

User-experience and patient satisfaction with quality of tuberculosis care in India: A mixed-methods literature review



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ABSTRACT

Background: Tuberculosis affected 2.7 million people in India in 2017. The Revised National TB Control Programme has achieved milestones in coverage, however quality of TB care remains highly variable and often poor, with significant gaps in provider knowledge, practices, and patients consistently lost to follow-up. These quality gaps are largely informed by studies on provider practices or objective chart abstractions and case data. Per the knowledge of the author, no review has been conducted on first-hand patient perspectives on the quality of TB care they receive. This mixed-methods literature review aims to synthesize evidence on user-experience and patient satisfaction with TB care in India and inform areas for service quality improvement.

Methods: Five medical databases, including PubMed, EMBASE, Global Health (Ovid), Web of Science, and CINAHL were searched for empirical studies on patient perspectives on TB health services published between January 1st, 2000 to December 31st, 2017. Studies in English with adult patients with any form of TB in the public or private health system were included. Studies prior to entering the health system, on distance to health facilities and cost were excluded. Seven Indian journals were hand searched and a grey literature search was conducted in GoogleScholar. Studies were assessed for methodological quality and thematic analysis was conducted by categorizing data using NVivo 12.

Results: A total of 498 studies were screened, of which 23 met the inclusion criteria. 16 supplementary studies were identified from Indian journals and grey literature. Of the 39 total studies included most were quantitative (29; 74%), based in South India (17; 44%) and focused on drug-sensitive TB patients (19; 49%) within the public health system (25; 64%). Data collection methods were highly heterogeneous which limited synthesis and comparisons across population demographics, health sectors, or regions. Overall quantitative patient satisfaction measured in seven studies was high. Two major themes identified were provider-related factors ($n = 26$ studies) and convenience ($n = 25$), and six minor themes were supplies and equipment availability ($n = 12$), confidence ($n = 10$), information and communication ($n = 10$), waiting time ($n = 8$), stigma ($n = 4$), and confidentiality ($n = 4$). Each reported positive and negative user-experiences. Most significantly, DOTS did not fit the daily needs and obligations of many patients, particularly due to conflicts with employment and frequency of visits; while positive provider support, information, and flexibility helped patients adhere to treatment.

Conclusion: Although quantitative patient satisfaction was found to be high, data were not collected using robust, validated tools. Qualitative and quantitative user-experiences in each theme were variable, making them both barriers and facilitators of good quality TB care. Poor user-experiences were often responsible for patients interrupting treatment or dropping out of TB care. Patient-centeredness, or user-friendliness of TB care can be improved by introducing individualized or flexible DOTS that is responsive to user circumstances and needs. User-experience data should be systematically collected using a standardized, national tool for identification of specific bottlenecks and successes in quality of TB care from the patients' perspective.

1. Introduction

India accounts for the highest burden of tuberculosis (TB) in the world, with 26% of all TB cases [1]. In 2017, there were an estimated 2.7 million new cases of TB and 420,000 related deaths. The

Government of India has committed to the elimination of TB through rapid declines in disease burden, mortality, and morbidity by 2025 [2]. To achieve this, the Revised National TB Control Programme (RNTCP) has reached country-wide coverage of the TB programme and the Directly Observed Therapy, Short course (DOTS) strategy, providing free

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medications and diagnostic services at public health facilities. This strategy has treated more than 10 million people between its full launch in 1997 and 2017 [2]. While there has been significant progress in coverage and scale up of basic TB services, gaps in the quality of care still remain.

Quality of TB care has frequently been found to be substandard and highly variable across India's public and private health systems [3–6]. Patients consult up to three providers and face delays of up to two months prior to receiving a proper diagnosis [7]. Simulated, standardized patient studies have shown that only 21% of private practitioners managed cases of TB correctly (when benchmarked loosely against the Standards of TB Care India) [8]. This has huge implications, as over 70% of general patients first seek care in the private sector [9] and 46% of all TB patients are managed there [10]. Within the public sector, a cascade of care analysis estimated that nearly one-fifth of prevalent TB patients (520,000 annually) interface with public TB services yet are either not successfully diagnosed or are lost to follow-up (LTFU) before starting treatment [11]. As such, whether it be the public sector [3,12] or private [6,13–17], TB patients must navigate between and within health systems that possess several gaps in quality. Exploration of the user's experiences may be a key step to finding out why TB care may be “missing millions” that go undiagnosed, untreated, or unreported, despite patients engaging with the health system [12,18]. A previous systematic review of 47 studies on quality of TB care in India included studies that primarily evaluated chart abstractions and quantitative provider knowledge, attitudes, and practices [4]. No review has been conducted on the service user, i.e. the patient's perspective of the quality of TB care they receive.

Quality of care is fundamental to ensuring a patient's right to health and achieving optimal health outcomes, i.e. cure for TB patients [19]. According to the Lancet Global Health Commission on High-Quality Health Systems, health systems are underpinned by four values: for people, equitable, resilient, and efficient [19]. Due to the unique perspective of patients as first-hand service users, patient- or user-experience informs each value as a key component of the processes of care. Patient satisfaction is another measure that can be valuable for health service improvement when assessed using specific, well-designed, psychometrically-tested tools [20–22]. Hence, patient satisfaction (i.e. whether a patient's expectations of care are met [23]) and user-experience (i.e. what events and experiences occurred within the health system) are some of the most important indicators of quality of care [20,24–28]. Non-health industries recognize that positive customer satisfaction and reviews lead to economic benefits like company growth, recommendations, and customer loyalty [29]. Likewise, higher patient satisfaction and positive user-experiences have been positively associated with greater utilization of services, patient retention, adherence to treatment regimens, confidence in health systems, better quality of life, and improvements in objective health outcomes such as mortality and medical errors [30–35].

Patient-centered care is where patients' needs, preferences, and empowerment are central to healthcare delivery [36,37]; user-experience is considered especially important when determining the patient-centeredness of care delivery and identifying areas for improvement [23]. Patients' evaluation of care has been applied for strategic decision-making, informing effective organization of care, and transforming provider practices and health systems, particularly in high-income settings using established tools such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) suite of surveys [38–40]. Patients are shifting from being passive receivers of care to active collaborative partners in health service delivery [24,27,30,41–45]. Hence, as India's National Strategic Plan (2017 – 2025) prioritizes the provision of patient-centered care, this mixed-methods literature review seeks to provide a comprehensive overview of available evidence on the user-experiences and patient satisfaction with quality of care, amongst adult TB patients in India. The objective is to describe TB patient experiences (user-experience) within the Indian healthcare system. Results from this

review may help identify gaps along the patient cascade of care from the patient's perspective, and areas for service quality improvement for the provision of patient-centered, high-quality TB care.

2. Methods

2.1. Search strategy and screening

A systematic search for studies from January 1st 2000 to December 31st 2017 was performed in 5 databases, including PubMed, EMBASE, Global Health (Ovid), Web of Science, and CINAHL. The search terms and search strategy were approved by a medical librarian and composed of variations of the following key terms: 1) tuberculosis, 2) patient satisfaction or experience or perspective, and 3) health care service delivery. This search was conducted for a larger systematic review of patient perspectives across all low- and middle-income countries [46]. For this focused review, studies specific to India were identified by searching “India” within the retrieved references in EndNote X7. Titles and abstracts were screened by two independent reviewers using the predetermined inclusion criteria below. Disagreements were resolved through discussion. Full-text articles were retrieved via EndNote or contacting authors, and screened by one reviewer. A brief grey literature search in Google Scholar was also conducted. In addition, to increase the yield of relevant articles, an electronic search of seven Indian journals related to TB and public or community health were hand searched for studies from January 1st 2000 to October 1st 2018 (see supplementary materials for the search strategy and journal list).

2.2. Inclusion and exclusion criteria

Studies were included if they were in English language and located in any region of India. The population was adult patients (older than 15 years of age) with presumptive TB or diagnosed with any form of TB (including comorbidities such as HIV-TB). There was no restriction on study design, the service being evaluated (e.g. screening, diagnosis, treatment, case management, counselling, other), or type of health system (public, private). The public sector was defined as any service provided by the government and/or under the RNTCP. The private sector was defined as any service outside of government-provided services including by private providers (PPs), non-profit organizations and informal providers (e.g. faith healers, pharmacy staff). PPs include practitioners of various systems of medicine, including modern allopathic medicine and Indian traditional medicine (i.e. ayurveda, yoga, unani, sidda, homeopathy (AYUSH)), and encompass facilities that range from small clinics to hundred-bed hospitals. Studies were excluded if they did not describe standard care (e.g. interventions, prison health systems), were not from the patient's perspective (e.g. family or provider perspective), and if they focused on patient experience outside of the quality of health system for TB (e.g. stigma in the community, knowledge of TB, HIV care). Data on the financial burden of TB care and distance to health facilities were excluded having been previously well-documented across several reviews [47–50].

2.3. Data extraction and quality assessment

The following data was extracted from each study; study details (i.e. authors, publication year, setting, population, etc.), data collection methodology, and any relevant findings (see supplementary materials for data extraction form). The data were recorded and tracked using Microsoft Excel. Included studies were assessed for quality to describe the range of their methodological quality. Quantitative studies were assessed using the Critical Appraisal tool for Cross-Sectional Studies (AXIS) tool [51]. Qualitative studies were assessed using the CASP Qualitative Checklist [52]. For mixed-methods studies, the quantitative and qualitative components were assessed separately using their respective tools.

2.4. Data analysis

Thematic analysis was conducted for both quantitative and qualitative studies [53]. The results sections of each study were read line-by-line and relevant findings were categorized into themes and sub-themes, using NVivo 12 Pro software (QSR International Pvt. LTD, Melbourne, Australia). For qualitative studies, both author summaries of findings and patient quotes were coded. For quantitative studies, the variable labels from surveys were extracted as 'themes' in the same way conceptual themes are extracted from qualitative reports [54]. Guided by principles of segregated mixed-method synthesis by Sandelowski et al., themes were developed separately for quantitative and qualitative studies, then combined and presented complementarily [55]. Themes were developed in an inductive manner, with no predefined framework to guide the analysis. When synthesizing data, overlapping themes from the quantitative and qualitative analyses were combined and refined. Themes that did not overlap were maintained as their own conceptual themes. All evidence informing a theme were tabulated, including qualitative quotes and quantitative descriptive statistics. Studies that reported overall patient satisfaction percentages were tabulated separately. Major themes (greater than 50% of included studies containing the theme) and minor themes (less than 50%) were identified *post hoc*.

3. Results

3.1. Composition of included studies

The search yielded 498 titles and abstracts for screening, of which 112 were duplicates and 23 met the inclusion criteria. Additionally, 16 studies were found from hand-searching journals and grey literature (Fig. 1). Of all 39 studies reviewed, 29 (74%) were quantitative and 10 (26%) were qualitative. Quantitative studies mainly used a questionnaire with a semi-structured or structured interview to collect data (27/29; 93%) and qualitative studies used in-depth interviews (7/10; 70%) and focus group discussions (3/10; 30%). As shown in Table 1, 25 studies (64%) assessed perceptions of services offered by the public health system/RNTCP, 1 (3%) assessed services in the private sector, and 13 (33%) assessed experiences in both. Seventeen studies (44%) were located in South India, 10 (26%) in North, 6 (15%) in West, 3 (8%) in Central and 1 (3%) in East. Two other studies (5%) were located in multiple regions of India. Most studies (19; 49%) evaluated perspectives of patients with drug-sensitive TB (DS-TB) (including pulmonary and extrapulmonary TB), 4 (10%) assessed presumptive TB patients, and 12 (31%) did not specify. Four (10%) studies assessed perspectives of MDR-TB or MDR-TB/HIV co-infected patients, all of which were qualitative.

3.2. Quality assessment

The quality assessment found that 8 of 29 quantitative studies (28%) did not use a questionnaire that was pilot tested, 18 (62%) used a pretested questionnaire but did not describe the methodology of testing, and only 3 (10%) utilized and fully described pre-tested tools. None used previously published, validated and reliable tools. Information on non-responders was only included in 4 (14%) studies, which raises concerns over non-response bias. Five studies (17%) did not include information on ethics reviews or patient consent. Several studies did not adequately describe the methods (16; 55%), results (9; 31%), and discussions (18; 62%), with insufficient information to allow replication or lack of consideration of limitations. Qualitative studies fulfilled most criteria, however, none of the studies considered the relationship between the researcher and participants. Results of the full quality criteria and assessment can be viewed in the supplementary materials.

3.3. Themes of user-experience

Thirty-six (92%) studies in the review informed on themes of user-experience (the other three reported solely on overall patient satisfaction). Provider-related factors and convenience were major themes with more than 50% of studies including information on them, and supplies and equipment availability, confidence, information and communication, waiting time, stigma (enabled by the health system), and confidentiality were minor themes. Fig. 2 illustrates the number of studies that contained each theme. Major findings from each theme are summarized in Table 2. Evidence for each theme, including specific quantitative data and qualitative findings from each primary study are tabulated and available in the supplementary materials.

When the influence of factors including type of TB, geographic region, or type of health system were explored, no discernible patterns were observed. Most studies did not consistently define, report, or differentiate between variables; for example, although some studies did include EPTB, TB-Diabetes, and TB-HIV patients, their experiences were not disaggregated. This was consistent with studies evaluating both public and private sector care. Thus, it was determined appropriate to synthesize findings across all studies. Any differences with regards to these factors that may have emerged are noted in the below text.

3.3.1. Provider-related factors (26/36 studies; 72%)

Poor experiences with providers' availability, technical capacity, or attitude often influenced patients to switch providers or not adhere to treatment [62,63,72–76].

Availability: The consistent, reliable availability of health workers affected the user-experience of patients in 8 studies [58,59,68,72,73,77–79]. In 2 quantitative studies in Uttar Pradesh (UP), a majority of patients agreed that a DOTS provider was regularly available [58,59]. In other regions, the irregular availability or absence of DOTS providers led to significantly more patients stopping treatment [COR: 11.9, 95% CI: 4.8, 29.8] [73], to patients facing barriers completing diagnosis or treatment [68,72], feeling dissatisfied [58,77], and missing injections and pills for DOTS [79].

Technical capacity: In 14 studies, the competence, efficiency and technical ability of health workers to provide TB services, including diagnosis, treatment, and counselling also impacted user-experiences [59,61–63,66,71,74,75,79–84]. Several patients, predominantly in Mumbai and Karnataka, reported experiencing health system delays and frustration due long, redundant pathways to diagnosis [75,82], the doctor advising inappropriate, unnecessary diagnostic tests [75,80,81], suggesting and treating for incorrect diagnoses [74,75,81], and lengthy symptomatic treatments prior to a diagnosis [75,81]. Once diagnosed, patients also experienced provider-related barriers to initiating treatment [66]. In 3 studies in Delhi, several patients were refused enrollment in treatment as they were deemed unsuitable for the commitment required for DOTS [62,63,83]. For MDR-TB/HIV patients in Mumbai, DOTS providers did not supervise the drug intake, leaving patients to self-administer while sitting at the clinic [79]. Patients in Delhi and Karnataka expected health workers to provide psychological and medical support when facing side-effects but were disappointed to not receive appropriate counselling [62,84].

"If a patient gets vomiting sensation after taking tablets, TB centre staff should take care of the patient. But these people just ask the patient to go away and vomit." [65 year old male TB patient, Karnataka] [84].

Alternatively, quantitative studies in rural Karnataka and UP report patients satisfied with professional competence, skill and efficiency to treat [71] and appreciation of personal attention for side effects through DOTS [59], respectively.

Respect: The behaviour and attitude of health workers were cited in 16 studies by patients as having impacted their user-experience [57–62,68,73,75,77–79,83–86]. In 5 studies that specifically quantified patient perceptions of providers' behaviour or attitude, a majority of

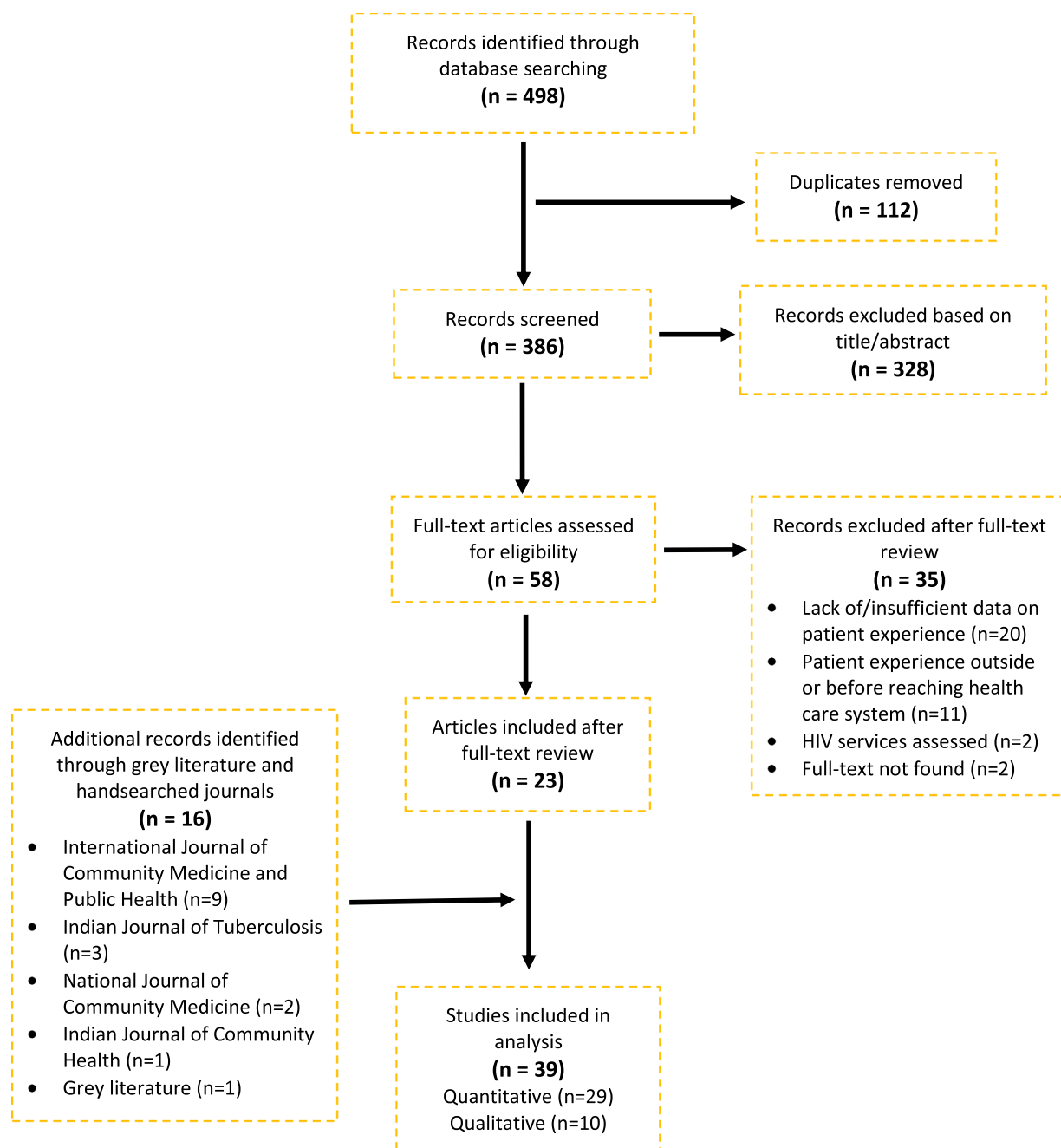


Fig. 1. PRISMA flow diagram for review on TB patient experience in India [56].

patients reported being satisfied or viewed it favourably [57–61]; 4 of these studies were conducted amongst patients attending DOTS in UP, while 1 study was in Madhya Pradesh (MP). Positive experiences are supported by qualitative evidence from Karnataka, Delhi and Mumbai where patients narrated instances where providers went out of their way to support patients psychologically [85], financially [62], or by adapting to patients' unique needs and preferences for DOTS [79,84,85]. Patients greatly appreciated this flexibility and trust, particularly from PP's [84] and in rural regions [85] in South India, including DOTS providers coming early in the morning [84,85] or allowing patients to take their medicines at home where they are more comfortable when experiencing immediate side-effects [79].

On the other hand, rude behaviour of staff was blamed by some patients in various regions for dissatisfaction with care [58,77], dropping out of care [73], and as a barrier to completing treatment [68,78]. Patient narratives from qualitative studies in Delhi and Karnataka

highlighted unhelpful staff attitude and disrespectful behaviour towards patients, in particular for not sympathizing with side-effects [62,75,84]. This disrespect caused patients to switch providers or refuse further DOT treatment.

3.3.2. Convenience (25/36 studies; 69%)

Ease of use: Twenty-four studies from across regions included patients impacted by the ease of use of TB care delivery, including the frequency of visits and schedules of DOTS centres [57–65,68,70,73,74,76–79,83–89]. Out of these, 22 studies included patients finding the timing and schedule of care delivery inconvenient and difficult to use. Patients consistently found the frequency of DOTS visits to be a challenge and barrier during treatment [57,60–62,64,68,70,76,84,85]. The unsuitable timings of clinics conflicted with work and daily activities, which were reported in 15 studies as reasons for DOTS non-compliance or interruption [63,65,73,74,79,83], delays during treatment and diagnosis [64,77,86,87], and as a general problem or

Table 1
Characteristics of included studies (n = 39).

Study	City, State or UT (Region)	Study design	Study setting	Type(s) of health service evaluated	Sample size	Study population
QUANTITATIVE (n = 29)						
1. Charles et al., 2010	Chennai & Madurai, Tamil Nadu (South)	Cross-sectional	Community Government facilities	Public, Private	640	Chest symptomatics
2. Dandona et al., 2004	Andhra Pradesh & Tamil Nadu (South), Maharashtra (West), Rajasthan (North)	NR		Public	314	PTB, EPTB patients
3. Dhingra et al., 2004	Delhi (North)	NR	New Delhi TB Centre	Public	36	PTB patients with pleural effusion
4. Divija et al., 2015	Tamil Nadu (South)	Cross-sectional	DOTS or DMC centres in 4 medical colleges	Public	20	NSP TB patients
5. Goel et al., 2011	Karnataka (South)	Cross-sectional	DOTS centres	Public	98	NSP TB patients receiving DOTS
6. Grover et al., 2003	Punjab (North)	Cross-sectional	Community	Public, Private	192	Chronic chest symptomatics
7. Gupta et al., 2010	Delhi (North)	Retrospective cohort	Tertiary-level TB institute	Public, Private	366	PTB, EPTB patients
8. Gupta, 2015	Uttar Pradesh (North)	Cross-sectional	DOTS centres	Public	400	Patients attending DOTS
9. Haque et al., 2014	Uttar Pradesh (North)	Longitudinal	DMCs	Public	117	Patients registered for DOTS
10. Jaggarajama et al., 2009 ^a	Chennai, Tamil Nadu (South)	Cross-sectional	Government facilities	Private	104	Patients who shifted from private to public health facility
11. Jebamalar et al., 2018	Chennai, Tamil Nadu (South)	Cross-sectional	Government facilities	Public, Private	197	Newly diagnosed PTB patients registered for intensive phase of Category 1 ATT)
12. Mallick et al., 2017	West Bengal (East)	Unmatched case control	Community (registered under RNTCP)	Public	202	NSP TB patients registered for DOTS [99 cases (treatment non-completion) + 103 controls (completion)]
13. Mehra et al., 2013	Uttarakhand (North)	Prospective descriptive	Referral hospital	Public	98	SP PTB patients that defaulted after referral to district TB centre for DOTS
14. Mistry et al., 2016	Maharashtra (West)	Retrospective survey	Slums	Public, Private	76	PTB patients who had completed treatment including TB-diabetes (n = 6) and TB-HIV (n = 4)
15. Patel et al., 2013	Ahmedabad, Gujarat (West)	Cross-sectional	DOTS centre	Public	160	PTB patients with treatment delay
16. Paul et al., 2012	West Bengal (East) and Andhra Pradesh (South)	Retrospective cohort	Government facilities	Public	150	PTB patients with treatment delay
17. Pranavi et al., 2017	Puducherry (South)	Cross-sectional	DMC	Public	200	Presumptive TB patients referred to DMC
18. Rai et al., 2015	Madhya Pradesh (Central)	Observational	DMC cum DOTS centres	Public	67	Non-adhering PTB, EPTB patients
19. Rai et al., 2017	Madhya Pradesh (Central)	Cross-sectional	DMC cum DOTS Centres	Public	337	Patients registered for DOTS
20. Rashmi & Vijaykumar, 2010	Karnataka (South)	Cross-sectional	Government PHC	Public	30	TB patients attending PHC
21. Sawase et al., 2016	Maharashtra (West)	Cross-sectional	DOTS centre in Malvani slum	Public	65	Smear positive, smear negative, & EPTB patients taking DOTS
22. Selvam et al., 2007	Tamil Nadu (South)	Cross-sectional	Government facilities	Public	601	NSP PTB patients, diagnosed and treated at government facilities
23. Srinath 2018	Karnataka (South)	Cross-sectional	TB Unit	Public	160	PTB patients that visit TB unit
24. Srivastav and Mahajan, 2014	Uttar Pradesh (North)	Cross-sectional	DMCs	Public	220	Diagnosed TB cases enrolled in DOTS
25. Srivastava et al., 2017	Uttar Pradesh (North)	Observational	DMCs	Public	300	PTB, EPTB patients registered at DMC
26. Sudha et al., 2003	Tamil Nadu (South)	Longitudinal	Community	Public, Private	98	Chest symptomatics
27. Sukumaran et al., 2002	Kerala (South)	Cross-sectional	District TB centres	Public	100	PTB patients registered for DOTS
28. Tiwari & Wavare, 2015	Madhya Pradesh (Central)	Cross-sectional	DOTS centre	Public	150	PTB, EPTB patients referred to DOTS centres
29. Yamini et al., 2017	Andhra Pradesh (South)	Cross-sectional	Tertiary care hospital	Public, Private	100	SPTB patients in hospital TB ward
QUALITATIVE (n = 10)						
30. Benbaba et al., 2015 ^{b,c}	Mumbai, Maharashtra (West)	NR	MSF Clinic	Public, Private	12	DR-TB patients
31. Furin et al., 2014 ^b	Mumbai, Maharashtra (West)	NR	MSF Clinic	Public, Private	12	HIV-MDR-TB coinfecting patients
32. Isaakidis et al., 2013 ^b	Mumbai, Maharashtra (West)	NR	MSF Clinic	Public, Private	12	HIV-MDR-TB coinfecting patients
33. Jaiswal et al., 2003	Delhi (North)	NR	Chest clinics and DOTS centres	Public	40	PTB, EPTB patients who stopped treatment
34. Rakesh et al., 2016	Kerala (South)	NR	Community	Public	29	TB patients that just completed treatment (or in last month)
35. Singh et al., 2002	Delhi (North)	NR	Chest clinics	Public	59	Patients who refused
or were denied DOTS						
36. Tripathi et al., 2015 ^c	Uttar Pradesh (North)	Grounded theory	DR-TB Centres	Public	12	MDR-TB patients
37. Yellappa et al., 2017	Karnataka (South)	NR	Community	Public, Private	4	TB (n = 3) & TB-diabetes (n = 1) patients
38. Yellappa et al., 2016 ^d	Karnataka (South)	NR	Government facilities	Public, Private	33	PTB, EPTB patients
39. Yellappa et al., 2017 ^d	Karnataka (South)	NR	Government facilities	Public, Private	33	PTB, EPTB patients

ATT = Anti-tubercular treatment, RNTCP = Revised National TB Control Program; DMC = Designated Microscopy Centre; DOTS = Directly Observed Therapy, Short course; PHC = Primary Health Centre; MSF = Médecines Sans Frontières; SP = smear-positive; PTB = pulmonary TB; EPTB = extrapulmonary TB; MDR-TB = multi-drug resistant TB; WHO = World Health Organization. a = the study reported data from 1997 (pre-RNTCP) and 2005 (post-RNTCP) separately, only 2005 data were included in this review. b = data from these three studies originate from the same larger pool of data. c = these studies are mixed-method, however only their qualitative component was relevant and assessed for this review. d = data from these two studies originate from the same larger pool of data.

dissatisfaction in availing treatment [57,58,60,78,88].

“...If he [another TB patient] does not go for his treatment, he will die and if he does not go for work, his children will die” [65 year old male TB patient, Karnataka] [84].

Qualitative data reveal that patients had to make adjustments to their daily routines, and in some cases endure pain and breathlessness to reach the facility every alternate day [62,84,85]. Contrastingly, 2 studies in rural settings in UP and MP, reported a majority of patients finding timings of DOTS centres convenient or not affecting work [59,61]. Few studies included certain vulnerable populations that expressed facing further inconveniences and difficulties undertaking treatment; these included poor individuals, sole wage earners, and daily wage labourers [84,85], as well as persons with physical disabilities [88], respiratory co-morbidities [62], mental health issues [74], and the weak and ill [64,65] who found it arduous and unfeasible to physically attend and commit to DOTS regularly. Outside of DOTS, the frequency of visits to various labs and facilities during diagnosis was also a cause for negative user-experience [89].

Continuity of care: Ensuring continuity of care in circumstances requiring travel and attending social or emergency events was a concern for patients in 6 studies in various regions [62–65,74,85]. Patients reported DOTS non-adherence due to having to leave town [63,65,74], attend family functions such as weddings [64,74,85], and emergencies such as an illness or death in the family [62,74]. Continuity was particularly a concern for patients with roots in rural villages who would need to travel back home, and those whose work requires migration for business or a new placement [62]. Two studies in Delhi reported that a notable number of patients had returned to their home village and halted treatment due to a lack of programme mechanisms facilitating re-entry into care [62,63].

3.3.3. Supplies and equipment availability (12/36 studies; 33%)

Twelve studies informed on the impact of supplies and equipment on patient perspectives [57,62–66,68,70,71,78,84,88]. Having sufficient material resources at a health centre, such as a reliable supply of affordable medicines [57,62,84] and drinking water at the DOTS centre [88] facilitated a positive user-experience. Negative user-experiences were caused by inadequate supply or shortage of drugs [63,68,78], inadequate seating provision or drinking water at DOTS centre [65], and lack of diagnostic equipments [70,71]. In 1 study in rural West Bengal, a large number of patients reported a lack of diagnostic testing at the original clinic and subsequent need for referral to a Designated Microscopy Center (DMC) [66].

3.3.4. Confidence (10/36 studies; 28%)

In 10 studies from various regions, confidence emerged as a part of user-experiences [62,63,65,67–69,73,82,86,89]. Patients reported a lack of faith, trust, or belief in the efficacy of their treatment [63,65,67,82], and in the RNTCP or a government doctor [62,68,73]. Lack of confidence in the treatment was cited in 5 studies by patients as a reason for treatment interruption [62,63] and non-completion [65,67,73]. Alternatively, some patients in South India expressed faith in their chosen provider (public or private) [69,89], and the trusted reputation of the DMC [86].

3.3.5. Information and communication (10/36 studies; 28%)

Out of 10 studies, 7 studies from South India and 3 from North reported some patients feeling frustrated or lost due to being provided inadequate information [58,62,65,70–72,75,78,85,89]. This included information on the disease and prevention, the tests and explanation of test results, treatment regimens, side-effects and complications. In some cases, lack of awareness of a monitoring schedule led to MDR-TB patients missing follow-up examinations [70] and migrants not being aware of a transfer facility [74]. On the other hand, health education and communication from health workers helped several patients stay

informed and be equipped to manage their side-effects and alcoholism [58,71,78,85].

3.3.6. Waiting time (8/36 studies; 22%)

Eight quantitative studies informed on waiting time [58,60,61,68,71,78,88,90]. A large proportion of patients in 2 studies were satisfied with the waiting time at DOTS centres in MP and Karnataka [61,71]. In Mumbai and UP, the waiting time to receive DOTS medicines for a majority of patients was less than 10 min in 2 studies, but longer than 20 min for some [60,88]. A small number of patients perceived waiting time as a barrier during treatment [78,90], diagnosis [68], and for having a satisfactory experience with care [58].

3.3.7. Stigma enabled by health system (4/36 studies; 11%)

Qualitative studies showed how aspects of TB care can promote stigma according to some patients [62,85,89,91]. For HIV/MDR-TB co-infected patients in Mumbai, taking medicines and experiencing side-effects in front of others during DOTS was embarrassing and demeaning and reinforced the stigma of having both TB and HIV [91]. Similarly in Karnataka, patients felt stigmatized during diagnosis when having to cough violently to produce a sputum sample in front of others [89]. In Delhi, being labelled and perceived as a “defaulter” prevented several patients from being able to re-join treatment or be treated with respect from health staff [62].

3.3.8. Confidentiality (4/36 studies; 11%)

Confidentiality emerged as a concern for patients in 4 studies based in South India [84,85,89,92]. Patients were found to prefer taking DOTS from a distant place [84,85] or visiting a private provider or a non-community DOTS provider [84,85,92], even if its inconvenient, in order to protect their confidentiality and avoid social stigma. Coughing to produce a sputum sample for diagnosis also required privacy, and patients were willing to go home or switch providers to achieve this [89].

“I was offered treatment from a DOT provider nearby, but I denied due to confidentiality issues.” [24 year old female with lymph TB, Kerala] [85].

3.4. Patient satisfaction

Seven out of 39 included studies (18%) directly measured patient satisfaction with various aspects of TB care in India, including services provided at a DOTS centre or DMC, RNTCP treatment, DOTS medicines, and treatment with current provider (including private) (Table 3) [57,58,60,61,93–95]. No meta-analysis was conducted due to the high level of variability in aspects of care assessed and sampling methodologies. The proportion of patients reporting as satisfied or fully satisfied ranged between 68% and 97% amongst all studies. Out of the 7 studies, 5 (71%) were in North India and 6 (86%) evaluated satisfaction within public sector care. In other studies, general dissatisfaction with services was reported by patients a reason for discontinuing care with a provider [77,90], initial provider-preference [69,92], treatment interruption [67,73], and delay in diagnosis [86,87].

4. Discussion

This review of 39 studies provided a comprehensive overview of available data on user-experience with quality of TB care in India. Overall, user-experience was highly impacted by two major themes: providers and convenience, as well as six minor themes of confidence, supplies and equipment, information, waiting time, stigma, and confidentiality. Negative and positive experiences were reported for each theme, suggesting that they act as both barriers and facilitators, and as important determinants of good quality care from the patients’ perspective. The themes were also observed to interact and overlap in some

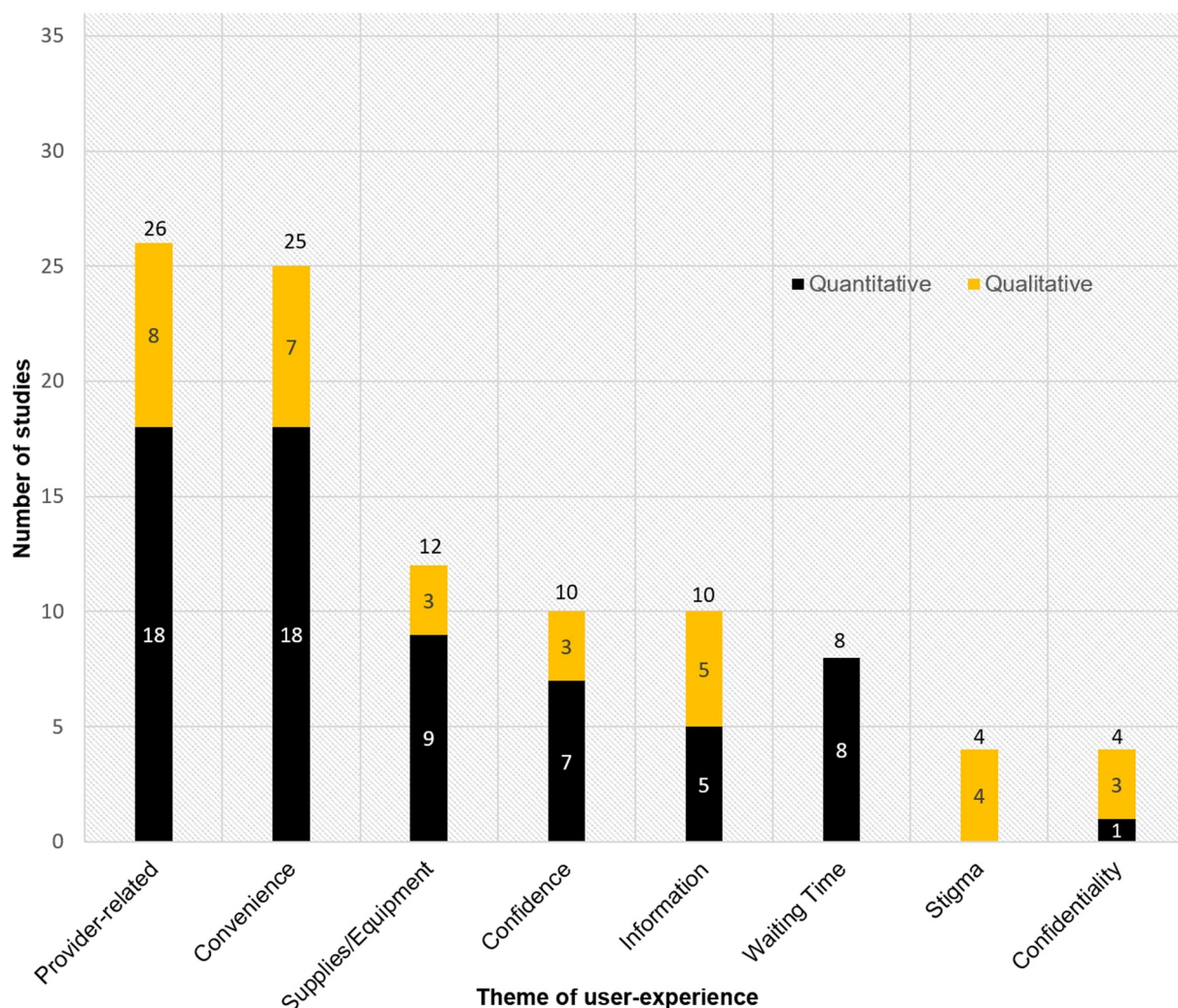


Fig. 2. User-experience themes identified for TB quality of care in India.

instances; providers often enabled convenience, determined information received, and inspired confidence in care; while convenience (particularly the structure of DOTS) impacted confidentiality and stigma, choice of providers, and was enabled by available supplies and short waiting times.

Seven studies that directly quantified patient satisfaction reported a majority of patients being satisfied with various aspects of care. High overall satisfaction with TB care has been found in several other low- and middle-income countries (LMICs), including Brazil, Ethiopia, Nigeria, and South Africa, although they often mask substantive shortcomings in specific aspects of care such as staff availability [31,96–98]. Similarly, in this review, major deficiencies that often influenced patients to give up treatment or switch providers, were 1) dissatisfaction with the inconvenient timings and frequency of visits for DOTS which conflicted with work, travel, emergencies and other life priorities; and 2) providers being unavailable, disrespectful, or unable to diagnose, treat or counsel patients appropriately.

One explanation for the discrepancy between high patient satisfaction and varying or negative user-experiences is the limitations in the measure of patient satisfaction. Satisfaction is only an indication of acceptable or expected care, as opposed to superior service [99,100]. Hence, patient satisfaction is based on subjective expectations of care, which in turn can be influenced by an individual's personal characteristics and sociodemographic variables such as present health status, education, or age [101–104]. Vulnerable populations can be most

unwilling to express criticism as they fear losing health services as a consequence [105]. In several studies in this review, patients' main reasons for reporting high satisfaction were early improvement from symptoms and free medicines available [57,60,95]. Hence, it is possible that present health status (early symptomatic relief) and socio-economic status of TB patients, that are largely low-income [106–108], may have influenced their expectations.

In addition, the questionnaires used in the quantitative studies to evaluate both patient satisfaction and user-experiences were not previously published, validated or reliable, which is important when collecting accurate data on patient views for improvements in quality of care [109]. Further, most studies were in a limited number of Southern and Northern States, largely within the public sector amongst pulmonary, drug-sensitive TB patients, and did not stratify experiences of people in poverty or with disabilities and comorbidities. This demonstrated the dearth of patient perspective studies in several high-burden regions of the country, on patients with DR-TB and comorbidities, within the private sector, and amongst vulnerable populations.

Regardless, available user-experiences data can provide insight into gaps in quality of care and why patients may be leaving public TB services. Barriers and facilitators related to the major themes, provider and convenience, have been reported by patients in many other LMICs, including the aforementioned countries, as well as Burkina Faso, Iran, Pakistan, and Senegal [96,110–118]. Stigma from healthworkers [119], information and communication [96,111], waiting time [96,97,115],

Table 2
Main findings on user-experience themes for quality of TB care.

Theme	Key findings
Provider-related factors (n = 26) <i>Availability (n = 8)</i> <i>Technical capacity (n = 14)</i> <i>Respect (n = 16)</i>	<ul style="list-style-type: none"> ● A majority of patients in 5 quantitative studies experienced positive or acceptable provider behaviour or attitude <ul style="list-style-type: none"> ■ 298/300 (99%) in UP viewed attitude of DMC staff as cooperative [57] ■ 105/117 (90%) in UP listed good behavior of DOTS providers as an advantage [58] ■ 327/400 (82%) in UP said Yes to satisfaction with behaviour of DOT provider [59] ■ 116/220 (52.7%) in UP perceived attitude of DOTS staff as fully sympathetic and 55 (25%) as somewhat sympathetic [60] ■ 304/337 (90%) in MP were satisfied with behavior of DOTS centre staff [61] ● Patients appreciated flexibility in DOTS schedule and understanding by providers ● Those that stopped treatment sometimes blamed rude and unhelpful staff behaviour ● Some found poor counselling support, especially for managing side-effects, while others were motivated due to health worker communication ● Providers were largely reported as available in 2 quantitative studies <ul style="list-style-type: none"> ■ 115/117 (98%) listed regular availability of DOTS provider as an advantage in UP [58] ■ 317/400 (79%) said Yes to regular availability of DOTS provider in UP [59] ● However, several patients that stopped treatment viewed non-availability of DOTS provider as a barrier ● In 12 studies, provider performance and inability to detect and treat TB efficiently often resulted in poor user-experiences with diagnosis and initiating treatment, including being refused treatment
Convenience (n = 25) <i>Ease of use (n = 24)</i> <i>Continuity of care (n = 6)</i>	<ul style="list-style-type: none"> ● In most [22] studies, regular DOTS viewed as inconvenient and time-consuming due to frequent visits and unsuitable timings that conflict with daily work and life activities <ul style="list-style-type: none"> ■ 34/62 (55%) patients in UP dissatisfied due to non-suitable opening time of DOTS centres [58] ■ 60/201 (30%) cited attendance of DOTS as most common problem in availing treatment in UP [60] ■ 17/39 (44%) identified difficulty to come on alternate days as reason for dissatisfaction in UP [57] ■ 125/337 (37%) were not satisfied with frequency of visits to DOTS centre in MP [61] ● In contrast, a majority of patients in 2 studies in rural areas found DOTS convenient <ul style="list-style-type: none"> ■ Of 117 patients in UP, 107 (92%) report DOTS was not time consuming and 82 (70%) report it did not affect their work [59] ■ Of 337 patients in MP, 314 (93%) were satisfied with timing of DOTS centre, 317 (94%) with location, and 212 (62.6%) with frequent visits [61] ● Data on vulnerable populations was very limited, however some studies reported poor patients feared missing work due to regular DOTS attendance and people with physical or mental disabilities that had trouble physically attending frequent visits ● DOTS was often interrupted when social events, emergencies, travel arise, particularly for patients working in urban regions with homes in rural areas <ul style="list-style-type: none"> ■ 12/40 (30%)(62) and 12/50 (22%) [63] patients in Delhi interrupted DOTS due to returning to their home village ■ 58/160 (36%) in Gujarat delayed treatment due to having to attend social events [64] ■ 38/160 (24%) in Karnataka stopped treatment as they had to go out of station [65]
Supplies and Equipment Availability (n = 12)	<ul style="list-style-type: none"> ● A reliable supply of medicines and diagnostics was important to patients and caused positive and negative experiences <ul style="list-style-type: none"> ■ 130/150 (87%) faced delays in treatment initiation due to lack of smear microscopy in the original clinic in rural West Bengal and Andhra Pradesh [66] ■ 175/261 (67%) were satisfied due to availability of free medicines in UP [57] ● Only 2 studies mentioned experiences with amenities such as drinking water and seating
Confidence (n = 10)	<ul style="list-style-type: none"> ● Patients primarily lacked faith or trust in their treatment or in the RNTCP/government providers and cited lack of confidence as a reason for not completing treatment <ul style="list-style-type: none"> ■ 44/98 (44.8%) of patients who stopped treatment attributed it to limited trust in the curative ability of DOTS in Uttarakhand [67] ■ 19/47 (40.4%) that faced barriers initiating treatment lacked confidence in their provider [68] ■ 87/262 (33%) first chose a private provider due to faith in them in Tamil Nadu [69] ● Others were confident in their chosen provider (public or private) and in the services of the DMC
Information and Communication (n = 10)	<ul style="list-style-type: none"> ● Information and awareness on the disease, prevention, tests, results, treatment, transfer facilities and particularly side-effects were not always readily available, but desired by patients <ul style="list-style-type: none"> ■ 7/12 (58%) of MDR-TB patients in UP missed follow-up examinations because they were not informed about the monitoring schedule [70] ● Provider communication facilitated information-giving for several patients <ul style="list-style-type: none"> ■ 277/400 (69%) in UP were explained by health staff about the disease [58]
Waiting time (n = 8)	<ul style="list-style-type: none"> ● Waiting times were generally positively rated, usually less than 10 min for receiving DOTS medicines <ul style="list-style-type: none"> ■ 290/337 (86%) satisfied with waiting time to get medical care in MP [61] ■ 26/30 (87%) satisfied with duration to wait in Karnataka [71] ● A small number of patients found long waiting time to be a barrier
Stigma enabled by health system (n = 4) Confidentiality (n = 4)	<ul style="list-style-type: none"> ● Taking medicines and coughing to produce sputum in front of others made patients feel stigmatized ● Patients labelled as “defaulters” also faced stigma from health workers and were rejected from re-entry into treatment ● Confidentiality was important to maintain during DOTS and diagnosis ● Some patients preferred far away places and non-community-based DOTS providers to protect confidentiality

RNTCP = Revised National TB Control Program; DMC = Designated Microscopy Centre; DOTS = Directly Observed Therapy, Short course; MDR-TB = Multi-Drug Resistant TB; MP = Madhya Pradesh; UP = Uttar Pradesh.

Table 3
Patient satisfaction reported for TB care in India (n = 7).

STUDY, YEAR State (Region), Health Sector Evaluated	SAMPLE SIZE	SATISFACTION REPORTED	SATISFACTION WITH
Dhingra et al., 2004 <i>Delhi (North), Public</i>	36	97% satisfied 2.8% unsatisfied	DOTS medicines
Gupta, 2015 <i>Uttar Pradesh (North), Public</i>	400	67.8% highly satisfied 16.7% just satisfied 15.5% not satisfied	RNTCP treatment
Grover et al., 2003 <i>Chandigarh (North), Public/Private</i>	192	70% satisfied	Treatment with current provider
Rai et al., 2017 <i>Madhya Pradesh (Central), Public</i>	337	71.5% fully satisfied 28.5% somewhat satisfied	Services provided at DMC cum DOTS centres
Srivastav and Mahajan, 2014 <i>Uttar Pradesh (North), Public</i>	220	78.6% fully satisfied 8.2% somewhat satisfied 13.2% unsatisfied	Services provided at DOT centers
Srivastava et al., 2017 <i>Uttar Pradesh (North), Public</i>	300	87% satisfied 13% not satisfied	Services of the DMC
Sukumaran et al., 2002 <i>Kerala (South), Public</i>	100	91% satisfied 6% unhappy 3% stopped treatment after 2nd month	DOTS

confidence [116,120] and confidentiality [96,110] were also factors in some studies, including in Nepal and Vietnam. The common themes demonstrate that these aspects of quality of TB care may be important for users globally in a variety of contexts. This review also re-iterated findings in these studies and previous literature reviews on patients' appreciation of an individualized and flexible DOTS approach to enhance convenience and patient-centered care [121–125]. Additional themes in these studies that did not play a major role in this review included patient involvement or autonomy in decision-making [110], general conditions of facilities (i.e. cleanliness) and amenities (such as toilets) [96,97,112,115], co-ordination or organization of care [96,111], as well as additional support services such as nutrition and food supplements [111,112]. This could be because the studies in this review did not evaluate these aspects in their questionnaires and interviews, however these are important to explore in the Indian context for future research.

Several patients in this review were found to switch between public and private health sectors due to poor user-experiences, often including limited provider support and mistrust of the public health system. When undertaking treatment with PPs, some patients perceived greater protection of confidentiality and allowance of flexibility in DOTS, and hence more user-friendly or patient-centered care. Studies from TB providers' perspective support this finding as they express patients prefer them due to a lack of confidence in the often overburdened public sector, where patients feel alienated and ignored due to less time with the doctor [126,127]. PPs describe how their TB patients prefer private facilities because of convenience and personalized care that is able to meet individual needs, as opposed to the rigid control activities of the district TB programme. It has been noted that the rigid enforcement of DOTS may be threatening optimal adherence and patient dignity, particularly for vulnerable groups [128–130].

The perceived enhanced convenience, confidentiality and confidence in the private sector may explain why some patients prefer to receive care with PPs, despite the provision of free medicines and diagnostics by the government. However, public practitioners have been found to be more technically competent compared to PPs, with regards to detecting and treating TB appropriately [126,131,132]. This is an important consideration as user-experiences were largely impacted by the kind of provider patients choose, have access to, or the DOTS provider they are assigned, consistent with systematic reviews and studies showing patient-practitioner relationship being the most important health service factor impacting satisfaction [104,133].

In addition to the provider, patient- and context-related factors also play a role in determining user-experiences and explaining the variability in this review. This includes socio-economic status or the caste

system which is highly relevant in the Indian context. Lower social caste has been significantly associated with longer waiting times ($p < 0.0001$) in private facilities [134]. Studies on TB providers' perspectives in India suggest that they may treat patients differently, providing poor and less educated patients with less information and agency as they question their ability to understand medical information and perceive them as irrational when prioritizing life concerns over adherence [126,127,135]. Varying gender roles may have also influenced experiences. Both women and men may find the structure of DOTS inconvenient, as generally female TB patients struggle with managing daily child-care and household responsibilities [136,137], and male TB patients are concerned with retaining employment, being typically the primary earners [138,139]. Studies in South India and Maharashtra have also found that women face greater social consequences of having TB, such as marriageability, divorce, familial rejection and harassment [136–141]; this may make confidentiality and stigma a greater concern amongst women. Further, predominantly more male TB patients are impacted by addiction to substances (primarily alcohol and tobacco) [64,65,93,141,142] which suggests additional counselling needs from providers.

Differences in experiences may also be due to varying urban and rural contexts. Rural facilities may not always be equipped with full diagnostic services, making availability of supplies and equipment a greater concern [143,144]. In addition, patients from rural regions living and working in urban regions also have unique needs as indicated in this review, particularly for maintaining continuity of DOTS when temporarily migrating for work or family emergencies. This aligns with the finding that rural-to-urban migration may increase the risk of loss-to-follow-up amongst TB patients [143,145]. Further, important commitments such as weddings, festivals, and functions have been previously associated with TB treatment non-completion in several regions of India [146]. The cultural significance of such events may be unique to the Indian context and explored further with regards to maintaining continuity of TB care.

5. Limitations

This study has certain limitations. Firstly, the data analysed in the review were often part of studies wherein the primary goal was to assess diagnostic delays, care-seeking pathways, provider-preference, or patient adherence to treatment, not to directly assess patient satisfaction or experiences. This may have also skewed answers and results to be more negative as the sample in several studies consisted of patients who stopped or delayed care or were dissatisfied with services. Secondly, only one reviewer conducted the full-text screening, data

extraction and analysis, therefore there is a possibility of bias in the study selection and results presented. Thirdly, the search strategy did not contain keywords related to India (such as RNTCP or names of States) and only searched seven journals, which may have resulted in missing some studies. Finally, included studies did not report disaggregated data and were heterogeneous in data collection, thus data synthesis was limited and no concrete conclusions could be made on specific factors affecting user-experience and patient satisfaction.

6. Recommendations for TB programme and future research

For greatest impact within the TB programme, two broad, interconnected areas in line with the major user-experience themes are recognized as areas for quality improvement: the interpersonal aspect of care and the patient-centeredness of care. For improving interpersonal care, providers should be adequately trained in TB care, particularly with an emphasis on the practices of counselling, information-giving, and empathy, including ways to support and understand patients' side-effects and external circumstances. To improve the patient-centeredness of care, DOTS should be negotiated in partnership with the user according to their unique needs and circumstances. Flexibility in DOTS has become increasingly accepted and may make for more efficient TB control in resource-limited settings, as it focuses on the most at-risk populations that require adherence monitoring [147,148]. This can involve the co-design of an individualized schedule, location, and provider with patients that ensures adherence while being logistically feasible and emotionally desirable to patients. The schedule should also be dynamically adaptable to maintain continuity of care during life events and migration. The scale-up and institutionalization of effective digital innovations, such as 99DOTS and videoDOTS, may also promote the user-friendliness of DOTS [123,149,150].

To design these service quality improvements, it is recommended that the programme use principles of human-centered design, including end-user engagement in every stage of decision-making and strategizing. User consultations and joint working groups with patients, providers, and programme staff could enable the co-design of services that ensures patient satisfaction, user empowerment, and improved TB programme performance, as well as introduce equity and human-centeredness in a traditionally top-down approach [41,151]. In addition, it is recommended that the TB programme develop or adapt a tool to assess patient perspectives nationally and collect user-experience data systematically as part of routine monitoring and evaluation activities. A validated, standardized tool that includes qualitative narratives and disaggregates demographic data will allow for user-experience to be measured across states, sectors, populations, and types of TB for robust comparative assessments and identification of targeted populations, regions, and interventions for service quality improvement [152]. In so doing, the programme will not only be able to pinpoint bottlenecks for effective decision-making and resource-allocation, but also highlight areas where service delivery is achieving high user-satisfaction and successful outcomes, to emulate. Harnessing user-experience data in this way to inform service quality improvements is likely to improve patient retention, usability, confidence and value of public sector TB care.

7. Conclusion

This review identified several important themes of user-experience with TB quality of care in India, particularly provider-related factors of availability, respect and technical capacity, as well as convenience, namely the schedule and frequency of DOTS that can conflict with patients' daily lives. While several aspects of care were viewed favourably by patients, poor user-experiences were often responsible for patients stopping treatment and dropping-out of the public health system. Patient-centeredness, or the user-friendliness of TB care can be improved by introducing individualized and flexible DOTS, and

ensuring trained, compassionate providers. Due to heterogeneity amongst studies, there is a need for standardized data collection using validated tools to allow for stronger conclusions and assessments of experiences across populations and contexts, and to collect missing data on vulnerable people, patients with DR-TB and comorbidities, and the private sector. To close gaps in the cascade of care and reach the 'missing' millions, it will be important to address these quality of care dimensions that are important to patients and to co-design a more user-centric system with them.

Declaration of Competing Interest

The Author declares that there is no conflict of interest.

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Supplementary materials

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