

User experience and patient satisfaction with tuberculosis care in low- and middle-income countries: A systematic review

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ABSTRACT

Background: Patient-centered care is at the forefront of the End TB strategy, yet little is known about user (patient's) experience and patient satisfaction with TB services. Our study aims to systematically review quantitative studies evaluating user experience and TB patient satisfaction within the health care system.

Methods: Five medical databases were systematically searched between January 1st, 2009 and December 31st, 2018. English studies assessing user experience and patient satisfaction within the healthcare system from a TB patient's perspective in low and middle-income countries, were included.

Results: Thirty-five studies from 16 low and middle-income countries evaluated three major themes; facilities and patient centeredness ($n = 23$), patient-provider relationship ($n = 22$) and overall satisfaction ($n = 19$). Overall study quality was low as they used varying tools to measure user experience and patient satisfaction.

Conclusion: Our study shows large variability in measurement of user experiences and patient satisfaction. Studies reported that patients were mostly satisfied with TB care services, and those that were dissatisfied were substantially more likely to be lost to follow-up. The high satisfaction rates could have been due to lack of education on good quality patient care or fear of losing access to health care. A standardized patient centered tool could be designed to help assess user experience and patient satisfaction to allow comparisons among health systems and countries.

1. Background

Tuberculosis (TB) is the leading cause of infectious diseases mortality worldwide, affecting 10 million people globally and killing 1.3 million in 2018 [1]. In the same year, there were an estimated 500,000 new cases of rifampicin-resistant TB (RR-TB) of which 78% were multi-drug resistant TB (MDR-TB) cases, partly a consequence of the mismanagement of TB [1]. The End TB Strategy has an objective of providing TB patients with high-quality care, in which a patient's human rights are central to the design and delivery of TB services [2].

Although patient-centered care is the focus of the End TB strategy, poor quality care is widespread across many low- and middle-income countries (LMICs) [3–5]. Several studies have assessed the quality of TB care in different settings and the resulting impact on patients. In India

and South Africa there have been large losses to follow-up of patients at different points of the cascade of care, where 50% of patients are diagnosed and treated adequately. This was evaluated for latent TB infection (LTBI) globally where 20% of patients were diagnosed and treated adequately [6–8]. Healthcare providers are only correctly managing 21–50% of TB patients, and patients often visit multiple providers before receiving a correct diagnosis [9–12]. Furthermore, once patients in LMICs enter the health system, they are faced with long diagnostic delays and often have trouble accessing adequate treatment [13,14]. For TB patients, this can lead to devastating outcomes. Poor quality care has led to an estimated 469,956 amenable TB deaths in 2016 [15].

The recently published Lancet Global Health Commission on High Quality Health Systems in the SDG Era has acknowledged the need to

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improve quality of care in LMICs and has recommended that health systems be measured according to elements of competent care and user experience [5]. Improving user experience in health care is crucial to improve retention in care, adherence to treatment and public trust in the health system. The Lancet Global Health Commission defined a positive user experience as being treated with dignity and respect, having a health provider who communicates clearly, provides autonomy and confidentiality and avoids discriminatory behaviours [5]. Health services should also be easy to navigate, with short wait times and be attentive to people's values and preferences. This can also be defined as patient centered care. TB being a disease that is stigmatized and primarily affects vulnerable social groups, emphasizes the importance of patient-centered care [16]. Previous studies have highlighted complex pathways to diagnosis [17,18] and high healthcare costs for patients [19], but little is known about the user experience and satisfaction with the health system. To our knowledge, there has been no systematic review of the literature examining TB user experience or satisfaction within the health system. The themes identified in this review can serve as a first step in understanding the reasons for poor quality user experience in TB care.

2. Methods

Our study aims to systematically review the current quantitative literature on user experience and satisfaction within the health system, synthesize current evidence, and identify further areas of research.

The protocol for this exploratory systematic review was registered on PROSPERO (CRD42018091504). The systematic review was classified as exploratory as the studies were expected to have varying exposure and outcome definitions. Hence, a broad definition of user experience and patient satisfaction were used for this review. In this study, user experience was defined as a patient's experience in the health system [20]. Patient could be a presumptive TB patient, asymptomatic patient and/or a confirmed TB patient. Patient satisfaction was defined as a patient's evaluation of the services offered within the health system, relative to their expectations of care [20]. Finally, the health system was defined as services received from both formal and informal healthcare providers.

2.1. Search strategy

Using a broad search strategy, five medical databases were searched; PubMed, Embase, Ovid Global Health, CINAHL, and Web of Science. The initial search strategy for PubMed was approved and verified by a medical librarian at McGill University (see Appendix A). An initial search was conducted on October 24th, 2017 and an updated search was conducted in April 2019. The search included all articles from January 1st, 2009 to December 31st, 2018. No language or geographic restrictions were applied.

2.2. Study selection

Two independent reviewers conducted the title/abstract and full text screening of all articles (Fig. 1). Articles were assessed using predefined inclusion criteria, and any conflicts were resolved by a third independent reviewer. The following studies were eligible for inclusion; (1) quantitative study design (2) studies with full text articles in English, (3) studies assessing user experiences with standard of TB care within the health system, (4) studies assessing user experiences from the patient's perspective (first person), (5) studies involving all types of TB patients and presumptive TB patients (including latent TB infection), and (6) studies conducted amongst adults (>15 years old). Studies were excluded if: (1) qualitative study design, (2) conducted in high-income countries (as defined by the World Bank), (3) assessed user experience outside the health system (including accessibility to health care facilities) (4) evaluated costs of health care, (5) assessed user

experience or satisfaction through a third person perspective (i.e. from health care worker perspective), (6) in the grey literature, (7) involved services provided outside of the health system's standard of care (e.g. prisons, interventions), (8) studies assessing user experiences outside the standard of TB care (i.e. quasi-experimental studies, RCTs) and (9) studies where no full text could be found were excluded.

2.3. Data extraction

A data extraction form was created and piloted. It aimed to collect information on study characteristics, themes of user experience and patient satisfaction, frequencies and associations to outcomes (i.e. treatment outcomes, treatment delay and treatment adherence). Data was extracted by two independent reviewers using Excel. All discrepancies were resolved by consensus between the two reviewers.

2.4. Quality assessment

A quality assessment was conducted for all studies, however studies were not prioritized and/or excluded due to their quality. The Cochrane and National Heart, Lung, and Blood Institute (NHLBI) Quality Assessment Tools for Observational Cohort, Cross-Sectional Studies, and Case-control studies [21] were used. The main elements of quality assessed were selection bias, information bias, measurement bias, and confounding. All discrepancies between quality assessments were discussed among the two independent reviewers and resolved.

2.5. Data analysis

Studies used a wide number of measures that reflected components of user experience and satisfaction. Hence an inductive approach, informed by qualitative methodology, was applied to identify key themes relating to the review question. Measures of patient satisfaction from a random sample of 5 (14%) articles were accordingly first coded independently by two reviewers, after which consensus on 3 key themes was reached through full team consultation. Each study was then reviewed for reporting on one or more of these 3 themes (see Table 1).

Studies were categorized based on theme (e.g. patient provider relationship) and were analyzed based on frequency of themes identified, using Excel. Subsequently, descriptive statistics such as mean, median and frequencies were reported for themes of TB patient experience and patient satisfaction. Associations between aspects of user experience and treatment outcomes, delay or adherence (odds ratios, risk ratios and/or hazards ratios) were also reported.

Study variables, and exposure and outcome measures varied largely thus pooling and meta-analyses were not conducted.

3. Results

As shown in Fig. 1, 35 quantitative studies were eligible for inclusion in our systematic review. Studies assessed user experience in TB care by evaluating the patient's perspective on the health care facilities, the providers, or by assessing overall satisfaction. Table 1 shows the main study characteristics and themes identified for each study. Studies were conducted in 16 LMICs namely; Botswana, Brazil, China, Ethiopia, India, Indonesia, Kenya, Morocco, Myanmar, Nigeria, Pakistan, Peru, Serbia, South Africa, Sudan, and Uganda.

3.1. Quality assessment

Figs. 2 and 3 represent the quality assessment for cross sectional, cohort and case-control studies ($n = 35$). Most studies (22, 63%) did not report sample size and power calculations. Among cross-sectional and cohort studies ($n = 25$), 18 (72%) either did not report or did not have a participation rate of over 50% which could have led to selection bias. In the cohort study, the exposure was measured only once over

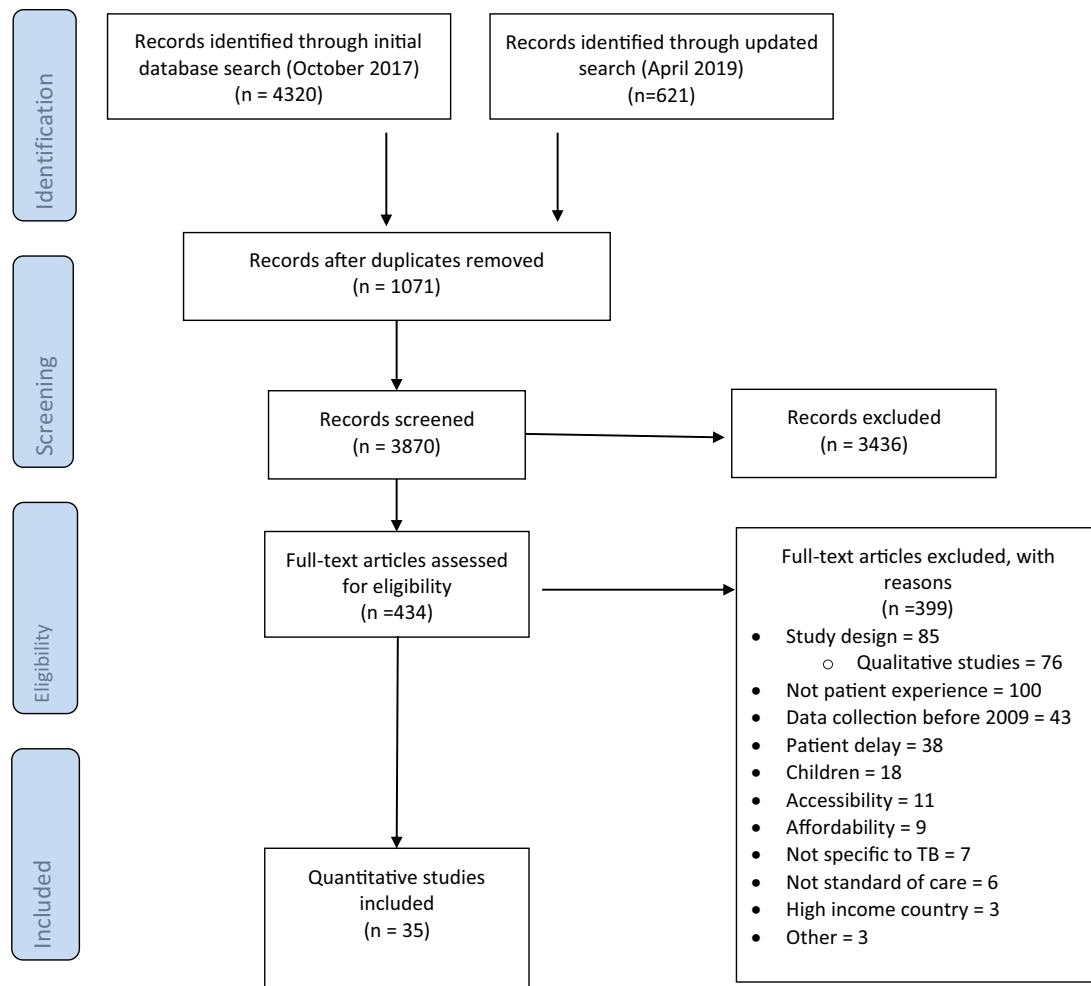


Fig. 1. PRISMA diagram on study selection.

time. All case control studies, and the cohort study did not blind or did not report on whether the assessors of exposure (i.e. patient experience) were blinded to the patient's case or control status ($n = 10$). Further, there was large variability in tools used for measuring user experience and patient satisfaction (Table 1). Ten (29%) studies adapted pre-existing tools; of which two (20%) were based on each other [22,23]. Five (14%) tools were developed by the authors of the studies but were not validated before use, while six (17%) studies developed and validated their tools. One (3%) study used a pre-validated stigma scale. Eight (23%) did not report the details of their tool.

3.1.1. Facility infrastructure and patient-centeredness

Twenty-three studies (23/35, 66%) identified characteristics and patient-centeredness of the facilities as a theme influencing patient's experience with TB care. The theme of facility patient-centeredness was divided into four subthemes: wait times, ease of use, availability of equipment/supplies, and cleanliness. Six (6/23, 26%) studies evaluated overall satisfaction with facilities. For example, a study in Nigeria used a five-point Likert scale to evaluate patient satisfaction scores with different aspects of patient care. 'Amenities' was given an overall average satisfaction score of 3.27/5.00 [0.49] by patients, which was one of the least satisfying areas of care [24]. A study from Pakistan found that the lack of gender specific facilities in the health centers contributed to patient delay [25]. Five studies (5/23, 22%) reported that the cleanliness of the facility affected patient satisfaction. Cleanliness referred to comfort and proper hygiene.

Fifteen studies (15/23, 65%) examined how a patient's wait time contributed to their experience. Seven studies (7/15, 47%) measured

satisfaction with wait times. Responses varied among studies, where studies in Uganda, South Africa and India [26–28] reported that long wait times contributed to low satisfaction with services but studies in Brazil, Ethiopia and India reported that patients were satisfied with wait times [23,29–31]. Five studies (5/15, 33%) reported associations of wait times with loss to follow up (LTFU). For example, one study reported that patients were more likely to be LTFU if wait times exceeded 2 h (OR = 4.2, CI 2.18–8.02) [32]. Certain studies observed that inconvenient clinic hours resulted in LTFU. A study in South Africa described that TB patients enrolled in public health facilities were more likely to be LTFU during treatment when clinic hours were inconvenient (OR: 3.4, CI 2.2–5.2) [33]. In Indonesia, being unable to collect TB medication from a community lung clinic was significantly associated with patient LTFU (HR 22.00, CI 3.88–124.78) [34].

Eight (8/23, 35%) studies highlighted that the medical equipment or supplies in a facility affected patient experience. Two studies, in Thailand and India, reported that availability and quality of drugs influenced their choice of provider and sector [27,35]. Further, two studies observed that the absence of drugs and supplies such as syringes, needles, and microscopes in public facilities led to non-adherence to treatment and dissatisfaction, respectively [30,36]. In contrast, another study in Ethiopia demonstrates that 278 (99%) of patients in public facilities reported that drugs were always available [37].

3.1.2. Patient-provider relationship

Twenty-two (22/35, 63%) studies reported patient-provider relationship as a theme affecting a patient's experience in the health system. The subthemes identified were confidentiality, technical

Table 1
Study characteristics and themes of TB patient experience (n = 35).

Author	Year	Country	Study design	Sample size	Health care sector	Disease type	Data collection methods	Data collection tool used	Gender distribution		Age distribution (mean, SD)		Themes identified			
									Male N	Female N	Mean	SD	Patient provider relationship	Facility infrastructure and patient-centeredness	Overall satisfaction	
Ali and Prins	2016	Sudan	Case control	315	Public	PTB/EPTB	Medical records and interviews	NR	205	110	34.9	33.7	14.7	Yes	Yes	Yes
Adane et al.	2013	Ethiopia	Cross sectional	280	Public	PTB/EPTB	Self administered questionnaire	Self made, not validated	157	123	43.9	32.9	14.8	Yes	Yes	No
Babikako et al.	2011	Uganda	Cross sectional	133	Public/private	PTB	Individual interviews	Adapted the PS-13 and SIMS scales	67	66	49.6	33.6	10.55	Yes	Yes	Yes
Brunello et al.	2009	Brazil	Cross sectional	100	Public	NR	Individual interviews	Self-made, not validated	69	31	31.0			Yes	No	Yes
Burapat et al.	2009	Thailand	Cross sectional	756	Public	PTB/EPTB	Individual interviews	Self-made, not validated	528	228	30.2	34	NR	Yes	Yes	No
Charles et al.	2010	India	Cross sectional	606	Public/private	Presumptive TB	Individual interviews	Self-made, not validated	NR	NR	NR	NR	NR	Yes	Yes	Yes
Chimbindi et al.	2014	South Africa	Cross sectional	296	Public	NR	Individual interviews	Self-made, validated	140	156	52.7	38		Yes	Yes	Yes
Culqui et al.	2012	Peru	Case Control	870	Public	Pulmonary TB	Individual interviews	Questionnaire adapted from Lalone Laframboise model ^a	522	348	40.0	NR		Yes	No	No
Elbireer et al.	2011	Uganda	Case Control	344	Public	NR	Individual interviews	Self-made, not validated	176	168	48.8	36	8	Yes	Yes	No
Finlay et al.	2012	South Africa	Case Control	1164	Public	PTB/EPTB	Self administered questionnaire	Self-made, adapted from previous study	100	1064	91.4	NR	NR	Yes	Yes	No
Hla et al. [50]	2009	Myanmar	Case Control	400	Public	NR	Self administered questionnaire	Self-made, validated	NR	NR	NR	NR	NR	Yes	Yes	No
Lafaiete et al.	2011	Brazil	Cross sectional	88	Public	NR	Self administered questionnaire	Validated and adapted from Villa and Ruffino-Netto ^b	NR	NR	NR	NR	NR	Yes	Yes	No
Mehra et al.	2013	India	Cross sectional	555	Public	PTB	Self administered questionnaire	NR	379	176	31.7	NR	NR	Yes	No	Yes
Ndwiga et al. [51]	2016	Kenya	Cross sectional	140	Public	NR	Self administered questionnaire	NR	86	54	38.6	35	NR	Yes	No	No
Nezenga et al.	2013	Ethiopia	Cross sectional	531	Public	NR	Self administered questionnaire	Adapted from Birhanu et al. 2010 and Grant Marshall and Ron Hays (1994) ^c	291	240	45.2	NR	NR	Yes	Yes	Yes
Onyeonoro et al.	2015	Nigeria	Cross sectional	258	Public/private	NR	Individual interviews	Adapted from used by Nwabueze et al. (2010) (PS-38) ^d	139	119	46.1	34	12.8	Yes	Yes	Yes
Pinto & Udwardia	2010	India	Cross sectional	200	Private	TB	Individual interviews	NR	NR	NR	NR	NR	NR	Yes	Yes	Yes
Portela et al.	2014	Brazil	Cross sectional	4345	Public	NR	Individual interviews	Adapted from Babikako et al. (2011)	2507	1838	42.3	40.9	NR	Yes	Yes	Yes
Rankosha and Ehlers [52]	2016	Botswana	Cross sectional	101	NR	PTB/EPTB	Individual interviews	NR	56	45	44.6	NR	NR	Yes	No	Yes

(continued on next page)

Table 1 (continued)

Author	Year	Country	Study design	Sample size	Health care sector	Disease type	Data collection methods	Data collection tool used	Gender distribution			Age distribution (mean, SD)			Themes identified	Overall satisfaction
									Male N	%	Female N	%	Mean	SD		
Rashmi and Vijaykumar	2010	India	Cross sectional Cohort	30	Public	NR	Individual interviews	Module 6, Agha Khan foundation	NR	NR	NR	NR	No	Yes	Yes	
Rutherford et al.	2013	Indonesia	Cohort	265	Public	PTB/EPTB	Individual interviews	Self-made, validated	119	44.9	146	55.1	NR	Yes	Yes	
Salame et al. [53]	2017	Brazil	Cross sectional	236	Public	LTBI	Individual interviews	Adapted from Rutherford et al. (2013) ^b	NR	NR	NR	40	Yes	Yes	Yes	
Satti and Nagaraj	2016	India	Case Control	240	Public	PTB/EPTB	Individual interviews	Self-made, validated	144	60.0	96	40.0	9	Yes	No	
Shalini and Harsh	2014	India	Cross sectional	220	Public	TB	Individual interviews	NR	160	72.7	60	27.3	NR	Yes	Yes	
Slama et al. [54]	2013	Morocco	Case Control	320	Public	PTB/EPTB	Individual interviews	Self made, validated	258	80.6	62	19.4	33	Yes	No	
Sseengooba et al.	2016	Uganda	Cross sectional	178	Public	MDR-TB	Self administered questionnaire	NR	76	42.7	102	57.3	NR	Yes	Yes	
Sulaiman et al.	2013	Sudan	Cross sectional	107	Public	PTB	Individual interviews	Self made, adapted from NTP questionnaire	76	71.0	31	29.0	41	Yes	Yes	
Tamhane et al. [55]	2012	India	Cross sectional	126	Public/private	PTB	Individual interviews	Self made, validated	75	59.5	51	40.5	NR	No	No	
Xu et al.	2017	China	Case Control	1425	NR	MDR-TB	Other*	NR	1025	71.9	400	28.1	44.5	No	No	
Megene et al. [56]	2016	Ethiopia	Cross sectional	251	Public	NR	Individual interviews	Self made, adapted from Hill et al. (2005) ^c	119	47.4	132	52.6	40	Yes	Yes	
Ruru et al. [57]	2018	Indonesia	Case Control	264	Public	NR	Individual interviews	NR	155	58.7	109	41.3	NR	No	No	
Saqib et al.	2018	Pakistan	Cross sectional	269	Public/private	PTB	Individual interviews	NR	139	51.7	130	48.3	NR	Yes	Yes	
Stosic et al. [58]	2018	Serbia	Case Control	124	NR	MDR-TB	Individual interviews	Health survey in Serbia for 2013 and European TB related stigma scale by Yang (2016) ^g	84	67.7	40	32.3	NR	Yes	No	
Yin et al. [59]	2018	China	Cross sectional	1342	NR	NR	Self administered questionnaire	Health Survey 2nd wave for 2013 and European TB related stigma scale by Yang (2016) ^g	905	67.4	437	32.6	47.72	Yes	No	
Htun et al. [60]	2018	Myanmar	Cross sectional	210	Public	MDR-TB	Individual interviews	Guidelines of management of MDR-TB, Myanmar (2013)	131	62.4	79	37.6	41	No	No	

^a Ministerio de Salud. Norma Técnica de Salud para el Control de la Tuberculosis. Lima: Dirección General de las Personas; 2006.
^b Villa TCS, Ruffino-Netto A. Questionário para a avaliação de desempenho de serviços de atenção básica o controle da TB no Brasil. J Bras Pneumol. 2009; 35(6):610–2.
^c Birhanu Z, Assefa T, Woldie M, Morankar S. Determinants of satisfaction with health care provider interactions at health centres in central Ethiopia: a cross sectional study. BMC Health Serv Res 2010; 10:78; Marshall GN, Ron D: Hays The Patient Satisfaction Questionnaire short- form (PSQ-18). Santa Monica, CA: RAND; 1994.
^d Nwabueze SA, Adogu POU, Ilika AL, Asuzu MC. Comparative analysis of patient satisfaction levels in HIV/AIDS care in secondary and tertiary health care facilities in Nigeria. Afrimed J. 2010;1(2):1–9.
^e Rutherford M, Ruslami R, Anselmo M. Management of children exposed to Mycobacterium tuberculosis: a public health evaluation in West Java, Indonesia. Bull WHO Press. 2013; Article ID: BLT.13.118414.
^f Hill PC, Stevens W, Hill S, Bah J, Donkor SA, Jallow A, Lienhardt C (2005). Risk factors for defaulting from TB treatment: a prospective cohort study in Gambia. International Journal of TB and lung diseases 9(12):1349–1355.
^g Yang TT. Development and evaluation of tuberculosis-related stigma scale. J Public Health Prevent Med 2016; 27: 119–122.

Author	Research Question defined	Study population defined	Sample Size	Controls selection	Valid and reliable identification/definition of cases & controls	Cases clearly defined and differentiated from controls	Randomly selected from eligible cases/controls (if < 100% of eligible cases and/or controls were selected)	Use of concurrent controls	Exposure/risk occurred prior to event defining a case	Exposure/risk were clearly defined, valid, reliable	Blinding of case or control status	Confounding variables measured and adjusted
Ali & Prins	Green	Green	Green	Green	Green	Green	Red	Green	Green	Green	Yellow	Green
Culqui et al.	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Yellow	Green
Elbireer et al.	Green	Red	Red	Green	Red	Green	Red	Green	Green	Green	Yellow	Green
Finlay et al.	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Yellow	Green
Hla et al.	Green	Green	Yellow	Green	Green	Green	Yellow	Green	Green	Green	Red	Green
Satti et al.	Green	Red	Red	Green	Green	Green	Yellow	Yellow	Green	Green	Yellow	Red
Slama et al.	Green	Green	Red	Green	Green	Green	Green	Green	Green	Green	Green	Red
Xu et al.	Green	Red	Red	Yellow	Red	Green	Yellow	Yellow	Green	Green	Yellow	Green
Ruru et al.	Green	Green	Red	Green	Green	Green	Green	Green	Green	Green	Yellow	Green
Stosic et al.	Green	Green	Green	Green	Green	Green	Grey	Green	Green	Green	Yellow	Green

*green= yes, yellow=not reported, red=no, grey=not applicable

Fig. 2. Quality assessment of included case-control studies (n = 10)

*green = yes, yellow = not reported, red = no, gray = not applicable.

capacity of healthcare workers (i.e. ability to provide diagnosis, treatment and counselling), responsiveness, health education and stigma. Most studies (14/22, 63%) reported overall positive experiences with healthcare providers, and seven (7/22, 32%) reported overall negative experiences. For example, a study conducted in Brazil among patients

in the public sector observed that the highest rates of satisfaction (>89%) were due to doctor availability during consultation and privacy during attendance [23]. However, a study conducted in South Africa among patients visiting the public sector observed that 267 (44%) patients were dissatisfied with the provider [38]. Factors

Author	Research Question defined	Study Population defined	Participation Rate <50%	Subject Recruitment	Sample Size & Power	Exposure prior to outcome	Sufficient timeframe	Levels of exposure measured	Valid, reliable exposure measure	Exposure over time	Valid, reliable outcome measure	Blinding	Loss to follow up <20%	Confounding variables measured and adjusted
Adane et al.	Green	Green	Green	Green	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Green
Babikako et al.	Green	Green	Yellow	Green	Green	Red	Green	Red	Green	Red	Green	Yellow	Grey	Green
Brunello et al.	Green	Green	Green	Green	Green	Red	Yellow	Green	Red	Yellow	Green	Yellow	Grey	Red
Burapat et al.	Green	Green	Green	Green	Green	Red	Green	Green	Green	Green	Green	Yellow	Grey	Green
Charles et al.	Green	Red	Green	Red	Green	Red	Yellow	Red	Green	Green	Red	Yellow	Grey	Red
Chimbindi et al.	Green	Green	Yellow	Green	Green	Red	Green	Red	Green	Red	Green	Yellow	Grey	Red
Lafaiete et al.	Green	Green	Yellow	Green	Green	Red	Yellow	Red	Green	Red	Green	Yellow	Grey	Red
Mehra et al.	Green	Green	Green	Green	Green	Red	Green	Red	Green	Red	Green	Yellow	Grey	Red
J. Ndwiwa et al.	Red	Green	Yellow	Green	Green	Red	Yellow	Green	Yellow	Yellow	Red	Yellow	Grey	Red
Nezenega et al.	Green	Green	Green	Green	Green	Red	Yellow	Green	Green	Red	Green	Yellow	Grey	Red
Ornyeonor et al.	Green	Green	Yellow	Green	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Red
Pinto et al.	Green	Green	Green	Red	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Red
Portela et al.	Green	Green	Red	Green	Green	Red	Yellow	Green	Green	Red	Green	Yellow	Grey	Red
Rankosha & Ehlers	Green	Green	Green	Green	Green	Red	Green	Green	Red	Red	Green	Yellow	Grey	Red
Rashmi & Vijaykumar	Green	Red	Yellow	Red	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Red
Salame et al.	Green	Green	Yellow	Red	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Green
Shalini and Harsh	Green	Green	Yellow	Green	Green	Red	Yellow	Green	Green	Red	Green	Yellow	Grey	Red
Ssengooba et al.	Green	Green	Green	Green	Green	Red	Green	Green	Red	Red	Green	Yellow	Grey	Red
Sulaiman et al.	Green	Green	Green	Red	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Red
Tamhane et al.	Green	Green	Yellow	Green	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Red
Megene et al.	Green	Green	Yellow	Green	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Green
Sagib et al.	Green	Green	Red	Red	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Green
Yin et al.	Green	Green	Yellow	Green	Green	Red	Yellow	Green	Yellow	Red	Green	Yellow	Grey	Green
Htun et al.	Green	Green	Yellow	Green	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Green
Rutherford et al. ¹	Green	Green	Red	Green	Green	Red	Green	Green	Green	Red	Green	Yellow	Grey	Green

¹ This study was a cohort study. Green= yes, yellow=not reported, red=no, grey=not applicable; LTFU: loss to follow up

Fig. 3. Quality assessment of included cohort and cross sectional studies (n = 25)

¹This study was a cohort study. Green = yes, yellow = not reported, red = no, gray = not applicable; LTFU: loss to follow up.

influencing their dissatisfaction were: indifference by healthcare providers, delay and non-availability of healthcare providers. A study in Indonesia observed that patients who were not satisfied with their provider were more likely to be LTFU (Hazard Ratio (HR): 2.58, 95%CI: 0.99–6.75) [34].

Seven studies (7/22, 32%) reported that staff and/or health professional attitudes affected patients' experiences. A study in Sudan reported that 96% of patients found providers to be receptive [39]. However, a study in India reported 20 (9%) of DOTS patients felt that the staff was rude [40]. A Ugandan study reported that bad or fair staff conduct was significantly associated with treatment LTFU (OR 2.7, 95% CI: 1.02–7.25) [32]. Six studies (6/22, 27%) observed provider responsiveness as one of the factors influencing patient-provider relationships. Responsiveness included availability to listen, recording of patients' complaints, referrals from the provider, talking about the disease, and clarification of patients' doubts. A study in Brazil among patients in the public sector found that 56 (64%) of patients felt that reception of providers was good. Further, 53 (60%) of patients felt that providers had good availability and 55 (62.5%) of patients thought there was good guidance from the health team [31]. A study conducted in Uganda found that not being given the chance to express concerns about TB treatment was significantly associated with patient LTFU (OR: 3.5, 95% CI: 1.67–7.21) [32].

Three studies (3/22, 14%) observed that the capacity to keep information confidential and the technical capacity of providers were factors influencing a patient's experience. A study conducted in India identified that confidentiality was the most influential factor in choosing a medical provider for patients (468, 62%) [35]. A study conducted in Peru observed that 175 (67%) of patients felt discomfort during their treatment, due to having a bad relationship with the health worker and doubting their technical capability [41]. Six (6/35, 17%) studies identified information and health education as factors affecting a patient's experience in the health system. A study in Uganda in the public sector identified a significant association between not receiving adequate health education during treatment and the treatment discontinuation (OR 5.3 [95% CI: 1.94–14.57]) [32]. A study conducted in Morocco among TB patients in the public sector found that the perception of a patient having little or no explanation about the disease was significantly associated to LTFU (aOR 2.87, 95%CI 1.53–5.36).

Stigma was observed amongst HIV/TB or multi-drug resistant TB (MDR-TB) patients in eight studies (8/35, 23%). A study in India observed that those working at DOTS centers discriminated against HIV-TB co-infected patients more than other TB patients (aOR: 7.38; 95% CI: 2.32–23.39) [42]. A similar result was found with MDR TB patients, compared to drug sensitive TB patients (OR = 3.32; 95% CI = 1.40–7.86). Five studies (5/8, 63%) evaluated the association between stigma in the health system and TB patient treatment outcomes. A study in South Africa noted that feeling ashamed of having TB was associated with LTFU from treatment (aOR 2.0, CI 1.3–3.0) [33].

3.1.3. Overall patient satisfaction

Nineteen studies (19/35, 54%) measured the level of patient satisfaction with TB services in the health system overall without investigation of the specific aspect of the experience that influenced satisfaction. The tools to measure satisfaction are outlined in Table 1. Thirteen studies (13/19, 68%) measured patient satisfaction in only the public health system, while 4 (4/19, 21%) measured it in both the public and private, and 1(1/19, 5%) the private health system. Overall, studies reported that patients were either fully satisfied or satisfied with the availability and effectiveness of public TB services received [22,24,25,34,38,40,43]. For example, a study in Uganda measured patient satisfaction scores (maximum of 100) of the technical quality of care and management of a public and a private hospital [22]. The technical quality satisfaction score was 49.2 [4.7] for public health care and 96.6 [9.5] for private health care and were significantly different (p -value < 0.001). Management, defined as overall satisfaction with

patient care and hospital services in general, was scored at 91.1 [10.9] in the public hospital and 89.7 [13.2] in the private hospital, with no significant difference [22]. Five studies (5/19, 26%) reported that dissatisfaction of TB services was a reason for loss-to-follow-up (LTFU) or delaying treatment. In Indonesia, poor satisfaction of services in a community lung clinic was significantly associated with LTFU during treatment (HR = 3.85, CI 1.17–12.62) [34].

4. Discussion

This exploratory systematic review aimed to synthesize the quantitative published literature on user experience and patient satisfaction with TB care across LMICs. The studies found assessed TB patients' perspectives on the patient-centeredness of facilities ($n = 23$), the patient-provider relationship ($n = 22$) and overall patient satisfaction with TB services ($n = 19$). Studies reported that patients were mostly satisfied with TB care services, and those that were dissatisfied were substantially more likely to be LTFU. Within patient-centeredness of facilities, four subthemes were identified; wait times, ease of use, equipment and supplies, and cleanliness. Patient-provider relationship included six subthemes; staff and/or health professional attitudes, confidentiality, technical capacity of healthcare workers, responsiveness, health education and stigma.

Within each subtheme, negative patient experience was often reported to be associated with LTFU or treatment non-adherence. Healthcare staff and providers have the potential to improve patients' negative experiences, especially regarding increased patient health education, staff attitudes and technical capacity. Improving the technical capacity of healthcare workers and increasing the flow of information to patients can be addressed through healthcare staff trainings and medical workshops. To improve other aspects of care such as staff attitudes and stigma, encouraging the development of skills in patient counselling, cultural sensitivity and other soft skills may be required in medical trainings [16].

Although some studies reported negative patient experiences, the majority of studies reported high overall satisfaction of TB services. This is discrepant with evidence of widespread low quality of TB care (e.g. broken cascades of care and poor medical outcomes) [3]. The measures of satisfaction used in these studies may have been subject to acquiescence response bias, which tends to be more common among questionnaires comprising agree/disagree questions [44]. Further, patients from vulnerable and stigmatized populations are often less likely to express dissatisfaction with healthcare due to low expectations or fear of loss of services. For this reason, they may report a higher satisfaction for low quality care [5, 45]. These lower expectations could be from the lack of exposure to a good quality health system, and little access to information on health care [16]. It is therefore important to assess qualitative data to further understand reasons why patients are expressing high and/or low quality of TB services, as well as increase education on quality care.

Our study also shows large variability in measurement of user experiences and patient satisfaction. All studies used questionnaires to measure different aspects of care. Some studies ($n = 10$) used previously validated questionnaires, whereas others ($n = 5$) used self-created questionnaires which were not validated, and some ($n = 6$) used self-created questionnaires which were validated (i.e. piloted). Further, the questionnaires used had varying types of scales (i.e. 3-point Likert scale, vs yes/no vs 5 point-Likert scale). Since a standard measure of patient satisfaction was not used in these studies, the task of synthesizing the findings was challenging. Standardizing measurements of patient satisfaction can be beneficial, as data can be used for quality monitoring and improvement, within and across health facilities [46]. An example of an assessment tool to measure person-centered care was developed and validated in Kenya in 2017 for maternal health [47]. It contains 30 questions that cover 10 domains, several of which were similar to the themes identified in our study. They include dignity and

respect, privacy and confidentiality, communication, stigma, health facility environment and trust [47]. Of the studies included in our review, data collection was not repeated at a different point in time to document changes in patient experience. A standardized tool would be valuable for monitoring interventions that address user experience or patient satisfaction, in order to assess if quality is improving over time. There is a need for a standardized approach to measure user experience and patient satisfaction within TB care, and to ensure the tool's validity, acceptability, feasibility and reliability [48].

When measuring patient-centered care, patients can be included in the design of these tools, to ensure that their experience is being accurately represented [20]. This can be done through focus group discussions with patients, or through cognitive and pilot testing of questionnaires with patients [20,48]. While a tool can help to document user experience and patient satisfaction, the variability in our results represents the diversity of experiences that a TB patient can have. This can depend on the many factors listed in this review as well as the expectations of each patient [20]. To ensure that TB interventions and a quality improvement programs take into consideration the needs and expectations of patients in differing contexts, it is recommended that TB service and intervention design also directly involve patients. In the United States of America, among eight health organizations known for their successful patient-centered care, a variety of approaches to ensure patient engagement are utilized. This includes patient membership in advisory committees and quality improvement committees [49].

4.1. Limitations

There were several limitations to this study. Firstly, a reference back check was not conducted, which may have resulted in missing studies. Our search strategy was comprehensive, and we purposely searched a wide array of medical databases, but despite this we may have missed certain articles (especially since we limited the study to English language papers). Secondly, studies focusing on qualitative results and using a qualitative data collection method (i.e. focus groups) were excluded. This was due to the large number of articles resulting from our search and feasibility of analysis with a small team. Thirdly, this review may be biased with studies reporting positive results. It is possible that studies with negative patient experiences were not published, or that settings with poor user experience are unlikely to conduct such studies. Lastly, accessibility and cost of TB services were excluded from this review, as there have already been reviews published on these topics. They should continue to be considered when planning quality improvement measurements and programs.

5. Conclusion

Overall, user experience and patient satisfaction with TB care were documented in 35 studies conducted in 16 LMICs, in this systematic review. Areas of care that are important to TB patients were identified including; the patient-centeredness of facilities and patient-provider relationships. There is large variability in patient satisfaction within these areas due to subjective definitions of satisfaction, different methods of capturing user experience, and individual expectations of care. Standardized data collection tools to measure user experience and patient satisfaction with TB care are needed in order to minimize this variability, as well as to monitor and improve on patient-centered quality of TB care. Additionally, patient involvement would be crucial in the creation of these tools in order to reliably and accurately measure their experience and also reduce the frequent loss to follow up associated to user experience. TB programs should focus on improving user experiences and encourage retention to care, in order to help achieve the targets of eliminating TB by 2035.

Ethical statement

This study is a systematic review of published literature. Therefore, no human subjects were involved, and no ethics approvals were needed.

CRediT authorship contribution statement

Danielle Cazabon: Conceptualization, Data curation, Formal analysis, Validation, Visualization, Writing - original draft, Writing - review & editing. **Tripti Pande:** Conceptualization, Data curation, Formal analysis, Validation, Visualization, Writing - original draft, Writing - review & editing. **Paulami Sen:** Data curation, Writing - review & editing. **Amrita Daftary:** Conceptualization, Writing - review & editing. **Catherine Arsenaault:** Writing - review & editing. **Himani Bhatnagar:** Data curation, Writing - review & editing. **Kate O'Brien:** Writing - review & editing. **Madhukar Pai:** Conceptualization, Writing - review & editing.

Declaration of Competing of Interest

The authors do not have any conflicts of interest.

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DC, TP, AD and MP conceptualized and designed the systematic review study. DC and TP wrote the protocol, screened and extracted the papers, performed data analysis and wrote the manuscript. PS and HB assisted in screening, resolved disagreements and helped in data extraction. All co-authors assisted in revising the manuscript.

Appendix A. Search strategy

PUBMED

(tuberculosis[mesh] or tuberculosis[ti] or TB[ti])

AND

((patient satisfaction[mesh] OR patients/psychology[mesh] OR (patients[mesh] AND (qualitative research[mesh] OR "interviews as topic"[mesh] OR "community based participatory research"[mesh] OR narration[mesh])) OR ((patient[tiab] OR patients[tiab]) AND (experience*[tiab] OR perception*[tiab] OR perspective*[tiab] OR attitude*[tiab] OR qualitative[tiab] OR ethnograph*[tiab] OR narrative*[tiab] OR view*[tiab] OR ((action[tiab] OR participatory[tiab]) AND research[tiab]) OR mixed method*[tiab] OR mixed study[tiab] OR mixed studies[tiab] OR barrier*[tiab] OR facilitator*[tiab])) OR patient reported outcomes[mesh] OR patient reported[tw] OR patient acceptance of health care[mesh] OR patient acceptance[tw] OR patients acceptance[tw]) OR (patient satisfaction[tw] or patient rights[mesh]))

AND

((Delivery of health care[mesh:noexp] OR health system*[tw] OR health services[tw] OR health facilities, proprietary[mesh] OR health services[mesh] OR healthcare[tw] OR care[tw] OR patient care[mesh] OR caring[tw] OR health services accessibility[mesh]))

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