the TB treatment centres in the study area within 6 months prior to the implementation of the project (i.e. December 2016) were selected for the patient survey.

For the community health care worker (HCW) interviews, three engaged HCWs were purposively sampled from each LGA (total 18 interviews). This was chosen based on feasibility of data collection and also to ensure data saturation.

Instruments and data collection

The community survey was carried-out using pre-tested semi-structured interviewer-administered questionnaires adapted from USAID/TBCARE II (19). A scoring system was applied to assess the level of knowledge of each respondent: one point was awarded for each correct answer; no points were given for an incorrect answer (20). In addition, participants were asked to respond to questions related to their beliefs about and/or attitudes towards TB. A scoring system was also applied, with one point given for each positive answer and no points given for a negative answer (20).

The FGD and KII guides probed on how TB control services can be improved and the type of support needed in the community. For the qualitative study, FGDs were based on the Explanatory Model Interview Catalogue (EMIC) framework for cultural epidemiology (21). This framework was chosen to ensure internal/face validation of the FGD guide. The study instruments were reviewed by a group of academics, epidemiologists and public health physicians, social scientists and TB control specialists involved in the State Tuberculosis, Leprosy and Buruli ulcer Control Programmes of Delta and Bayelsa States who considered them to have face validity. The reviews led to the removal of sections of the original tool not related to this study (19). The instruments were developed in English, but interviews were conducted in Pidgin spoken by respondents in the study areas. The questionnaire was pretested among 20 adults in a rural community and 10 health care workers outside the study area and subsequently modified.

In total, 9 FGDs were held (five with males and four with females), consisting of 73 community members engaged in farming and fishing. Five of the FGDs were held among younger adults (18 – 40 years) and four were held among older adults (>40 years). In addition, 15 key informant interviews (KIIs) were conducted with Local Government TB & Leprosy supervisors - who coordinate TB control in their respective local government areas and the next most experienced TB health worker. The interviews drew on health workers' experiences with, and attitudes of TB patients who were diagnosed and treated in their Local Government Areas (LGAs).

Data analysis

The questionnaire data were checked and double-entered, cleaned and analysed using Epi Info 3.4.1 (CDC, Atlanta, GA USA). A knowledge score for TB was calculated for each participant. Respondents with a knowledge or attitude score of >50% were considered to have good knowledge or attitude, while those with ≤50% were considered to have poor knowledge or attitude to TB. Continuous variables were summarized as means ±SD, and categorical variables as proportions. Categorical variables were compared using the Chi Square (χ^2) test for proportions. Multivariable logistic regression analyses were performed to determine factors associated with good knowledge or attitude to TB. A p-value <0.05 was considered significant. The FGDs and KIIs were transcribed in English immediately after the interview and entered into a Microsoft word processing package. Four reviewers analysed the transcripts using thematic analysis. Analysis of transcripts proceeded based on coding and a framework for analysis; the meaning units were then built up into themes and subthemes and used to develop textual descriptions of the experiences. Disagreements in coding interpretation were reviewed and decided by consensus. For each key analytic theme, data extracts were identified on the basis of being representative or interesting illustrations of an emerging issue.

Ethics Statement

The study was approved by the health research ethics committee of the Delta State Ministry of Health, Asaba, Delta State Nigeria with reference number HC/218/VOL IV/134. Also, permission was obtained from the State TB, Leprosy and Buruli Ulcer Control Programme of Delta and Bayelsa State. A signed informed consent was obtained from all study participants. Participants were informed that their participation in the survey/interviews/FGD would not have any bearing on their medical care/access

Results

The response rates for community, patients and HCWs were 99% (597/600), 100% (51/51) and 83% (15/18), respectively. Community members and HCWs who did not participate were unable to do so due to timing constraints. Table 1 represents sociodemographic characteristics of all study participants. In the narrative below, community perspectives are presented followed by patient and HCWs perspectives.

Characteristics of the respondents

As shown in Table 1, within the community, more males 335 (56.1%) than females 262 (43.9%) were surveyed. Among TB patients this dynamic was reversed with slightly more females 29 (56.9%) than males 22 (43.1%) interviewed. Of the community members interviewed, 361 (60.5%) were aged ≤40 years while 51, 37 (72.5%) of the TB patients surveyed were aged ≤40 years. Secondary education was the highest education level achieved by 304 (50.4%) of community members and 33 (64.7%) of TB patients. Most community members and TB patients lived in rural settings and were from the Ijaw ethnic group. Farming was the most common occupation among community members (253, 42.4%), and 26 (51.0%) of TB patients were unemployed. For the TB patients, 50 (98.0%) had pulmonary TB and all were bacteriologically confirmed. Only TB patients were tested for HIV with 49 (96.1%) reporting as being HIV negative.

Nine FGD sessions comprising 73 adults (40 male; and 33 female) and KIIs were held with 15 health workers. All the participants for the FGD resided in the study area, and KIIs were held with health workers involved in providing TB services in the study communities.

Community perspective: facts and fiction

Knowledge of, and attitude towards TB: Table 2 illustrates the aggregate knowledge and attitude questionnaire scores by community members. The overall mean [SD] knowledge score was 6.1 [2.2] (maximum 10). A total of 391 (65.5%; 61.5 – 69.3%) of the respondents had good knowledge of TB. Older (>40 years old) respondents had a higher overall knowledge of TB compared to younger (≤40 years old) participants (71.2% vs. 61.8%; p=0.018).

However, during the FGDs with both younger and older community members, it was mentioned that TB is transferrable through sharing utensils, eating with a person with TB, and is caused by excessive drinking and/or smoking as well as contaminated foods or water.

"[TB] is a transferable disease caused by cough, you can get it by sharing utensils".

Male FGD participant (18-29 age group), Brass

In two FGDs, participants mentioned witchcraft and spiritual attacks as a cause of TB. Patients in all nine FGDs identified cough as a cause for TB and weight loss was mentioned by participants of eight FGDs.

The mean (SD) attitude score was 4.8±1.9 (maximum 12) suggesting that generally they had a poor attitude towards TB. A total of 492 (82.4%; 79.15 – 85.26) had poor attitude towards TB. Only 105 (17.6%; 14.7 – 20.9%) of the community members had appropriate attitude towards TB. When asked about attitudes and beliefs, community members believed that the onset of TB would result into job loss, but most did not think that women with TB will be infertile.

Access to TB services and health-seeking behaviour for tuberculosis: Community members' access to TB diagnostic services and their perceived health-seeking behaviour for TB symptoms are shown in Table 3. Only 161 (27.0%) of the community members had received some information about TB in the six months

preceding the survey by healthcare providers 75 (46.6%), mass media 43 (26.7%), family/friends 20 (12.4%) and religious places 12 (7.5%). Overall, 589 (98.7%) of the community members reported that it would take them an hour or more to get to the nearest health facility that diagnoses and treats TB in their community. Also, 356 (59.6%) of the community members reported having to pay for transportation to get to the health facility. Furthermore, 163 (27.3%) and 273 (45.7%) of the community members reported that they have to pay out-of-pocket to access a healthcare provider and laboratory services respectively in the health facility. Self-treatment (181, 30.3%), medicine vendors (86, 14.4%) and public clinic/hospital (120, 20.1%) were the most popular ways/sites of first visit for cough among surveyed community members.

FGD participants from South Ijaw and Ekeremor indicated that local chemists were their first point of care for TB. In these groups, visiting traditional healers and pastors or churches for treatment were also mentioned.

"Some people might go to meet their pastors to pray for them before going to the clinic. Believing that God is the solution to all problems, that is why they go to meet their pastors." Female FGD participant (aged 40 and over), Ekeremor

Perceptions around TB and gender: Across all communities, 348 (58.3%) of survey participants also thought men were more likely to get TB than women. When asked about attitudes and beliefs, community members believed that the onset of TB would result in job loss, but most did not think that women with TB will be infertile as is common in some other communities (22). Furthermore, 395 (66.2%) community members thought that women would need to ask permission from their husbands and/or relatives to access healthcare.

Delays in accessing TB services: The community members' perceived mean (±SD) patient delay was 2.2(±2.9) weeks (median; inter quartile range 1; 1 – 2 weeks). Also, the community members believed that presumptive TB patients in their community will require a mean (SD) 2.1(±1.2) health facility visits (median, IQR; 2, 1-3) to get a diagnosis of TB in their community. Also, their perceived mean (SD) delay from contact with the health system to receiving a diagnosis of TB was 5.7(±7.3) days (median, IQR; 3, 1 – 7 days), and the perceived mean (SD) treatment delay was 6.7(±13.7) days (median, IQR; 3, 1 -7 days).

Concerns about costs associated with TB treatment and care and lack of knowledge/understanding of the fact that TB treatment and care were provided for free were among the top causes of treatment delay according to most FGDs. In Patani, FGDs with both males aged over 40 and females aged 18-39 also indicated that shame could be a reason why some people with TB do not seek care.

"Some actually know the treatment is free, but they are still ashamed to go for treatment"

Female FGD participant (aged 18 to 39), Patani

In Southern Ijaw and Ekeremor, where traditional healers were mentioned, the FGD participants stated that getting native drugs and relying on native treatment first was the cause of delay for many.

In all, FGD themes such as the need for more awareness around TB in the community, bringing health centres and health workers closer to the communities with the most need to alleviate travel costs for patients, and the need to support people with TB in the community with travel allowances and treatment adherence services came through.

Factors impacting knowledge and attitude towards TB: Logistic regression analysis was used to understand factors associated with knowledge and attitude towards TB. Educational status (p = 0.028), residence (p = 0.006), ethnicity (p = 0.045), occupation (p = 0.008) and monthly household income status (p = 0.004) were associated with good knowledge of TB. In multivariable logistic regression analyses (see Table 4), only older age (adjusted odds ratio (aOR) 1.5, 95% CI 1.1–2.3), rural residence (aOR 2.4, 95% CI 1.7–4.0), Itsekiri ethnic group (aOR 3.0, 95% CI 1.1–8.8), and having a regular household income (aOR 2.4, 95% CI 1.4–3.9) were independent predictors of good knowledge of TB. Additionally, good knowledge of TB among the community members was associated with good attitude (p = 0.001). Furthermore, formal education (aOR 5.8, 95% C.I.1.3–25.6), Itsekiri ethnicity (aOR 6.1, 95% C.I. 1.6–23.6), and good knowledge (aOR 2.5, 95% C.I. 1.5–4.4) were independent predictors of positive attitudes for TB.

Patient Perspectives and Experiences

Knowledge of TB: The TB patients surveyed generally had a good knowledge of TB (Table S4). The overall mean (SD) knowledge score was 6.8±1.5 (maximum 8). Table 5 shows that that 13 (25.5%) patients didn't know that TB is caused by an infectious agent/germ and 12 (23.5%) didn't know that TB can be transmitted through inhalation of air droplet from affected persons. Overall, 45 (88.2%; 76.1 – 95.6%) of the patients had good knowledge of TB.

Perceptions of TB and access to TB care: Table 6 presents TB patient's perceptions of TB, where 29 (56.8%) of patients indicated that they felt scared when they found out they had TB; 40 (78.4%) said that they informed their family and friends that they had TB, and 30 (58.8%) patients did not feel discriminated against by the community. When asked about acquiring diagnosis, all patients reported having to travel longer than 1 hour to reach the health facility (Table 3) for diagnosis and treatment of TB; 37 (72.5%) had to pay for transportation to reach the facility and 33 (64.7%) found that the health facility had convenient hours of service. A total of 35 (68.6%) of the patients had received some information about TB in the six months prior to their diagnosis; and healthcare providers 23 (45.1%), and family/friends 14 (27.5%) were the major sources of information on TB.

Table 7 shows patients' health seeking behavior for TB. Fifty (98.0%) of patients reported taking a previous treatment prior to being diagnosed with TB, and 43 (84.4%) reported that their symptoms either worsened or remained the same. Patients had repeated visits with the same provider (22, 43.1%) as well as different providers within the same facility (16, 31.3%). When asked reasons for delaying seeking care, 35 (68.6%) of patients reported that they were not aware of the severity of the symptoms.

Diagnostic and treatment delay: The TB patients' mean [SD] delay from the onset of TB symptoms to visit to any health facility was 16.3 [18.7] weeks (median; inter quartile range 12; 4 – 24 weeks) with 32 (62.7%) of patients seeking care after four weeks of symptom onset. Also, the delay from the patient's first visit to any health facility until they were informed they had TB was a mean [SD] 3.7 [6.9] weeks (median, IQR; 1, 1 – 4 weeks). Thus, the overall mean [SD] diagnosis delay of the TB patients was 20.0 [21.7] weeks (median; inter quartile range 13; 5 – 25 weeks).

Thirty-eight (74.5%) of patients started treatment within three days of TB diagnosis. The mean [SD] treatment delay following a TB diagnosis was 3.5 [5.1] days (median, IQR; 1, 1 -4 days). Mean diagnosis delay did not differ among patients with good vs poor knowledge of TB (19.3 [18.9] vs 25.5 [35.2] weeks; p = 0.515). Furthermore, the mean diagnostic delay did not differ according to the patients' demographic characteristics (p>0.05), access to care (Table S5; p>0.05), and their health-seeking behavior (Table 7; p>0.05).

Health workers Perspectives

Causes of patient delay and assessment of resources: Fifteen KIIs with HCWs were conducted. The major themes emerging from these KII's regarding provider attitudes were: availability of materials for testing, provider trainings, challenges to testing, increasing knowledge of TB and motivating HCWs towards TB. HCWs mentioned that materials and drugs were not a problem for their facilities. All facilities had drugs provided by the state and materials were immediately available to conduct TB diagnostic testing and treatment. However, HCWs did mention some challenges to testing, specifically sputum transportation and communication of results post testing. HCWs focused largely on motivating HCWs towards TB. Some HCWs indicated that training personnel through institutions or Non-Governmental Organizations (NGOs) would be a good way to increase awareness of TB. Others indicated that incentives and providing salaries would help increase HCW motivation towards TB testing.

"If something (money) can be given to the DOTS workers, maybe quarterly, just to encourage them to be active, especially now that the Government does not pay salaries"

[KII TBLS Patani].

When asked regarding patient delay, HCWs noted that patients only come to them when they are in critical condition.

“They first go to spiritual homes and when they have tried all that without success, then they come to us” (KII Asst. TBLS Southern Ijaw).

“S*ince they think it’s a spiritual attack, some go to churches. Some use leaves, roots and herbs. They only come to the hospital when the sickness gets worse”* (KII Brass DOTS FP).

These themes were similar to those presented by the community as well as the TB patients above.

Discussion

This study reveals the contextual circumstances influencing the demand and supply of TB services in the riverine areas of Nigeria. It also suggests mechanisms that may inform their improvement.

In this study, we have shown that community members and TB patients in the Niger Delta region of Nigeria have above average knowledge of TB. Our results also demonstrate gaps in knowledge around aetiology of TB, mode of transmission of TB as well as where care is best sought to address the disease. These gaps may have led to negative community attitudes, and perceptions about TB as well as treatment delays. Some community members indicated that TB was due to witchcraft and sharing of utensils. Similar findings have been shown in studies conducted in Nepal, India and Lagos, Nigeria (23–25). These observations are also consistent with observations in other hard-to-reach rural populations where awareness of TB may be high but population level knowledge of the aetiology and mode of transmission of the disease is low [26–27]. In addition, we found that older age, residence, ethnicity and having a regular monthly household income predicted good knowledge of TB, and having a formal education and good knowledge predicted appropriate attitude towards TB. Improved TB case detection in hard-to-reach riverine populations of Nigeria can be achieved through undertaking appropriate health education programmes especially targeting the young, the poor and those living in rural areas.

This study also reveals inappropriate community attitudes, and poor patient perceptions about TB in hard-to-reach riverine areas. Most of the deficits in the community members’ attitude to TB centred on the most at-risk groups and gender differences in TB. In addition, we found that one-fifth of TB patients surveyed had not disclosed their illness status to their family members/friends, and 72.5% were afraid or depressed upon learning of their TB diagnosis. This poor attitude to, and poor perceptions of TB may be because of their lack of knowledge about the disease and the improper understanding that TB has

supernatural causes e.g., witchcraft. It is reassuring that good knowledge of the disease predicted better community attitude to TB.

Our study also shows that there is poor community access to TB services and poor health seeking by community members and TB patients in riverine areas.. Almost all the participants perceived that it will take a trip of over one hour to get to a TB diagnostic and treatment facility nearest to their community. All the TB patients surveyed also experienced this. In agreement with community members and patients, HCWs also identified accessibility as a major issue affecting delay in diagnosis of TB. Furthermore, HCWs noted that due to inaccessibility of health clinics, patients would visit them as a 'last resort'. Such challenges are common for other high-burden settings, where patients experience tremendous challenges to care, incurring catastrophic costs along the way (28). To address these barriers, implementers could look into conducting outreach interventions using motorboats. Use of incentives for individuals with presumptive TB, to compensate for travel costs, may assist in reducing the distance to health facilities and thus increase TB service uptake.

HCWs in facilities without TB diagnostic capacity experienced many challenges with sputum transportation, as well as tracing registered TB patients who were lost to follow-up. HCWs also noted that lack of incentives and salaries for staff may be affecting the number of staff working in TB. National programs may benefit from providing incentives to HCW to attract/retain staff working in TB thus increasing patient interactions and education/counselling of TB diagnosis/treatment.

In addition, this study showed that patient related delay was the greatest contributor to total delay. This is consistent with findings from a study in Nigeria, where patient related delay was the greatest contributor to total delay in TB diagnosis (29). Moreover, because TB services are not readily available in their communities and expensive marine transport is needed to get to where they are located, TB patients in riverine areas of Nigeria experience very long delays in TB diagnosis and treatment compared with the delays observed in other hard to reach populations in the country [17, 20]. Even when the community members / patients decided to seek care, they tended to favour informal health providers such as PMVs who are readily available and who charged lower fees. This finding emphasizes the need for increased education and trainings for community members on causes of TB, as well as the need to engage with PMVs and/or local chemists when planning TB case finding activities to bring services closer to hard-to reach populations.

A key strength of this study was that it was carried out in hard-to-reach riverine communities in the Niger Delta where very few TB case detection strategies are implemented and where little research has been previously conducted. In addition, data source triangulation strengthened the validity of our quantitative findings because it ensured wider representation of community experiences and views on TB in riverine areas thereby increasing its potential for relevance in other low-resource settings in Sub-Saharan Africa. Therefore, the findings of this study may serve as a guide to programme managers and health policymakers in designing culturally-sensitive community education and active TB case-finding interventions in riverine areas.

This study has a few limitations. Firstly, causal inferences were not possible based on the findings of our quantitative analysis. Second, the small sample size of the TB patients suggests that the findings of the bivariate analysis should be interpreted with caution. Third, there was possibility of interviewer and response bias where the research assistant or participant consciously or subconsciously gave cues or answers influenced by the other. Finally, there were no FGDs or KIIs with TB patients which is a potential limitation of the study, however, because of high discovered TB prevalence in the communities, community members could act as proxies for people with TB for the FGDs.

Conclusions

There are knowledge, access, cultural, structural and economic barriers that affect TB case detection and management in hard-to-reach riverine communities in Nigeria. Our study suggests that an appropriately designed community intervention can improve TB service delivery in these communities. The main focus will be to address information asymmetry between service providers and the community, empower affected communities to find cases, engage informal providers such as PMVs, and strengthen the health system. Also, there is a need for the National TB Programme in Nigeria to develop culturally-sensitive community TB education programmes in this setting which should address local misconceptions and interpretation of TB, early care-seeking, and should emphasise that the disease is curable in order to reduce fears encountered by affected persons.

Abbreviations

aOR - adjusted odds ratio

CNR - Case Notification Rate

EMIC - Explanatory Model Interview Catalogue

FGD – Focus Group Discussion

HCW – Healthcare Worker

KII – Key Informant Interview

LGAs - Local Government Areas

MDR-TB - Multidrug-resistant TB

NGOs – Non-Governmental Organizations

PLHIV - Persons living with HIV

SD – Standard Deviation

TB – Tuberculosis

TBLS – TB Leprosy Supervisor

WHO - World Health Organization

Declarations

Ethical approval and consent to participate

The study was approved by the health research ethics committee of the Delta State Ministry of Health, Asaba, Delta State Nigeria with reference number HC/218/VOL IV/134. Also, permission was obtained from the State TB, Leprosy and Buruli Ulcer Control Programme of Delta and Bayelsa State. A signed informed consent was obtained from all study participants. Participants were informed that their participation in the survey / interviews / FGD would not have any bearing on their medical care / access

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests

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Authors' contributions:

CA, JNC, CCN and CCE conceived the study; CA, JNC, CCN, AOM, NE and CCE designed the study protocol; all authors collected data, performed data entry and carried out the data analysis and interpretation; KNU, CA, JNC, TP, and MS, drafted the manuscript; All authors critically revised the manuscript for intellectual content. All authors read and approved the final manuscript.

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Availability of data and material

The dataset are available from German Leprosy & TB Relief Association (dahw.nigeria@dahw.org) upon reasonable request

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Tables

Table 1: Socio-demographic characteristics of community members (N = 597) and TB patients (N=51)

Variables	Community members n (%)	TB patients n (%)
Age group (years)		
≤40	361 (60.5)	37 (72.5)
>40	236 (39.5)	14 (27.5)
Gender		
Female	262 (43.9)	29 (56.9)
Male	335 (56.1)	22 (43.1)
Educational status		
No formal education	44 (7.4)	3 (5.9)
Primary	137 (22.9)	13 (25.5)
Secondary	304 (50.9)	33 (64.7)
Tertiary	112 (18.8)	2 (3.9)
Marital status		
Single	152 (25.5)	18 (35.3)
Married	400 (67.0)	26 (51.0)
Separated/Divorced	27 (4.5)	7 (13.7)
Widowed	18 (3.0)	
Residence		
Rural	493 (82.6)	50 (98.0)
Urban	104 (17.4)	1 (2.0)
Ethnic group		
Igbo	27 (4.5)	1 (2.0)
Ijaw	463 (77.6)	41 (80.4)
Itsekiri	45 (7.5)	7 (13.7)
Other	62 (10.4)	2 (3.9)
Occupation		
Public servant	111 (18.6)	2 (3.9)
Professional	48 (8.0)	-
House wife	27 (4.5)	1 (2.0)
Private sector	32 (5.4)	4 (7.8)
Farmer	253 (42.4)	18 (35.3)
Unemployed	126 (21.1)	26 (51.0)
Monthly household income		
Irregular income	244 (40.9)	10 (19.6)
No defined income	212 (35.5)	30 (58.8)
Regular income	141 (23.6)	11 (21.6)
Site of TB disease		
Pulmonary		50 (98.0)
Extrapulmonary		1 (2.0)
Type of TB diagnosis		
Bacteriological		50 (98.0)
Clinical		1 (2.0)
Human immunodeficiency virus status		
Negative		49 (96.1)
Positive		2 (3.9)

Table 2: Distribution of community' knowledge of, and attitude to tuberculosis according to their age-group (N = 597)

Variable	n (%; 95% C I)	≤40 years n (%; 95% C. I.)	>40 years n (%; 95% C. I.)	P-value
Total	597	361	236	
% knowledge score				0.008
≤ 30	76 (12.7; 10.2 – 15.7)	44 (12.2; 9.1 – 16.1)	32 (13.6; 9.5 – 18.6)	
31 – 50	130 (21.8; 18.6 – 25.3)	94 (26.0; 21.7 – 30.9)	36 (15.3; 10.9 – 20.5)	
51 – 70	223 (37.4; 33.5 – 41.4)	134 (37.1; 32.2 – 42.4)	89 (37.7; 31.5 – 44.2)	
> 70	168 (28.1; 24.6 – 32.0)	89 (24.7; 20.4 – 29.5)	79 (33.5; 27.5 – 39.9)	
Good knowledge (>50%)	391 (65.5; 61.5 – 69.3)	223 (61.8; 56.5 – 66.8)	168 (71.2; 65.0 – 76.9)	0.018
Poor Knowledge (≤50%)	206 (34.5; 30.7 – 38.5)	138 (38.2; 33.2 – 43.5)	68 (28.8; 23.1 – 35.0)	
% attitude score				0.074
≤ 30	154 (25.8; 22.4 – 29.5)	80 (22.2; 18.1 – 26.9)	74 (31.4; 25.5 – 37.7)	
31 – 50	338 (56.6; 52.5 – 60.6)	217 (60.1; 54.8 – 65.2)	121 (51.3; 44.7 – 57.8)	
51 – 70	87 (14.6; 11.9 – 17.7)	54 (15.0; 11.5 – 19.2)	33 (14.0; 9.8 – 19.1)	
> 70	18 (3.0; 1.9 – 4.8)	10 (2.8; 1.4 – 5.2)	8 (3.4; 1.5 – 6.6)	
Appropriate attitude (>50%)	105 (17.6; 14.7 – 20.9)	64 (17.7; 14.0 – 22.2)	41 (17.4; 12.8 – 22.8)	0.911
Poor attitude (≤50%)	492 (82.4; 79.15 – 85.26)	297 (82.3; 77.9 – 86.1)	195 (82.6; 77.2 – 87.2)	

95% C I = 95% confidence interval for the proportion;

Table 3: Community and patient opinions on access to TB diagnosis for presumptive TB patients

Variables	Community (n=597) n (%)	Patients (n=51) n (%)
Duration to get to a health facility that diagnoses and treats TB?		
< 1 hour	8 (1.3)	0
≥ 1 hour	589 (98.7)	51 (100)
Availability of other health facility closer to the respondent's village		
Yes	344 (57.6)	13 (26.0)
No	253 (42.4)	37 (74.0)
Is the TB care health facility easy to get to?		
Yes	429 (71.9)	44 (86.3)
No	168 (28.1)	7 (13.7)
Do people have to pay for transportation to get to the health facility?		
Yes	356 (59.6)	37 (72.5)
No	241 (40.4)	14 (27.5)
Do they have to pay to see a healthcare provider?		
Yes	163 (27.3)	11 (21.6)
No	434 (72.7)	40 (78.4)
Do they have to pay to see have the laboratory test done?		
Yes	273 (45.7)	23 (45.1)
No	324 (54.3)	28 (54.9)
Does the health facility have convenient hour's services?		
Yes	311 (52.1)	33 (64.7)
No	286 (47.9)	18 (35.3)
Site of first visit in the community to seek care for cough		
Self-treatment	181 (30.3)	
Traditional healer	86 (14.4)	
Public clinic/hospital	120 (20.1)	
Private clinic / hospital	18 (3.0)	
Patent medicine vendors/'chemist'	191 (31.9)	
Prayer houses for faith healing	7 (1.2)	
Others	4 (0.7)	
Do you take self-prescribed medication before you visit the clinic when ill?		
Yes	405 (67.8)	
No	192 (32.2)	
Where do people prefer to be treated for TB?		
Government health facility	472 (79.1)	
Private hospital	94 (15.7)	
Others	31 (5.2)	
Received information about TB in the last six months		
Yes	161 (27.0)	35 (68.6)
No	436 (73.0)	16 (31.4)
Source of information about TB (N = 161)		
Healthcare provider	75 (46.6)	23 (45.1)
Mass media	43 (26.7)	1 (2.0)
Family/friends	20 (12.4)	14 (27.5)
Church	12 (7.5)	1 (2.0)
Patent medicine vendor / 'chemist'	11 (6.8)	12 (23.5)

Table 4: Predictors of good community knowledge of and attitude to TB in riverine areas of the Niger Delta

Variables	Crude OR 95% CI	Adjusted OR 95% CI	Adjusted p-value
Factors associated with good knowledge			
Older age (>40 years)	1.5 (1.1 – 2.2)	1.5 (1.1 – 2.3)	0.042
Male sex	1.0 (0.8 – 1.5)	1.0 (0.7 – 1.5)	0.875
No formal education	1.3 (0.7 – 2.5)	1.2 (0.6 – 2.5)	0.583
Rural residence	1.8 (1.2 – 2.8)	2.4 (1.7 – 4.0)	0.001
Ijaw ethnic group	2.3 (1.1 – 5.0)	2.2 (1.0 – 4.8)	0.056
Itsekiri ethnic group	2.0 (0.7 – 5.2)	3.0 (1.1 – 8.8)	0.043
Other ethnic group	1.3 (0.5 – 3.2)	1.4 (0.5 – 3.4)	0.515
Having irregular income	1.2 (0.8 – 1.7)	1.2 (0.8 – 1.8)	0.312
Having a regular income	2.2 (1.4 – 3.5)	2.4 (1.4 – 3.9)	<0.001
Being divorced/separated from partner	1.3 (0.6 – 3.4)	0.9 (0.3 – 2.3)	0.799
Being a widow	1.2 (0.4 – 3.3)	0.8 (0.3 – 2.5)	0.683
Being married	1.1 (0.8 – 1.7)	0.8 (0.5 – 1.3)	0.349
Factors associated with Appropriate attitude			
Older age (>40 years)	1.0 (0.6 – 1.5)	0.9 (0.5 – 1.5)	0.707
Male sex	1.0 (0.7 – 1.5)	0.9 (0.6 – 1.5)	0.757
Having formal education	4.8 (1.1 – 20.2)	5.8 (1.3 – 25.6)	0.020
Rural residence	0.5 (0.3 – 0.9)	1.1 (0.5 – 2.2)	0.846
Ijaw ethnic group	1.1 (0.4 – 3.2)	0.9 (0.3 – 2.8)	0.873
Itsekiri ethnic group	6.0 (1.8 – 20.2)	6.1 (1.6 – 23.6)	0.009
Other ethnic groups	0.6 (0.2 – 2.4)	0.6 (0.1 – 2.3)	0.421
Having irregular income	1.5 (0.9 – 2.5)	1.3 (0.7 – 2.1)	0.405
Having a regular income	1.4 (0.8 – 2.5)	1.1 (0.6 – 1.9)	0.905
Being divorced/separated from partner	0.8 (0.2 – 2.4)	1.0 (0.3 – 3.3)	0.972
Being a widow	1.3 (0.4 – 4.1)	0.8 (0.2 – 3.5)	0.805
Being married	0.9 (0.6 – 1.5)	1.1 (0.6 – 1.9)	0.786
Having good knowledge	2.3 (1.4 – 3.7)	2.5 (1.5 – 4.4)	<0.001

OR = odds ratio; TB -= tuberculosis

Table 5: Patients' knowledge of TB in the riverine areas of the Niger-Delta (N = 51)

Variable	Total correct n (%; 95% C.I.)
Total	51
Knowledge	
Have heard of or known about TB	41 (80.4; 66.9 – 90.2)
Knew that TB is a serious disease	46 (90.2; 78.6 – 96.7)
Knew that TB is caused by an infectious agent / germ	38 (74.5; 60.4 – 85.7)
Identified at least one common symptom of TB	47 (92.1; 81.1 – 97.8)
Knew that TB may be transmitted through inhalation of air droplet from affected persons	39 (76.5; 62.5 – 87.2)
Knew at least one means of diagnosing TB	51 (100; 56.1 – 82.5)
Knew that TB can be cured	49 (96.1; 86.5 – 99.5)
Knew that pulmonary TB treated for six months	36 (70.6; 56.2 – 82.5)

95% C I = 95% confidence interval for the proportion; TB = tuberculosis

Table 6: TB patients' perceptions of and experiences with tuberculosis in the Niger-Delta (N = 51)

Variables	n (%)
Do you think TB patients should be supported with:	
Free TB medicines	27 (52.9)
Food support	24 (47.1)
Transportation to access health centres	0 (0.0)
Should people with TB disclose their illness to other people?	
Yes	43 (84.3)
No	8 (15.7)
Which of these individual is more likely to get TB?	
Men	17 (33.3)
Women	29 (56.9)
I don’t know	5 (9.8)
What did you feel when you found out you had TB?	
Scared	29 (56.9)
Depressed	8 (15.7)
Denial	2 (3.9)
Calm	10 (19.6)
Other	2 (3.9)
Did you inform your family / friends that you have TB?	
Yes	40 (78.7)
No	11 (21.6)
Have your relationship with your family changed since finding-out you have TB?	
Yes	23 (45.1)
No	28 (54.9)
Are people with TB discriminated against in your community?	
Yes	21 (41.2)
No	30 (58.8)
Are male or female TB patients more discriminated against in the community?	
Male	11 (21.6)
Female	7 (13.7)
I don’t know	33 (64.7)
Have you been afraid you may lose your job if it is known that you have TB?	
Yes	5 (9.8)
No	46 (90.2)
Have you been afraid you may lose your marriage if it is known that you have TB?	
Yes	3 (5.9)
No	48 (94.1)
Do you think that TB will affect the ability of a woman to get pregnant and have healthy children?	
Yes	8 (15.7)
No	43 (84.3)
Do women need permission from their husbands/relative to access health services?	
Yes	6 (11.8)
No	45 (88.2)

Table 7: Patients' health-seeking behaviour for TB and relationship with mean diagnosis delay (n = 51)

Variables	n (%)	Diagnosis delay (wks)	p-value
First symptoms that made you to seek treatment			
Cough for more than two weeks	35 (68.6)	24.4 (24.6)	0.183
Sputum with blood	7 (13.7)	7 (4.9)	
Fever	8 (15.7)	13.8 (8.8)	
Chest pain	1 (2.0)	8.0 (0)	
Did you take any treatment before being diagnosed for TB?			
Yes	50 (98.0)	20.3 (21.8)	0.409
No	1 (2.0)	2.0 (0.0)	
After you were given the treatment, what happened to the symptoms?			
Improved	4 (7.8)	17.5 (15.2)	0.640
Worsened	19 (37.3)	21.9 (22.9)	
Remained the same	24 (47.1)	21.5 (23.4)	
I don’t know	4 (7.8)	6.8 (5.7)	
Why did you choose to come to this health facility to seek care?			
Close to my home	8 (15.7)	15.5 (24.6)	0.689
Family / friend recommended	27 (52.9)	21.6 (20.6)	
Referred	7 (13.7)	24.0 (28.4)	
Personal knowledge of the health provider	9 (17.6)	16.1 (19.5)	
Other			
Were you informed of the possibility of having TB when you came?			
Yes	29 (56.9)	16.8 (15.9)	0.246
No	22 (43.1)	24.1 (27.5)	
When (which visit/s) were you informed?			
First visit	24 (47.1)	21.3 (24.6)	0.703
Other visit	27 (52.9)	18.9 (19.3)	
In all, how many health facility visits did you undertake before you were told you had TB?			
One	22 (43.1)	21.2 (22.6)	0.499
Two	13 (25.5)	15.5 (21.6)	
Three	12 (23.5)	27.2 (22.8)	
Four or more	4 (7.9)	6.3 (4.0)	
With whom did you have repeated visits?			
With the same health provider	22 (43.1)	23.0 (25.8)	0.508
Different providers in the same facility	16 (31.4)	22.1 (22.0)	
Different providers	9 (17.6)	10.4 (9.6)	
I don’t know	4 (7.8)	16.8 (13.7)	
What type of health facility made the initial diagnosis?			
Government	48 (94.1)	20.4 (22.3)	0.713
Private	2 (3.9)	19.5 (6.4)	
Other	1 (2.0)	2.0 (0)	
What factors made you delay seeking care for symptoms that led to the diagnosis of TB?			
Not aware of the severity of the symptoms	35 (68.6)	22.4 (24.5)	0.762
Expensive	9 (17.6)	18.3 (13.7)	
Others	7 (13.8)	6.0 (4.44)	
Received information about TB in the six months prior to diagnosis			
Yes	35 (68.6)	20.1 (17.6)	0.956

No	16 (31.4)	19.8 (29.6)	
Source of information about TB			
Healthcare provider	23 (45.1)	22.3 (20.9)	<0.001
Mass media	1 (2.0)	6 .0 (0.0)	
Family/friends	14 (27.5)	14.9 (7.2)	
Patent medicine vendor / 'chemist'	1 (2.0)	15.0 (0.0)	
Others	12 (23.5)	15.7 (21.8)	

Figures

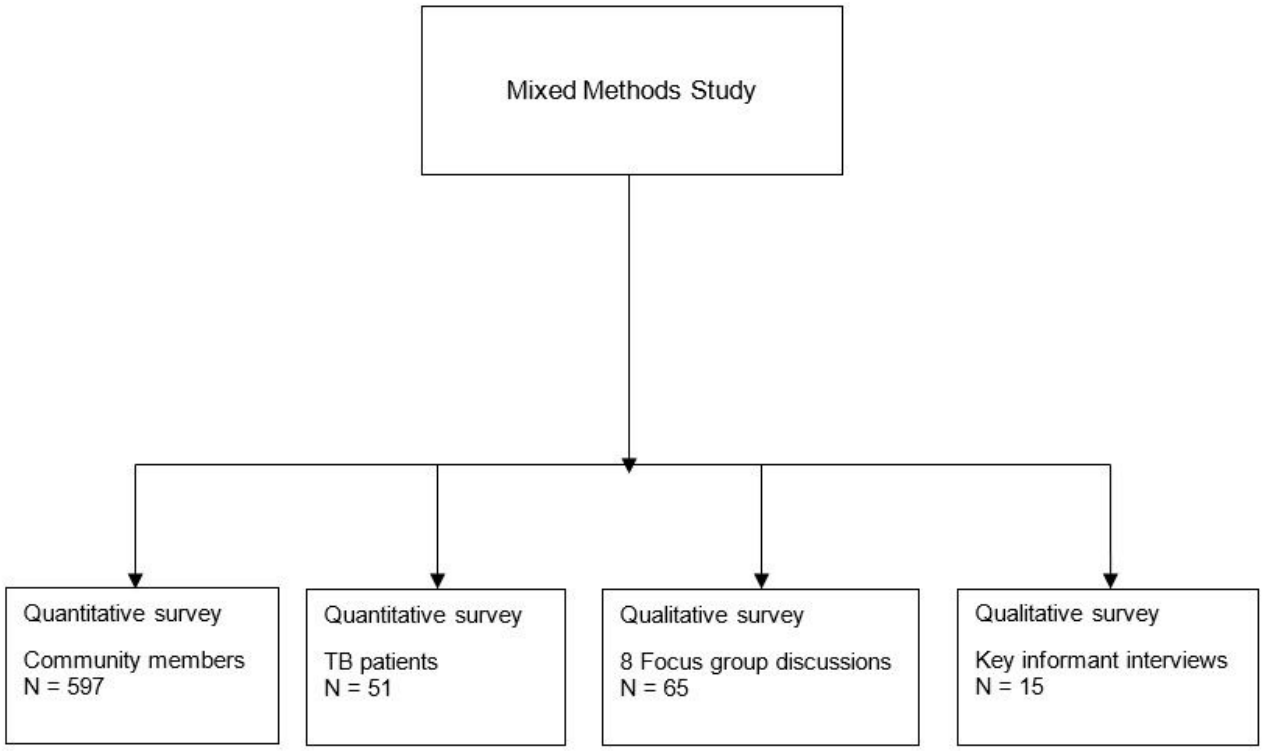

Figure 1

Sampling strategy for all patient groups in mixed-methods study

Supplementary Files

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