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Are people with drug-resistant tuberculosis at the centre of care – a reality check?

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Abstract

Background

Person-centred care (PCC) is a fundamental pillar of both the Global Plan to End Tuberculosis (TB) and the World Health Organization End TB Strategy. These strategies aim to provide a respectful and accessible service to individuals seeking treatment and care. This study quantifies PCC using the tool developed by TB REACH and assesses its feasibility for routine use in programmatic settings.

Methods

We conducted a cross-sectional study between February and April 2024. A total of 114 adult persons with drug-resistant tuberculosis (PwDR-TB) from 3 districts of rural Bihar were interviewed using consecutive sampling. Data were collected through telephonic interviews using a socio-demographic details form, covering nine domains (dignity/respect, privacy/confidentiality, autonomy, communication, accessibility/convenience, stigma/discrimination, cost/socioeconomic support, quality of care and trust; a mix of 25 Yes/No type) scoring varied per question with a min value of -1 and a high of + 1. The interviewer additionally rated each participant's ease of responding the questionnaire on a 5-point scale. Descriptive and subgroup analysis was performed using Jamovi 2.6.24.

Results

The domains of privacy and confidentiality and the quality of care captured negative mean scores (-0.31 and − 0.52) against the maximum score of '2'. 97% of participants reported that they were not offered comfortable settings to discuss their health-related concerns at the facilities, and 73% of the participants stated that they had not received information on their diagnostic tests. 88% reported experiencing a medication stockout situation and 15% of them informing that they incurred diagnostic expenses despite the free treatment policy. The interviewer rated 84/114 interviews (73.7%) as easy or very easy to complete, with the remaining interviews rated neutral; none were rated difficult or very difficult.

Conclusion

Using the PCC tool, we identified multiple gaps in current programmatic person-centred care approaches for PwDR-TB. The lacunae were evident in the domains of dignity, privacy, communication, costs, and quality of services and addressing them is essential to deliver respectful, effective and quality care for PwDR-TB.

Key Message

i) PwDR-TB reported important gaps in dignity, privacy, communication, accessibility, costs, and quality of services.

ii) PwDR-TB experiences varied by socio-demographic parameters, implying non-equitable access to services

iii) It was feasible to administer the PCC tools in programmatic settings, with the potential for it to guide quality improvement of TB Programmes.

Background

People with tuberculosis (PwTB) and especially those with drug-resistant TB (PwDR-TB) often endure significant hardships. The time between confirmatory diagnosis and cure itself affects the PwDR-TB's life across physical, emotional and financial domains [1]. Such challenges emphasize that there is a need to place individuals affected by TB at the centre of service delivery. This commitment is highlighted both in the Global Plan to End TB and the World Health Organization (WHO) End TB Strategy, where Person Centred Care (PCC) is considered as a fundamental pillar [2, 3]

The WHO outlines multiple core components of PCC, along with the need for evidence-based recommendations to improve the quality of TB care and support. PCC advocates for person-friendly care models, such as community or home-based treatment rather than facility-based care and emphasizes decentralizing treatment delivery for PwDR-TB. These strategies intend to make care more accessible, respectful, and responsive to individual circumstances [2, 4].

Over time, a consensus has emerged around four foundational attributes of Person-Centred TB care; i) Holistic care, which emphasizes viewing individuals with TB within the broader context of their lives and social circumstances, acknowledging the multiple factors that influence their health. ii) Individualized care, which involves tailoring services to each person's specific needs, concerns, and preferences, ensuring that treatment plans are responsive rather than uniform. iii) Empowering care which recognizes people with TB as active participants in their treatment journey, promoting shared decision-making and autonomy, and iv) Respectful care which upholds the person's dignity, privacy, and personal values through compassionate and considerate health services [5, 6].

The extent to which PCC currently forms part of existing TB programmes and approaches to monitor, evaluate, and report it, remains unclear. There have been limited efforts to assess user experience and satisfaction with TB services systematically. Most existing work consists of qualitative studies, which provide valuable insights into people's experiences, but these are less suitable for a routine programmatic evaluation [7–9]. Multiple studies have called for the development of a standardized, person-centred measurement tool that can quantitatively assess user experience and satisfaction, allowing for cross-setting and longitudinal comparisons [10–13]. In India, qualitative studies are conducted documenting stigma, psychological burden and gaps in patient-provider communication among PwDR-TB underscoring the need for programmatic quantifiable monitoring of PCC. [14, 15]

In 2023, India reported 66,248 cases of DR-TB (including isoniazid- and rifampicin-resistant TB), with Bihar alone contributing 5,195 cases [16]. The extended treatment duration of 6–21 months and frequent adverse drug reactions make the treatment journey particularly challenging for PwDR-TB.[17]

This underscores the importance of ensuring person-centred care (PCC) to support PwDR-TB throughout their treatment. As no quantitative tool currently exists to measure PCC within the routine TB programme, this study specifically aims to quantitatively describe PwDRTB's experience of person-centred care across different domains using newly developed PCC tool and assess feasibility of administering the PCC tool under programmatic conditions.

Methods

Study Setting

Innovators In Health (India) is a Non-Governmental Organization (NGO) founded in 2010, working to implement innovative, community-based approaches to reduce the TB disease burden in the difficult and remote geographies of Bihar through a community linked person care model. We conducted this study as part of an ongoing DR-TB project of IIH (India), across three districts of Begusarai, Madhubani, and Samastipur, which focused on early initiation of treatment and linkage to care for PwDR-TB, supported by the TB REACH Wave 9 grant. The three districts comprise a population of 15 million, with over 90% of the subjects residing in rural areas.[17] A total of 59 TB units (TBUs) is distributed across Begusarai (18 TBUs), Madhubani (21 TBUs) and Samastipur (20 TBUs) districts. Each of the district health facilities serves as a District TB Centre (DTC). These TBUs are supported by 55 functional NAAT (Nucleic Acid Amplification Test) facilities capable of detecting MTB and rifampicin resistance. Line Probe Assay (LPA) testing facilities are located at Darbhanga for Madhubani and Samastipur districts, and in Bhagalpur district for Begusarai district, requiring travel distance of at least 40 km. The DR-TB treatment initiation services for PwDRTB from Begusarai were provided at Patna; PwDR-TB from Madhubani were referred to Nodal DR-TB centre Darbhanga. PwDR-TB from Samastipur initiated their treatment either at DTC Samastipur or Nodal DR-TB centre in Darbhanga.

IIH's TB Reach Wave 9 project was implemented to reduce the pre-treatment loss to follow-up among the PwDRTB. Before the intervention anecdotal reports suggested that majority of PwDRTB were lost before the treatment initiation. The intervention districts followed the NTEP guidelines of DR-TB treatment regimen(s) (all-oral longer regimen, all-oral shorter regimen and H-monopoly to treat isoniazid resistance). As mentioned above a PwDRTB had to travel more than approximate 40 kms for their treatment initiation. The IIH team facilitated in sputum transport ensuring uDST among all the PwTB, linkage to care by navigating the complex health system and assisting in PwDRTB's follow-up tests. These interventions complemented the health system rather than replacing it.

Study Population

IIH (India) has been working since 2010 on an active case-finding approach for TB. The organization ensures a quality care cascade for all PwTB. As part of TB REACH activities, IIH(India) routinely provides services to PwDR-TB in three catchment districts. From the active PwDR-TB rooster, we approached 120 PwDR-TB, consecutively to participate in the study. All the participants were included in IIH's care package. Inclusion criteria for recruitment were, adults aged more than 18 years, on treatment for at least two months at the time of selection, with an active phone number, and currently residing in any of the three study districts. PwDR-TB who verbally consented to participate in the study, were interviewed telephonically.

Study Tool: TB REACH is a programme of Stop TB Partnership, that funds innovative projects to improve the diagnosis and management of TB. They developed a tool to validate and monitor PCC in DR-TB programmes. The TB REACH team developed the tool based on the existing literature and DR-TB care guidelines [7, 19–26]. It was piloted in two phases. In the first phase, the questionnaire was piloted in three countries: India, Pakistan, and Nigeria. In the second phase, it was piloted in seven countries across five projects. Based on the pilot experience and inputs from the TB REACH team, the PCC tool was subsequently finalized. The final questionnaire as seen in Table 1, included 25 items across nine domains: dignity and respect (2 items); privacy and confidentiality (3 items); autonomy (3 items); communication (3 items); accessibility and convenience (4 items); stigma and discrimination (4 items); cost/socio-economic support (2 items); quality of care (3 items); and trust (1 items). In the stigma and discrimination domain, one item that is 'Do you feel that you receive poorer care because of your race, skin colour, religion and gender' was not considered for assessment. After consultation with TB REACH team, it was deemed not relevant in our regional cultural settings. Each question was mixture of Yes/no or Likert type question and was scored with − 1, −0.5, 0, 0.5, 1, or 2. The tool was translated in Hindi and piloted among 10 PwDRTB prior to use in the study. Scoring criteria for the Hindi version of the tool are added in supplementary annexure-I. The interviewer assessed feasibility of implementing the tool based on the understanding and responses from the participants, which were graded on 5-point Likert scale as; 5: Not at all easy, 4: difficult, 3: Neutral/ Neither easy not difficult, 2: easy, 1: very easy. The interviewer assigned a response score based on participants' response patterns: a score of 1 was assigned when participants responded promptly, without pauses or repetition; a score of 2 when participants took a small pause before responding; and a score of 3 when participants asked for the question to be repeated or the interviewer had to repeat the question to elicit a response.

Table 1
English Version of Patient Centric Care Tool along with scoring criteria

Domain	Question	Response	Score
Dignity/ Respect	During your diagnosis and treatment for drug-resistant TB, did the healthcare staff introduce themselves to you when you first met them?	Yes	1
		No	0
	Do the healthcare staff treat you in a kind or friendly manner?	Always	1
		Mostly	0
		Sometimes	0
		Not at all	-1
Privacy/ confidentiality	When you are speaking to healthcare staff about your DR-TB diagnosis or treatment, are you in a place or room where you feel comfortable to talk about your health matters?	Yes	1
		No	0
	Do you feel like your health information was or will be kept confidential at the clinic or hospital?	Yes	0
		No	-1
	Did anyone ask your permission to tell other people in your household about your diagnosis?	Yes	1
		No	0
Autonomy	Did you get a choice in what support to help you take your medication or pills every day (e.g. pill box, directly observed treatment, video-DOT etc)?	Yes	1
		No	0
	Did you have a choice about which facility or where you receive your medications from?	Yes	1
		No	0
	Do you feel that the healthcare staff involve you in decisions about your treatment and care?	Not at all	-0.5
		Sometimes	0
		Mostly	0.5
		Always	1
Communication	Do the healthcare staff tell you the results of the tests that are done on the samples that you give?	Yes	1
		No	0
	Do the healthcare staff at the facility speak to you in words that you can understand?	Always	1
		Mostly	0.5
		Sometimes	0
	Did the healthcare staff talk to you about how the medications might make you feel?	Yes	1
		No	0

Domain	Question	Response	Score
Accessibility/ convenience	When you get to the clinic or hospital where you receive your treatment, how long do you have to wait?	< 1 hour	1
		1 + hours	0
	Do you get treatment for other health problems at the same place that you get your DR-TB treatment?	Yes	1
		No	0
	How many times did you need to visit a clinic or hospital before you were diagnosed with DR-TB?	Once	1
		2–4 times	0
		5 + times	-1
	Is it easy for you to get to the clinic or hospital where you receive your DR-TB treatment?	Yes	1
		No	0
Stigma/ discrimination	Have you had TB before you were diagnosed with DR-TB?	No	0
		If previous TB:	1
			0
	Do you feel that you are treated differently because you have had TB before?	Yes, better	-1
		No, about the same	
		Yes, worse	
	Do you feel that you are treated differently because you have DR-TB compared to normal TB?	Yes, better	1
		No, about the same	0
		Yes, worse	-1
	Do you feel that you receive poorer care because of your race, skin colour, religion or gender?	Yes	-1
		No	0
Costs/ socio-economic support	Did you have to pay to receive your DR-TB diagnosis?	Yes	0
		No	1
	Have you received any financial support to help you get through treatment?	Yes	1
		No	0
	Have you received any food support for you and your family or household?	Yes	1
		No	0

Domain	Question	Response	Score
Quality of care	Do you feel that you need more support from the clinic or hospital, in addition to what you are currently receiving, to keep taking your treatment every day?	Yes	0
		No	1
	Has anyone explained to you about what drug-resistant TB is and what is needed for treatment? If yes, how many sessions?	No	0
		Yes 1 session	0.5
		Yes, 2 + session	1
	Have there been times when the clinic/facility did not have the right medications for your treatment?	Yes	-1
		No	0
Trust	Would you recommend that any of your friends or family get the same care if they were diagnosed with DR-TB?	Yes	1
		No	0

For the interviewer only: In your view, did the participant find it easy to answer these questions?

(5: Not at all easy, 4: difficult, 3: Neutral/ Neither easy not difficult, 2: easy, 1: very easy.)

Data collection and analysis: Data was collected using telephonic interview by a trained interviewer from the IIH(India) tele counselling team, who was not a part of the ongoing Wave 9 DR-TB project implementation. Before data collection, the interviewer received training on the study protocol, informed consent, questionnaire administration including 'ease of understanding question' scoring. Up to 3 call attempts were made for each eligible participant. After obtaining verbal consent from the volunteering participants, she initiated the interview and recorded the responses in Kobo Collect (digital data collection tool) [Version v2023.1.2, Kobo Toolbox/Kobo, Inc., Massachusetts, United States] using unique identifiers. Each interview lasted approximately 20 to 25 minutes with an average of 11 minutes, and included introduction, consent, administration of the tool and closing remarks. A descriptive analysis included basic categorical analysis followed by cross tabulation for the variables: age, gender, duration of treatment and the districts across PCC domains was done using Jamovi [Version: 2.6.24, The Jamovi project, Sydney, Australia]. For calculation of maximum scores in each domain, positive responses were added. Mean for each domain was calculated by dividing the domain specific pooled scores by the total number of respondents.

Results

Participant Characteristics:

A total of 114 PwDR-TB consented to participate in the study. Table 2 describes the socio-demographic characteristics of the enrolled participants. The majority (67%) of the study subjects belonged to the 18–

30 years age group, and predominantly males (69%) participated. The participation from the three districts was uniform with most (68%) subjects being on treatment for 4–12 months.

Table 2
Socio-demographic distribution of PwDR-TB (n = 114)

Socio-demographic Variables	Frequency (%)
Age (years)	
18–30	76 (67%)
31–40	18 (16%)
41–50	12 (11%)
51+	8 (7%)
Gender	
Male	79 (69%)
Female	35(31%)
District	
Begusarai	37 (32%)
Madhubani	36 (32%)
Samastipur	41 (36%)
Treatment Duration	
2–4 months	11 (10%)
4–12 months	77 (68%)
12 + months	26 (23%)

#Table

Participant-reported PCC experiences by domain

Supplementary annexure 2 provides an overview of the proportions of PwDR-TB's responses to the PCC questionnaire. Some highlighted domain specific responses to the PCC questionnaire are as follows. In the dignity and respect domain, 61% participants reported that they felt like were always treated in a kind or friendly manner. In privacy and confidentiality, only 3% PwDR-TB reported being able to be in a private

and comfortable space, while discussing their DR-TB treatment options, with 61% of them believing that their health information would not remain confidential. Regarding autonomy, only 8% PwDR-TB reported having a choice in selecting the type of adherence support (such as pill boxes or DOT options). Similarly, 18% of PwDR-TB reported having a choice about the facility from which they received medications.

In the communication domain, 32% reported receiving information about their test results and 19% of them said that they were not made aware about the possible medication side effects.

Within the domain of accessibility and convenience, 77% reported waiting less than one hour at the facility, and 62% receiving treatment for other health conditions at the same facility. The diagnostic pathway, as self-reported, required at least 2–4 visits for the majority (60%) of the respondents, with 35% mentioning that they found it difficult to reach the health facility.

In the stigma domain, when asked about differential behaviour due to DR-TB status by health care workers, 54% PwDR-TB reported perceiving no difference in behaviour compared to drug-sensitive TB, one third of them (34%) feeling worse, and 11% feeling better treated.

As self-reported by participants, financial support during treatment was received by 54% of them, while in the quality-of-care domain, 93% expressed a need for additional support to maintain daily treatment adherence. 51% of them informed that did not receive any information about DR-TB and the treatment. Medication stockouts were common, with 88% reporting instances where the facility lacked the required drugs. In the trust domain, 100% of respondents stated they would recommend the same care to friends or family if they were diagnosed with DR-TB. Regarding the cost 15% of the participants reported incurring diagnostic expenses, despite free treatment services.

Subgroup Analysis

We included our analysis of the influence of gender, age, district and duration of treatment on the responses in supplementary annexure 3. A larger proportion of women waited less than an hour before receiving care: 86% compared to 73% for men. Also, a larger proportion, though still small, of women received the DRTB diagnosis at the first visit to the hospital: 6% compared to 0% of men. A larger proportion of men needed 5 or more visits to the health facility compared to women: 43% versus 29%. Women expressed more often that they were better treated because of the DR-TB diagnosis: 29% compared to 12% of men. Women received more frequent food support (74%) compared to men (56%). Health care workers explained about TB and its treatment more to women: 55% received at least 1 session of explanation, compared to 47% of men.

Responses to the questions varied across age groups: participants under 40 (52%) of age reported more often that their Health care professional introduced them compared to people aged over 40 (25%). Older people (75%) had less confidence that their health information would remain confidential. Participants also reported that Health care workers involve younger people (< 30 years of age) more in decisions on their care and treatment with older people (40 & above) being more often informed on the effect of the

medication (75%). The older age groups (> 40 years) more often felt treated the same during their DRTB treatment compared to their DSTB treatment.

The district of residence had some influence on their responses. Participants from Madhubani reported that Health care workers less often introduced themselves (75%) as compared to the other districts. Of the Samastipur participants, 20% responded not at all being treated friendly. They also had less confidence in their health information being kept confidential. Begusarai participants more often had a choice in their treatment support but felt less involved in decision-making on care and treatment. Almost half of Samastipur participants (49%) reported having 5 or more visits before receiving the DR-TB diagnosis. In Begusarai, participants felt mostly treated better during their DR-TB treatment, received more food support. However, they also experienced medication stockouts more often.

Time on treatment also mattered when responding to the questionnaire. Comparing treatment duration (2–4 months, 4–12 months and 12 + months), participants on treatment for 2–4 months, 82% reported feeling less involved in their care and treatment and 64% of them reported having information on the medication. Those on treatment for 12 + months, 46% of participants reported receiving results of the tests performed, socio-economic and food support.

Figure 1 shows the maximum and mean score across the domains. From the figure it becomes clear that only for trust the maximum and mean scores were the same. There was a large gap between the maximum and the mean score for the domains of privacy and confidentiality, autonomy, stigma and discrimination, and quality of care suggesting indicating more negative participant-reported experiences in these domains.

Feasibility of administering the PCC tool

On implementation of this PCC tool, the interviewer based on the responses received from participants observed and rated that almost all the participants were able to answer the questions without difficulty, and 74% understood the questions easily. Respondents from Begusarai and Madhubani were rated with a better ease of understanding of the tools than those from Samastipur district. Overall, as per the rating from the interviewer, for 10.5% participants, questions were “very easy” to answer, for 63.2% it was “easy” and for the rest it was “neutral/not easy nor difficult”. The interviewer rated Male participants (70%) as understanding the questions more easily than female participants (30%). Similarly, Participants aged 18–30 years were rated that the tool was easier to answer compared with those aged 41 years and above.

Discussion

Our study findings provide a varied picture of how participants perceived their programmatic DR-TB care to be person-centred. Additionally, we found that it was feasible to implement this questionnaire in the

programmatic settings of rural Bihar.

PwDR-TB are both physically and mentally vulnerable due to the social stigma associated with the disease, significantly impacting their health & life [27, 28]. Although the National TB Elimination Programme (NTEP) explicitly emphasizes providing respectful and person-centred care to all PwTB, including those with DRTB, [29, 30] our study findings highlight that most of the PwDR-TB do not get treated with dignity and respect during their treatment journey.

Many participants reported that they did not think their health information would remain confidential, were poorly explained of their diagnosis and treatment and even experienced stock-outs of medication during their treatment. However, they all still would recommend that friends or family get the same care, which seems contradictory. A possible explanation may be that PwDR-TB continues to perceive TB treatment as being effective and lifesaving, with the hope of being cured, outweighing the negative care experiences. Fear of progression of the disease, further complication of the drug resistance pattern may enable them to consider the possibility of recommending the same treatment to other family and community members. In addition, government-initiated treatment for DR-TB is often the only source to access DR-TB medications free of charge, which may not be available in private establishments, or too costly to afford across the duration of treatment [31–33].

Gender, age and the districts of the participants all influenced their responses, though not in a consistent way. Women reported having better accessibility to care as compared to men in our study. In a patriarchal social system as prevalent in Bihar, men may often delay health-seeking behaviour, prioritize work and avoid being seen as vulnerable. Similarly, women reported better accessibility to the food support as compared to men, this may be due to less hesitance in approaching other government institutions like Anganwadi Centres and Schools for Mid-Day Meal Scheme food as compared to men, even though they might face more stigma than men. The same has been explored in an intersectional study in Uganda, where they found women visiting government facilities more often (antenatal care, child immunization, childcare), being more familiar with public services and staff, easing their access to linked social benefits. This familiarity with the health staff, may also result in women having lesser waiting times and better and earlier access to care than men. [34] Older adults reported receiving better care than younger men; which may be due to different expectations and communication needs of younger men, which require further exploration [35]. Differences in health infrastructure, resource availability, and local health policies across districts can influence the quality and delivery of PCC. Variability in health care worker training, communication skills, and attitudes toward shared decision-making can lead to inconsistent PCC experiences across demographic groups and geographies [36].

Many participants reported having issues in the privacy and confidentiality domain. This raises critical concerns, as these practices can negatively impact the social environment of the individual because of stigma, discrimination and isolation. Consequently, studies reported beneficiaries lose trust in health care providers, hesitate to utilize health services, and withhold information, which can affect the quality of care and treatment outcomes [37, 38].

Most participants reported experiencing less autonomy. DR-TB treatment is guideline based, but decisions such as adherence support, treatment facility preferences wherever feasible, counselling, follow-up, and management of adverse effects can be explored to include PwDRTB's opinion. DR-TB treatment regimens themselves are long and complex, and having more autonomy, may help reduce apathy and disengagement, thereby reducing non-adherence and improving treatment outcomes. Management of DR-TB is protocol driven, however [39, 40].

Effective communication is a critical determinant of treatment adherence. Our findings highlight gaps in information exchange between PwDR-TB and providers affecting the PwDR-TB's understanding and engagement. Other studies have identified that clear communication characterized by two-way dialogue, and responsiveness is central and crucial in delivering person-centred care. Open, empathetic, and responsive communication builds trust between patients and providers, which is vital for navigating the lengthy and difficult DR-TB treatment journey [6, 7].

Many PwDR-TB reported having to make multiple visits to health facilities and wait for more than an hour to receive appropriate diagnostic or treatment services. Such delays, particularly where access to health facilities is challenging, may diminish trust in the healthcare system and contribute to disengagement from care before completion of the diagnostic process. [41, 42].

For decades, TB has been a stigmatized disease and a major social determinant of health that drives morbidity, mortality, and health disparities related to it [43]. Our study highlights that participants with a history of TB reported feeling treated worse because they had DR-TB. The PwDR-TB may be blamed for their illness being 'difficult to treat 'or be labelled as 'non-compliant'. Health systems may also be less responsive/ supportive to people with prior history of TB, because of resource constraints, negative attitudes toward PwTB or assumptions about their adherence [27, 44].

The economic burden of TB care is substantial, often placing PwTB and their households at risk of financial hardship or impoverishment [45]. Despite free diagnostic and treatment services, some participants reported incurred related expenses. Additionally, despite direct beneficiary transfer by the NTEP, and nutritional assistance, many participants reported that they needed more support to the existing support [46]. Many factors might be responsible for this including problems with bank accounts, unlinked Aadhaar bank details, paper-based documentation and lack of human resources for processing this DBT request, apart from lack of timely fund release, budget constraints, and overworked or insufficient staff contribute to non-payment or late payment.[47] This demonstrates that support mechanisms cannot be adequate if they are not provided.

Our study demonstrates there are still many gaps in care for people with DR-TB and that it is of utmost importance to come up with interventions to fill these gaps to improve treatment outcomes. Multiple studies in other Southeast Asian countries like China and Korea, have shown that PCC interventions substantially reduce loss to follow-up (LFU). Interventions such as regular counselling, home visits, and patient support groups may be particularly useful in bridging these implementation gaps [48–50].

This study has some notable strengths. It is one of the first studies to implement the TB REACH PCC Tool in the resource-constrained settings among PwDR-TB. The tool helped us to identify which PCC domains had the largest PwDR-TB reported gaps, supporting its potential use as a routine monitoring instrument in TB programmatic settings. However, there are several limitations to this study: the consecutive sampling design and restriction of the study to three districts may restrict the generalizability of the findings. By restricting the inclusion to participants who had a phone and who had at least been on treatment for 2 months, we may have missed people who prematurely stopped their treatment/ didn't have a working phone. Moreover, these participants linked to project care cascade may have relatively more positive experience than general population. Social desirability and recall biases may have influenced participants' responses, especially due to the telephonic nature of interviews. In addition, women were underrepresented in the sample which may limit generalizability of gender-based subgroup findings. Another limitation was that provider perspectives, facility audits, medicine stock out records, and related programmatic data were not collected, and it is not possible to verify reported experiences or identify the system-level causes of these gaps. Despite these limitations, the study provides valuable insights from the implementation of the PCC tool in a real-world setting. NTEP aims to eliminate TB in alignment with the SDG goals. The programme plans to achieve this by providing quality care in the context of diagnosis and treatment. However, this quality component is often ignored, with the push being towards achieving targets. The situation is challenging in high burden but low resource intensive states like Bihar. Assessing PCC enables the stakeholders to introspect the quality of services being provided and making impact at individual level, beyond the medication aspect.

What people need, may differ on who and where they are. Needs assessments at diagnosis may identify where people need assistance. While the NTEP programme alone cannot cover all the needs, therefore a coordinated and well-supported multisectoral response is needed to address the diverse needs of people with TB. Additionally, an effective implementation of quality local TB programmes can help strengthen PCC components through improved coordination, community engagement, referral, and linkage with relevant services and sectors, in line with the principles of the WHO Multisectoral Accountability Framework.[51]

Conclusion

This study highlights many gaps in the person-centred delivery of care for PwDR-TB in rural Bihar, including a lack of respectful communication, trust in maintaining confidentiality, limited involvement in decision-making, and inadequate access to health support services. It is possible to identify gaps in service delivery using the PCC tool. As the tool in this study has highlighted gaps in dignity, privacy, communication, costs, and quality of services, implying that there is scope for its use within programmatic settings. The tool can help guide strategies to strengthen DR-TB services and ensure more dignified and person-centred care to ease the treatment journey PwDR-TB goes through.

Abbreviations

DR-TB
Drug-Resistant Tuberculosis
DSTB
Drug-Sensitive Tuberculosis
IIH
Innovators In Health
IEC
Institutional Ethics Committee
IGIMS
Indira Gandhi Institute of Medical Sciences
LFU
Loss to Follow-up
NTEP
National TB Elimination Programme
NGO
Non-Governmental Organization
PCC
Person-Centred Care
PwDR-TB
Persons with Drug-Resistant Tuberculosis
PwTB
People with Tuberculosis
TB
Tuberculosis
WHO
World Health Organization

Declarations

Ethical consideration: We obtained approval from **Institutional Review Board of Indra Gandhi Institute of Medical Sciences (IGIMS), Patna vide Approval No: IGIMS-IEC:1208 dated 5/10/2023**. After administration of the subject information sheet to the participating PwDR-TB, the interviewer obtained verbal informed consent telephonically. Participants were informed that they could withdraw participation from the study at any point in time. We did not record any personal identifiers to maintain confidentiality, and we only used de-identified data for analysis. This study was conducted in adherence to the principles of the Declaration of Helsinki.

Clinical trial number

Not applicable

Consent for Publication:

Not applicable

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The authors declare that they have no Competing interest.

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Author Contribution

SS, NN and HC conceptualized the study and contributed to study design. NN, SS, MK and MB developed the methodology. RS, RKM, MSA and NN conducted the investigation and coordinated field activities. NN, MBr, NJ, SS, AS and CM curated and analyzed the data. NN, MBr, NJ, SS, AS and CM interpreted the findings. BKM, TG, RK, and SM provided programmatic and policy inputs. NN, MBr, NJ and AS drafted the manuscript. MBr, NJ, SS, CM critically reviewed and revised the manuscript. MK and MB provided overall supervision and project administration. All authors approved the final manuscript and are accountable for all aspects of the work.

Availability of data and materials:

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

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Figures

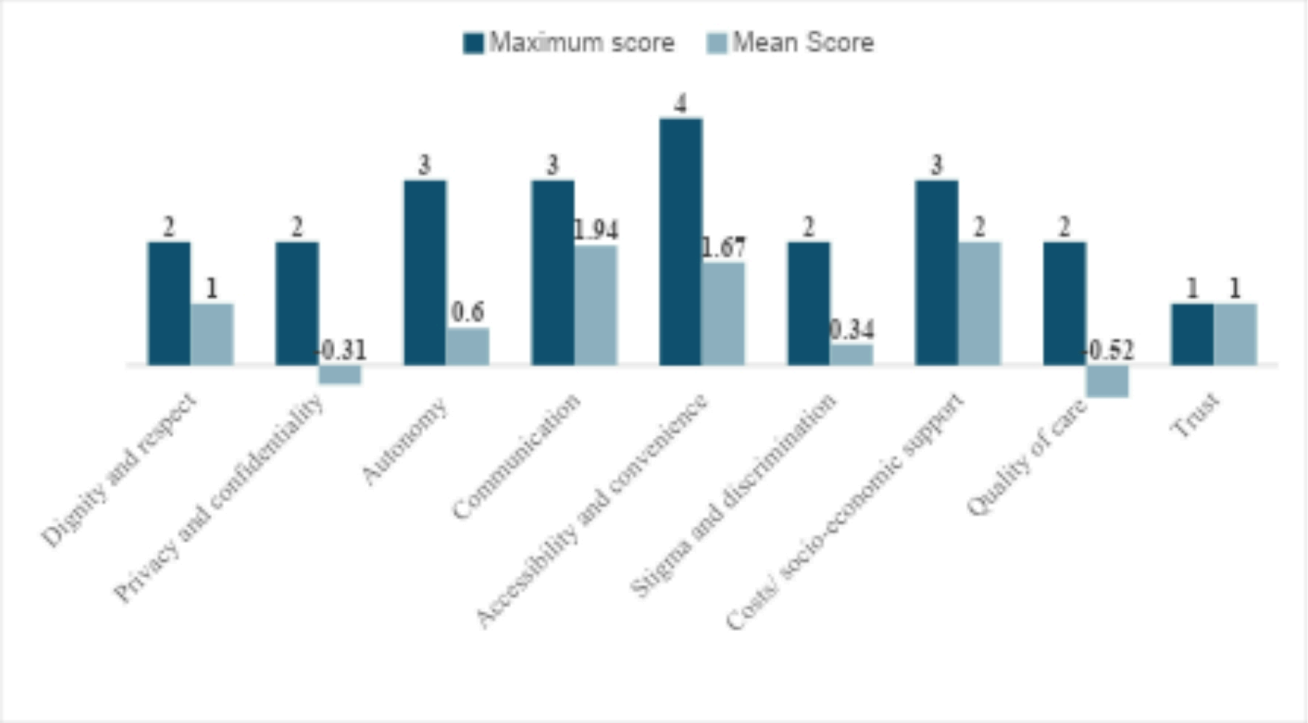


Figure 1

Average maximum vs. mean domain-specific PCC scores

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