PLOS GLOBAL PUBLIC HEALTH

Stigma, depression, quality of life, and the need for psychosocial support among people with tuberculosis in Indonesia: A multi-site cross-sectional study

Ahmad Fuady[1,2], Bustanul Arifin[3,4], Ferdiana Yunita[5], Saidah Rauf[6], Agus Fitriangga[7], Agus Sugiharto[1], Finny Fitry Yani[8,9], Helmi Suryani Nasution[10], I. Wayan Gede Artawan Eka Putra[11], Muchtaruddin Mansyur[1], Tom Wingfield[12,13,14]*

1 Department of Community Medicine, Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia, 2 Primary Health Care Research and Innovation Center, Indonesian Medical Education and Research Institute, Faculty of Medicine Universitas Indonesia, Jakarta, Indonesia, 3 Faculty of Pharmacy, Universitas Hasanuddin, Makassar, Sulawesi Selatan, Indonesia, 4 Unit of Global Health, Department of Health Sciences, University of Groningen, University Medical Centre Groningen (UMCG), Groningen, The Netherlands, 5 Department of Community Medicine, Faculty of Medicine, Universitas Gunadarma, Depok, Indonesia, 6 Department of Nursing, Politeknik Kesehatan Kemenkes Ambon, Maluku, Indonesia, 7 Department of Community Medicine, Faculty of Medicine, Universitas Tanjungpura, Pontianak, West Kalimantan, Indonesia, 8 Department of Child Health, Faculty of Medicine, Universitas Andalas, Padang, West Sumatera, Indonesia, 9 Department of Paediatric, Dr. M. Djamil General Hospital, Padang, West Sumatera, Indonesia, 10 Department of Public Health, Faculty of Medicine and Health Sciences, Universitas Jambi, Jambi, Indonesia, 11 Department of Public Health and Prevention Medicine, Faculty of Medicine, Universitas Udayana, Kota Denpasar, Bali, Indonesia, 12 Department of Clinical Sciences and International Public Health, Liverpool School of Tropical Medicine, Liverpool, United Kingdom, 13 Department of Global Public Health, WHO Collaborating Centre on Tuberculosis and Social Medicine, Karolinska Institute, Stockholm, Sweden, 14 Tropical and Infectious Disease Unit, Royal Liverpool and Broadgreen University Hospitals NHS Trust, Liverpool, Liverpool, United Kingdom

* tom.wingfield@lstmed.ac.uk

Abstract

Stigma towards people with tuberculosis (TB-Stigma) is associated with other psychosocial consequences of TB including mental illness and reduced quality of life (QoL). We evaluated TB-Stigma, depression, QoL, and the need for psychosocial support among adults with TB in Indonesia, a high TB burden country. In this primary health facility-based survey in seven provinces of Indonesia, from February to November 2022, we interviewed adults receiving (a) intensive phase treatment for drug-susceptible (DS) TB at public facilities, (b) treatment at private facilities, (c) those lost to follow up (LTFU) to treatment, and (d) those receiving TB retreatment. We used our previously validated Indonesian TB-Stigma Scale, Patient Health Questionnaire-9, and EQ-5D-5L to measure TB-Stigma, depression, and QoL. Additional questions assessed what psychosocial support was received or needed by participants. We recruited and interviewed 612 people, of whom 60.6% (96%CI 59.6–64.5%) experienced moderate TB-Stigma. The average TB-Stigma scores were 19.0 (SD 6.9; min-max 0–50; Form A-Patient Perspective) and 23.4 (SD 8.4, min-max 0–50; Form B-Community Perspective). The scores were higher among people receiving treatment at private facilities (adjusted B [aB] 2.48; 0.94–4.03), those LTFU (aB 2.86; 0.85–4.87), males (aB 1.73; 0.59–2.87), those losing or changing job due to TB (aB 2.09; 0.31–3.88) and those living in a

rural area (aB 1.41; 0.19–2.63). Depression was identified in 41.5% (95% CI 37.7–45.3%) of participants. Experiencing TB-Stigma was associated with moderately severe to severe depression (adjusted odds ratio [aOR] 1.23; 1.15–1.32) and both stigma and depression were associated with lower QoL (aB -0.013; [-0.016]-[-0.010]). Informational (20.8%), emotional (25.9%) and instrumental (10.6%) support received from peers or peer-groups was limited, and unmet need for such support was high. There is a sizeable and intersecting burden of TB-Stigma and depression among adults with TB in Indonesia, which is associated with lower QoL. Participants reported a substantial unmet need for psychosocial support including peer-led mutual support groups. A community-based peer-led psychosocial support intervention is critical to defray the psychosocial impact of TB in Indonesia.

Introduction

Tuberculosis (TB) remains a major global public health challenge leading to 1.6 million deaths in 2021 [1]. The World Health Organization's 2015 End TB Strategy called for worldwide TB elimination [2]. However, achieving key Strategy targets including reducing TB incidence and mortality, and eradicating catastrophic costs, is complex and has been challenged further in recent years by the COVID-19 pandemic.

TB is well recognized as a social infectious disease with determinants including poverty, limited healthcare access, and—the often overlooked—stigma [3, 4]. People with TB, their families, and even social networks face persistent stigma from others including in the neighborhood and workplace [5]. Stigma is deeply rooted in myths, misconceptions, misunderstanding, and erroneous health beliefs concerning TB disease and those affected [6, 7]. Such stigma is pernicious and associated with social discrediting and profound feelings of "shame, self-rejection, and self-loathing" amongst those affected [8].

Stigma towards and experienced by people with TB, herein termed TB-Stigma, has been recognized by the Global Fund [9] and United Nations [10] as a global public health challenge and a critical barrier to achieving the World Health Organization (WHO) goal of ending TB by 2050 [11]. TB-Stigma is classified into enacted or experienced, anticipated, and internalized or self-stigma, all of which complicate efforts to control and eliminate TB [12, 13]. Enacted and anticipated stigma, ranging from expectation and fear of discrimination to experiences of stigmatizing behaviour by others, can prevent people with TB from disclosing their symptoms and signs or seeking care and being identified for testing [14]. This can compound delays in healthcare seeking and TB diagnosis [15] and reduce treatment adherence and success [16]. TB-Stigma among people with TB, including in both formal and informal work sectors, may also lead to income loss and catastrophic health expenditure [17]. Enacted and internalized stigma and the economic consequences of each can precipitate or aggravate mental illness [18] and reduced quality of life (QoL) [19, 20].

There is a substantial burden of TB-Stigma in low- and middle-income countries (LMICs), particularly with high TB burden [19, 21, 22]. Indonesia is a LMIC with 969,000 TB cases annually, contributing 9.2% of the total estimated TB incidence worldwide [1]. Despite these stark figures and the recognition of the vital role that addressing TB-Stigma will play in eliminating TB, there is limited evidence concerning TB-Stigma and its impact in Indonesia [23]. Of the handful of qualitative studies exploring stigma among Indonesian people with TB [24–26], there has been negligible concomitant assessment of associated symptoms of depression,

mental illness, and QoL; and little consideration of potential interventions to mitigate these psychosocial consequences of TB.

For Indonesia to work towards ending TB, it will be essential to measure the "psychosocial" impact and consequences of TB such as TB-Stigma, depression, and QoL; and to identify and address the need for psychosocial support amongst TB-affected people. This much-needed data will support generation of evidence to inform the design and delivery of impactful, sustainable, and locally appropriate psychosocial interventions to reduce TB-Stigma, mitigate mental illness, and improve people with TB's QoL. As part of a larger program of research, this study aimed to fill this knowledge gap in Indonesia by assessing TB-Stigma, depression, QoL and their correlations, as well as measuring the need for psychosocial support among adults with TB in Indonesia. The results of this study will support design of a community-based psychosocial support intervention and influence related national and international TB-Stigma policy and practice.
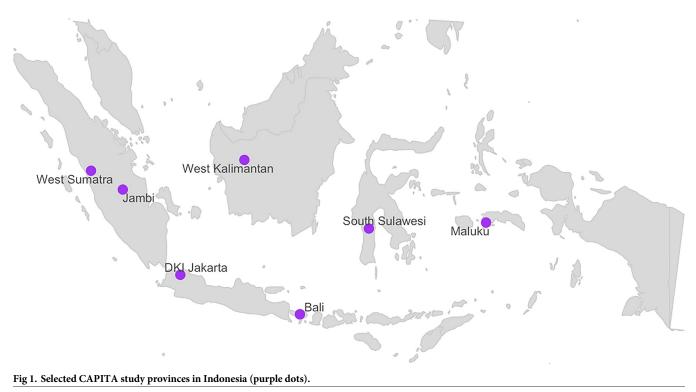
Methods

This study was part of the *Characterising and Addressing the Psychosocial Impact of Tuberculosis in Indonesia* (CAPITA) research programme, conducted from February to November 2022 [27]. The study findings will feed into the associated Medical Research Council Public Health Intervention Development-funded (MR/Y503216/1) "TB-CAPS" study to co-design and develop a community-based, peer-led psychosocial support intervention to combat TB-Stigma in Indonesia, which commences in July 2023.

Setting

CAPITA was a study consisting of a cross-sectional survey of adults with TB at primary health facilities in seven provinces of Indonesia. The provinces were selected purposively to represent areas of diverse geography (western, central, and eastern regions) and TB burden (medium to high) in Indonesia. Since TB-Stigma and TB psychosocial impact may vary between rural and urban areas [28, 29], we also purposively selected one urban city and one rural district in each province, based on Indonesian National Statistical Bureau data and consultation with the National TB Program (NTP) officers at the provincial level (**Fig 1**).

Participant selection

We interviewed adults aged ≥18 years at either public or private primary healthcare facilities receiving treatment for drug-susceptible (DS) TB free of charge under the coordination of the Indonesian NTP. We reviewed the NTP registers at each health facility and selected participants based on their TB treatment status. A priori, we pragmatically divided the potential participants into four groups to cover the broadest possible representative public-private mixed sample of people with DS-TB in Indonesia. *Group A* was people receiving DS-TB treatment regimen for the first time at a public primary healthcare facility and in the intensive phase (the first two months of a standard six-month DS-TB regimen). *Group A* participants were selected consecutively from the person most recently diagnosed, notified, and registered backwards. *Group B* was people receiving TB treatment at private primary healthcare facilities. *Group C* was people who were diagnosed with TB at public healthcare facilities but never started TB treatment termed "lost to follow up to treatment" (LTFU). Groups B and C are critical groups given evidence suggesting that a significant proportion of people with TB symptoms in Indonesia seek care at private healthcare facilities [30, 31] and that TB-Stigma may lead people with TB to be LTFU and/or seek TB care at private facilities [32]. *Group D* was people receiving a DS-TB retreatment regimen at either a public or private primary healthcare facility between

Fig 1. Selected CAPITA study provinces in Indonesia (purple dots).

https://doi.org/10.1371/journal.pgph.0002489.g001

the second week to the ninth month of the retreatment regimen. Group D was selected based on evidence suggesting that TB-Stigma affects people with TB's treatment adherence and can impair TB treatment success rates and increase the likelihood of retreatment, and that there is little evidence on TB-stigma amongst people receiving retreatment for TB [16, 33].

The primary health facility-based survey focused on measuring the "psychosocial" impact and consequences of TB on people receiving DS-TB treatment or retreatment, including TB-Stigma, depression, and QoL. This was supplemented with questions concerning participants' receipt of existing psychosocial support interventions and their perceptions of their unmet need for psychosocial support interventions (described in more detail below). We focused on people with DS-TB and excluded people with drug-resistant TB (DR-TB) because: there have been several studies in Indonesia on the psychosocial consequences for people with DR-TB [34–36]; people with DR-TB receive treatment at a limited number of specific DR-TB treatment primary healthcare facilities with appropriately skilled and trained staff or at secondary-level hospitals; and people with DS-TB contribute >90% of the total number of cases of TB in Indonesia and are at risk of developing acquired resistance if unable to adhere to TB treatment [37]. We also excluded people with DS-TB who had completed TB treatment by the time of recruitment and data collection because previous experience in the field has suggested that the responses of such participants may be unrepresentative or inaccurate due to a high probability of recall bias.

Sample size

Using data from related, recent research, we assumed that with an average TB-Stigma score of 27.6 (±6.1) with an alpha of 0.05, a precision of 0.7, and urban-rural stratification, we needed at least 584 participants in this study for the findings to be nationally generalisable in Indonesia [14].

Variables and instruments

The key co-primary outcome variables informing estimates of psychosocial impact were TB-Stigma, symptoms of depression, QoL, and receipt of and/or unmet need for psychosocial support. As described further below, the tools used to measure TB stigma, depression, and QoL have all been previously validated for reliability and internal consistency in the Indonesian context.

TB stigma scale

We first created, culturally adapted, and validated an Indonesian version of the TB-Stigma Scale [38]. The Scale consisted of two forms: Form A (Patient Perspective) with 11 questions across three domains (disclosure, isolation, and guilty); and Form B (Community Perspective) with 10 questions across two domains (isolation and distancing). The tool was reliable—with a Cronbach's alpha of 0.738 for Form A (Patient Perspective) and 0.807 for Form B (Community Perspective) [38]. Aligned with the original Van Rie Stigma Score [14], from which the Indonesian score was adapted, each item had four potential answer options: strongly disagree (1), disagree (2), agree (3), and strongly agree (4). TB-Stigma scores were calculated following the original tool's guidance of the: (sum of item scores x 50) / (3 x number of item). In addition, in line with existing TB stigma measurement guidance and to enhance interpretation and potential future policy dialogue [7, 39, 40], we also presented scores by cohort quartiles: no stigma (no stigmatisation in all items), low (TB-Stigma score ≤16.67), moderate (16.68–33.33), and high TB-Stigma (>33.33). (**S1 Appendix**).

In this study, we assessed the association between TB-Stigma, depression, and QoL because these elements often intersect [20, 41, 42], therefore may be better addressed in a multi-faceted, complex, or integrated psychosocial intervention instead of a uni-faceted intervention focused on a single element.

Patient Health Questionnaire-9 (PHQ-9)

We used the Indonesian-validated version of the Patient Health Questionnaire-9 (PHQ-9) [43], with a Cronbach's alpha of 0.837 [38], to assess the participants' symptoms of depression according to the pre-existing PHQ-9 categories: no depression (score of 0–4), mild (5–9), moderate (10–14), moderately severe (15–19), and severe (20–27) [41]. The PHQ also allows the interpretation of "major depressive disorder" (MDD) and "other depressive disorder". MDD is defined when a person indicates having more than five symptoms in PHQ9 more than half the days and *Symptom 1* (Little interest or pleasure in doing things) or *Symptom 2* (Feeling down, depressed, or hopeless) more than half the days. Other depressive disorder is defined when a person indicates having 2–4 symptoms in PHQ9 and *Symptom 1* or *Symptom 2* more than half the days. (**S2 Appendix**).

EQ-5D-5L

QoL was measured using the Indonesian version of EQ-5D-5L [44, 45] consisting of five locally-weighted dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression with five levels of severity [44]. This tool has been shown to be reliable in other studies with a Gwet's test and retest agreement coefficient of 0.85–0.99 and percentage agreement of 90–99% [44]. The assessment conformed with EuroQol guidance on QoL measurement and was locally-appropriate using the Indonesian value set of EQ-5D-5L [45].

Psychosocial support questions

We added ten questions to measure participants' receipt of and/or perceived unmet need for psychosocial support. The study team designed the initial questions related to needs and unmet needs for psychosocial support. Then, questions were shared with an expert panel including a pulmonologist, a psychologist, community medicine specialist, national TB program staff, and a member of a TB civil society organization. The panel evaluated the questions for content validity and iteratively refined the questions [38]. Questions were divided into three recognized domains: informational, emotional, and instrumental support [46]. (**S3 Appendix**). Informational support refers to any facts, advice, or other educational materials provided to people with TB to help them solve problems. Emotional support refers to care, encouragement, and empathy to garner a sense of security amongst TB-affected people. Informational support in this study was defined as a tangible help in practical form provided through material assistance or practical program, such as counselling or meeting. This question was to assess whether and what support was currently available to them. Second, we asked whether they perceived that they needed such psychosocial support, regardless of whether they received it or not. We then assessed whether they had "unmet need" for psychosocial support, which was defined as a perceived need but lack of receipt of psychosocial support.

We included several covariates in the analysis which have previously been demonstrated to be associated with TB stigma, depression, or quality of life in other studies [7, 8], which were age, sex (male/female), participant group (A, B, C, D), area (urban/rural), job loss due to TB (yes/no), and formal education level (no education/ elementary/high school/university).

Data collection

All psychosocial impact questions described above were combined in a single tool that could be completed with a participant in an interview of less than 15 minutes. To ensure the proper use of the tool, we recruited and trained interviewers with a background in health sciences in a one-day online training. The training included: a comprehensive explanation of the study background, rationale, methods, and participant selection; and a detailed review of the paper-based TB-Stigma tool, protocol, and Standardized Operating Procedure. Interviewers were trained to enter the data into the study's electronic database using the RedCap platform (https://redcap.fk.ui.ac.id). After data checking, cleaning, and validation, the data was analyzed using IBM SPSS Version 25.0.

Data analysis

We applied descriptive analysis to capture TB-Stigma among people with TB and their receipt of and/or need for psychosocial support. TB-Stigma scores were summarized by means with standard deviation (SD) and range. TB-Stigma tool items from patient and community perspectives and receipt of and/or need for psychosocial support were displayed in numbers (n/ N) and percentages (%). We identified clinical, health system, and socioeconomic factors associated with TB-Stigma using a general linear model (GLM) to estimate B values and their adjusted Bs (aBs). The B values were adjusted with presumed associated factors mentioned above [7, 8].

After reviewing literature, with special reference to the conceptual framework in Chen et al [19], we designed the model to look at the interaction between TB Stigma, depression, and QoL. The correlations between TB-Stigma and depression scores were evaluated by Spearman correlation tests to obtain their coefficient (Rs). We analyzed the association between TB-Stigma scores, depression, and QoL using multinomial regression (for depression symptoms), binary logistic regression (for MDD and other depressive disorders) and GLM (for

QoL) to obtain the crude odds ratios (cORs), adjusted ORs (aORs), cBs and aBs and their 95% confidence intervals (95% CIs).

Ethical considerations

This study received a support letter from the Indonesia's Ministry of Health, a research ethical approval from the Ethics Committee of the Faculty of Medicine, University of Indonesia (No. KET-60/UN2.F1/ETIK/PPM.00.02/2022, on January 17, 2022), and research permit from seven provincial authorities prior the implementation. All healthcare facilities involved in this study granted the permit and helped communicate with the potential participants. We provide a complete explanation to participants before they signed informed consent to participate in the study. Participants were allowed to withdraw their participation from this study at anytime without any consequences.

Patient and public involvement

This study involved patients and public in the study design, instrument development, and data collection. The research question and the development of tools to measure TB-Stigma was informed by experts from various background, including staff from the Ministry of Health, the NTP at the province and district levels, and civil organisation, which addressed patients' experience and preferences. This study was supported by the Ministry of Health, approved by local authorities, and involved with healthcare workers in public and private healthcare facilities. The respondents of survey were people with TB who were diagnosed with TB or received TB treatment. The patient and public involvement in this study continued throughout the research process and would be followed up in TB-CAPS Study, in which we develop a peer-led, community-based psychosocial support for people with TB. The study results will be disseminated to public through public seminar and scientific workshop.

Results

We recruited and completed interviews with 612 adults with TB and all recorded interviews were included in the analysis (**Table 1**). Most participants were male, married, lived in an urban area, and received treatment at public healthcare facilities. Of 383 participants who had income-earning jobs before TB diagnosis, 59 (15.4%) participants lost their job and 8 (2.1%) changed their job because of TB.

TB stigma scores

This study found that 60.6% (96%CI 59.6–64.5%) experienced moderate TB-Stigma. The average TB-Stigma score in Form A (Patient Perspective) was 19.0 (SD 6.9; min-max 0–50). Most participants (60.6%) experienced moderate TB-Stigma, which was predominantly related to feelings of guilt about having TB including: being a burden on their family (45.1%), having lifestyle behaviour that participants perceived to have contributed to their TB disease such as smoking tobacco or drinking alcohol (37.4%), and worrying about having HIV/AIDS (34.0%) (**Table 2**). A high proportion of participants reported fear of disclosure of their TB disease (18.0–49.2%) and felt hurt by others' reactions to their TB disease (25.2%).

The average TB-Stigma score in Form B (Community Perspective) was 23.4 (SD 8.4, min-max 0–50). Most participants (63.9%) reported moderate perceived TB-Stigma from their community, particularly the perception of being isolated from and by people in their community (38.2–66.7%).

Table 1. Participants' characteristics (N = 612).

Characteristics		n	%
Sex			
	Male	379	61.9
	Female	233	38.1
Age, *years old*, median (IQR)		42	(29–55)
Age, *years old*			
	18–30	166	27.1
	31–40	114	18.6
	41–50	124	20.3
	51–60	108	17.6
	>60	100	16.3
Marital status			
	Not married	140	22.9
	Married	431	70.4
	Widowed	41	6.7
Highest educational level attained[a]			
	No schooling	20	3.3
	Elementary to junior high school	187	30.6
	Senior high school	297	48.5
	College/University	108	17.6
Having income earning job before TB diagnosis			
	Yes	383	62.6
	No and of working age[b]	172	28.1
	No and not of working age[b]	57	9.3
Impact of TB on employment, n = 383			
	No impact	272	71.0
	Job loss or negative change because of TB[c]	67	17.5
	Job loss or negative change not because of TB[c]	44	11.5
Provinces			
	Jambi	93	15.2
	West Sumatera	110	18.0
	Jakarta	73	11.9
	West Kalimantan	109	17.8
	Bali	36	5.9
	South Sulawesi	107	17.5
	Maluku	84	13.7
Area			
	Urban	414	67.6
	Rural	198	32.4
People with TB receiving treatment at			
	Group A: Intensive phase at a public facility	404	66.0
	Group B: Private facilities	103	16.8
	Group C: LTFU to treatment[d]	51	8.4
	Group D: TB retreatment	54	8.8

[a]Usual age of children: 6–15 years (elementary to junior high school), 15–18 years (senior high school), and >18 years (college/university)

[b]Working age in this study was defined as aged less than 60 years (pension age)

[c]Negative change refers to a decrease in income or perceived lower level of job/role

[d]LTFU to treatment: lost-to-follow-up to treatment, is those diagnosed with TB but not following up with TB treatment.

https://doi.org/10.1371/journal.pgph.0002489.t001

Table 2. TB-Stigma from patient and community perspectives (N = 612).

Form A: Patient Perspective	n	(%)
TB-Stigma Category		
No Stigma	78	(12.8)
Low	153	(25.0)
Moderate	371	(60.6)
High	10	(1.6)
Domain: Disclosure		
P6. I am afraid to tell people outside my family that I have TB	208	(34.0)
P7. I am afraid to tell others that I have TB because others may think that I also have HIV/AIDS	169	(27.6)
P9. I choose carefully who I tell about having TB	301	(49.2)
P12. I am afraid of other people to tell my family that I have TB	110	(18.0)
Domain: Isolation		
P1. I feel hurt by how others react to knowing that I have TB	154	(25.2)
P2. I have lost friends when I shared with them that I have TB	75	(12.3)
P3. I feel lonely	97	(15.8)
P5. I am afraid of going to TB clinics because other people may see me there	90	(14.7)
Domain: Guilty		
P8. I feel guilty because my family has the burden of caring for me	276	(45.1)
P10. I feel guilty for getting TB because of my smoking, drinking, or other lifestyle behaviours	229	(37.4)
P11. I am worried about having HIV/AIDS	208	(34.0)
Form B: Community Perspective	**n**	**(%)**
TB-Stigma Category		
No Stigma	113	(18.5)
Low	59	(9.6)
Moderate	391	(63.9)
High	49	(8.0)
Domain: Isolation		
C13. Some people may not want to eat or drink with friends who have TB	364	(59.5)
C14. Some people feel uncomfortable about being near those with TB	288	(47.1)
C15. If a person has TB, some community members will behave differently towards that person for the rest of his/her life have HIV/AIDS	234	(38.2)
C16. Some people do not want those with TB playing with their children	355	(58.0)
C17. Some people keep their distance from people with TB	408	(66.7)
C22. Some people may not want to eat or drink with relatives who have TB	333	(54.4)
Domain: Distancing		
C18. Some people think that those with TB are disgusting	145	(23.7)
C19. Some people do not want to talk to others with TB	165	(27.0)
C20. Some people are afraid of those with TB	239	(39.1)
C21. Some people try not to touch others with TB	184	(30.1)

https://doi.org/10.1371/journal.pgph.0002489.t002

Factors associated with TB stigma

Form A (Patient Perspective) TB-Stigma scores were also higher among males (aB 1.73; 0.59–2.87), those losing or changing job because of TB (aB 2.09; 0.31–3.88), and those living in a rural area (aB 1.41; 0.19–2.63) (**Table 3**). These Patient Perspective scores were 2.48 and 2.86 points higher among people receiving treatment at private facilities (*Group B*) and LTFU (*Group C*), respectively, than people receiving TB treatment at public facilities (*Group A*). Form A (Community Perspective) TB-Stigma scores were 1.95 and 3.28 points higher among people receiving treatment at private facilities (*Group B*) and LTFU (*Group C*), respectively,

Table 3. Factors associated with TB-Stigma Scores from Patient (Form A) and Community (Form B) perspectives.

Variables		n	Mean	(SD)	cB	95%CI	aB	95% CI
A. Patient Perspective								
Group								
	A: Treatment at public facility	404	18.6	(7.1)		REF		REF
	B: Treatment at private facilities	103	20.3	(6.0)	1.74	0.24 to 3.24	2.48	0.94 to 4.03
	C: LTFU to TB treatment	51	21.1	(7.9)	2.51	0.49 to 4.53	2.86	0.85 to 4.87
	D: Retreatment	54	18.1	(6.2)	-0.48	-2.45 to 1.49	-0.26	-2.21 to 1.69
Area								
	Urban	414	18.7	(7.0)		REF		REF
	Rural	198	19.8	(6.8)	1.10	0.08 to 2.28	1.41	0.19 to 2.63
Sex								
	Female	233	17.9	(6.4)		REF		REF
	Male	379	19.7	(7.2)	1.77	0.64 to 2.90	1.73	0.59 to 2.87
Job loss or change because of TB								
	No	545	18.7	(6.9)		REF		REF
	Yes	67	21.6	(7.4)	2.85	1.09 to 4.61	2.09	0.31 to 3.88
Formal education								
	No school	20	20.8	(8.1)		REF		REF
	Elementary	187	18.8	(7.4)	-1.94	-5.17 to 1.28	-2.57	-5.75 to 0.62
	High school	297	19.2	(6.6)	-1.57	-4.74 to 1.59	-2.50	-5.75 to 0.76
	University or college	108	18.7	(7.0)	-2.06	-5.39 to 1.28	-2.83	-6.26 to 0.61
Age, *years*, mean (SD)		612	19.04	(6.9)	-0.03	-0.06 to 0.01	-0.05	-0.09 to -0.01
B. Community Perspective								
Group								
	A: Treatment at public facility	404	22.9	(8.0)		REF		REF
	B: Treatment at private facilities	103	24.2	(7.7)	1.24	-0.56 to 3.05	1.95	0.08 to 3.83
	C: LTFU to TB treatment	51	26.2	(10.8)	3.31	0.88 to 5.74	3.82	1.38 to 6.26
	D: Retreatment	54	22.3	(9.0)	-0.65	-3.02 to 1.72	-0.22	-2.59 to 2.15
Area								
	Urban	414	23.3	(8.3)		REF		REF
	Rural	198	23.5	(8.6)	0.25	-1.18 to 1.67	0.69	-0.80 to 2.16
Sex								
	Female	233	22.6	(8.0)		REF		REF
	Male	379	23.8	(8.6)	1.23	-0.13 to 2.60	1.35	-0.04 to 2.73
Job loss or change because of TB								
	No	545	23.2	(8.3)		REF		REF
	Yes	67	24.5	(9.0)	1.28	-0.85 to 3.41	0.62	-1.54 to 2.79
Formal education								
	No school					REF		REF
	Elementary	187	22.8	(8.6)	-1.14	-5.00 to 2.72	-2.28	-6.15 to 1.59
	High school	297	24.1	(8.4)	0.18	-3.61 to 3.97	-1.66	-5.61 to 2.30
	University or college	108	22.2	(7.5)	-1.68	-5.67 to 2.32	-3.36	-7.53 to 0.81
Age, *years*, mean (SD)		612	23.4	(8.4)	-0.05	-0.10 to -0.01	-0.07	-0.12 to -0.03

than people receiving TB treatment at public facilities (*Group A*). People of older age had lower TB-stigma scores from both the Patient and Community perspectives (Table 3). The models were fit (R-Square = 0.066, F = 4.238, p<0.001 for patient perspective; R-square = 0.046, F = 2.887, p = 0.002 for community perspective).

Table 4. Multivariable multinominal regression model of the association of TB-stigma and levels of depression symptoms.

TB-Stigma	No Depression (n = 358)	Mild-moderate (n = 220)			Moderately severe to severe (n = 34)		
	mean (SD)	mean (SD)	OR; 95%CI	aOR; 95%CI[a]	mean (SD)	OR; 95%CI	aOR; 95%CI[a]
Patient perspective							
Total score	17.50 (6.48)	20.47 (6.58)	1.07; 1.04–1.10	1.08; 1.05–1.11	25.94 (8.34)	1.22; 1.15–1.30	1.23; 1.15–1.32
Disclosure	18.68 (9.11)	21.59 (9.48)	1.03; 1.02–1.05	1.04; 1.02–1.06	28.06 (11.93)	1.11; 1.07–1.15	1.11; 1.06–1.15
Isolation	14.56 (7.40)	17.67 (8.55)	1.05; 1.03–1.08	1.06; 1.03–1.08	23.41 (9.40)	1.14; 1.09–1.19	1.16; 1.10–1.23
Guilty	19.86 (9.04)	22.70 (9.33)	1.03; 1.02–1.05	1.04; 1.02–1.07	26.47 (10.06)	1.08; 1.04–1.13	1.09; 1.05–1.14
Community perspective							
Total score	21.69 (7.77)	25.33 (8.44)	1.06; 1.04–1.08	1.06; 1.04–1.09	28.28 (9.42)	1.10; 1.06–1.15	1.11; 1.06–1.17
Isolation	24.06 (8.36)	27.89 (8.53)	1.06; 1.03–1.08	1.06; 1.04–1.08	31.29 (9.73)	1.11; 1.06–1.16	1.11; 1.06–1.17
Distancing	18.12 (9.02)	21.48 (10.96)	1.04; 1.02–1.05	1.04; 1.02–1.06	23.77 (10.64)	1.06; 1.02–1.10	1.07; 1.03–1.11

[a]Adjusted for age, sex (male/female), group (intensive phase at public facilities/private facilities/LTFU to treatment/retreatment), area (urban/rural), job loss due to TB (yes/no), and formal education (no school/elementary/high school/university).

https://doi.org/10.1371/journal.pgph.0002489.t004

TB stigma and depression

Depression was identified in 41.5% (95% CI 37.7–45.3%) participants. Of 612 participants, 220 (35.9%) had mild to moderate depression, and 34 (5.6%) had moderately severe to severe depression. TB-Stigma scores, for both Patient and Community perspectives, were significantly correlated with PHQ-9 score, with respective r_s of 0.295 and 0.254. The average and median values of TB-Stigma scores were higher among those with depression than those without depression (**Table 4** and **S1 Fig**).

The model assessing correlation between TB Stigma Scores and depression, with adjustment for age, sex, *Group*, rural vs urban area, and job loss due to TB, were fit (χ^2 = 96.926, p<0.001 for TB Stigma patient perspective; χ^2 = 66.670, p<0.001 for TB Stigma community perspective). Every unit increase in TB-Stigma score was associated with a 4–8% increase in the odds of having mild to moderate depression symptoms and 6–22% increase in the odds of having moderately severe to severe depression symptoms compared to having no depression. Thirty-nine (6.4%) participants were identified as having MDD and 47 (7.7%) had other depressive disorder. Every unit increase in TB-Stigma score was associated with a 20% increase in the odds of having a MDD and a 7% increase in the odds of having another depressive disorder (**S1 Table**).

TB stigma, depression, and QoL

The average QoL among adults with TB without depression was 0.9 (SD 0.13, min-max 0.28–1.00). The model assessing correlation between TB Stigma, depression, and QoL with adjustment for age, sex, *Group*, rural vs urban area, and job loss due to TB, were fit (R-square = 0.324, F = 23.878, p<0.001 for TB Stigma patient perspective; R-square = 0.104, F = 6.350, p<0.001 for TB Stigma community perspective). Stigma and depression were significantly associated with lower QoL (**Table 5**). QoL was lower among those with moderately severe to severe depression (aB -0.383; 95%CI -0.445 to -0.322) and mild to moderate depression (aB -0.155; 95%CI -0.184 to -0.126) than those without depression. Higher TB-Stigma scores correlated negatively with QoL, and this association was stronger in those with either mild-moderate or moderately severe to severe depression. (**Table 5**). While TB Stigma scores among those LTFU and those receiving treatment at private facility were higher lower than those treated at public facility, their QoL was significantly lower. (**S2 Table** and **S2 Fig**).

Table 5. Association of TB-stigma and levels of depression symptoms with quality of life (N = 612).

Variables		n	Quality of Life					
			Mean (SD)		cB	95%CI	aB	95% CI
Depression								
	No depression	358	0.91	(0.13)		REF		REF
	Mild to moderate	220	0.76	(0.21)	-0.155	-0.185 to -0.125	-0.155	-0.184 to -0.126
	Moderately severe to severe	34	0.53	(0.33)	-0.376	-0.439 to -0.314	-0.383	-0.445 to -0.322
A. Patient Perspective								
Stigma					-0.007	-0.010 to -0.005	-0.008	-0.01 to -0.005
Stigma*depression								
	Stigma*Mild to moderate				-0.007	-0.009 to -0.005	-0.007	-0.010 to -0.005
	Stigma*Moderately severe to severe				-0.013	-0.015 to -0.010	-0.013	-0.016 to -0.010
B. Community Perspective								
Stigma					-0.004	-0.006 to -0.002	-0.004	-0.006 to -0.002
Stigma*depression								
	Stigma*Mild to moderate				-0.004	-0.006 to -0.002	-0.004	-0.006 to -0.003
	Stigma*Moderately severe to severe				-0.010	-0.012 to -0.007	-0.011	-0.013 to -0.008

https://doi.org/10.1371/journal.pgph.0002489.t005

Needs and unmet needs of psychosocial support

Informational (20.8%), emotional (25.9%) or instrumental (10.6%) support from peer groups was limited (**Table 6**). Although the need for informational, emotional, and instrumental support from peers was reported to be lower than the need for support from other groups (family and healthcare workers), the unmet needs for such peer support was high (52.0% for emotional support, 63.0% for informational support, 76.4% for group meeting, and 77.5% for group counselling from peers). The unmet need for such supports were also consistently higher among those with higher TB-Stigma scores (**S3 Table**).

Discussion

Our novel findings from a nationally-representative cross-sectional survey show that there is a sizeable and intersecting burden of TB-Stigma and depression experienced by adult people

Table 6. Needs and unmet needs of psychosocial support among people with TB.

Psychosocial support	Received (N = 612)		Need (N = 612)		Unmet needs*	
	n	%	n	%	n/N	%
Information support						
TB information for myself by HCW	523	85.5	571	93.3	56/571	9.8
TB information for my family members by HCW	463	75.7	545	89.1	91/545	16.7
TB information in a peer group meeting	127	20.8	324	52.9	204/324	63.0
Emotional support						
Emotional support from HCW	535	87.4	565	92.3	38/565	6.7
Emotional support from family	565	92.3	577	94.3	18/577	3.1
Emotional support from peer	159	25.9	325	53.1	172/325	52.9
Instrumental support						
Home visit by HCW	314	51.3	419	68.5	135/419	32.2
Peer group meeting	65	10.6	237	38.7	181/237	76.4
Individual counselling	93	15.2	262	42.8	172/262	65.6
Group counselling	58	9.5	231	37.7	179/231	77.5

HCW, healthcare workers *Unmet needs are the proportion of those who need the support but did not receive it.

https://doi.org/10.1371/journal.pgph.0002489.t006

with TB in Indonesia, which negatively impacts on QoL. TB-Stigma scores were higher among males, younger people, people receiving TB treatment at private healthcare facilities, and those who lost or changed job due to TB. There were also high levels of unmet need for psychosocial support, especially related to peer-group activities and interventions.

The high levels of TB-Stigma experienced by people with TB in Indonesia related particularly to a reluctance to disclose to others about their disease and feeling guilty about having TB. Although the TB-Stigma scores in this study were lower than those found amongst people with TB in Thailand [14] and Cambodia [47], they were higher than those found amongst people with TB in Vietnam [48] and another Indonesian report that did not use a locally-validated stigma measurement tool [49]. Our findings suggests that many people with TB would choose carefully whom they inform about their disease and are afraid of telling people outside of their family. This result conforms with the participants' anticipation of behaviours from their community including keeping their distance from, and isolating, people with TB. Such TB-Stigma perceptions may stem from fear of being "blamed as the source of disease" in their neighbourhood [25], perceived as being disgusting or dirty [47, 50], losing social status [21], receiving verbal abuse or being the subject of gossip, [50] or associated decreased employment opportunities and job loss [12, 47], much of which stems from misunderstanding and/or erroneous health beliefs concerning TB [6, 7, 51].

TB-Stigma was higher among those receiving TB treatment at private facilities or those LTFU. Rather than being determinants of TB-stigma, these are likely to be consequences of TB-stigma experienced by these specific groups. People who have concerns about TB-stigma with relation to the visibility of attending the most commonly used public care facilities in their community are more likely to use private facilities initially or switch to private facilities during the course of their healthcare seeking journey [52, 53]. It is critical to explore the perceptions of people with TB symptoms about their preferences for optimal treatment facilities and services to reduce TB-stigma. Importantly, there has been evidence to suggest that private care providers have been reluctant to offer TB services due to TB-Stigma, including against healthcare workers who care for people with TB, and service fragmentation [54]. Given the high preference for seeking care at private facilities in Indonesia, particularly in a rural areas [30, 54], there is a pressing urgency to improve the quality of TB care delivered by private providers to increase treatment uptake and completion [55]. It is also vital to improve health- and TB-related education in both the private and public sector because improving people with TB's knowledge about the disease and the importance of TB treatment has been shown to reduce LTFU [6, 7].

The economic consequences of TB may play a significant role in TB-Stigma. This study found that TB-Stigma scores were higher among males, younger people of the most economically productive age, and those experiencing job loss or decreased economic productivity because of TB. Most primary income earners within households in LMICs, including Indonesia, are males. Related research from LMICs has shown that males are concerned by TB and related TB-stigma because they may collectively corrode their primary income earner status and hence their value and status more broadly within the household and community [47, 52, 56–58]. Improving knowledge about TB at community level, reducing misperceptions about TB infectiousness and transmission within workplaces, and strengthening social protection and employment legislation could all contribute to preventing unnecessary job loss or unnecessarily prolonged time unable to work [5]. Moreover, gender and gendered norms, including perceptions of masculinity, should be considered in the design and delivery of psychosocial and economic interventions for people, and especially men, with TB [59].

This study underlines the intersectionality of TB-stigma, depression and QoL. In addition to biological factors inducing depression among people with TB [60], TB-Stigma is among the

psychosocial factors contributing to depression, which is the most common comorbid mental health disorder in people with TB [42, 61]. Depression and TB-Stigma can occur from symptom onset, including relating to weight loss and changes in appearance and body habitus, and lead to delay in care seeking, diagnostic, and treatment initiation [61]. As suggested by our findings, TB-Stigma and depression experienced after TB treatment initiation may be associated with difficulties in adhering to TB treatment, LTFU, and impaired quality of life [20, 41, 62]. Hence, syndemic TB, TB-Stigma, and depression have the potential to act synergistically and thereby impact negatively upon QoL and levels of disability during and beyond TB illness.

Our findings support the use of routine screening for both TB-Stigma and depression as part of a holistic approach to addressing the needs of people with TB. To do this, linkage of TB care with mental health services, which has only been implemented in a handful of countries to date [63], could be critical. In LMICs, where specialist mental health services are often lacking, an integrative approach should facilitate the provision of mental health counselling in primary care. Training non-specialist healthcare workers at the primary care level will be essential to provide low cost and potentially cost-effective interventions to deliver mental health screening, triage, management, and prompt referral [64, 65]. Psychological counselling could act as a gateway to onward referral to other psychosocial intervention activities such as peer-led mutual support groups or "TB Clubs" [66].

Peer group support is an essential psychosocial intervention. Despite the increasing awareness of the importance of providing peer support to people with TB, to date this has been piecemeal, difficult to replicate, and had neither rigorous process nor effectiveness evaluation. Indeed, peer support for people with TB has been less frequently provided than for people living with HIV/AIDS, in which such groups are well established [42, 63]. We found that the reported need for peer group support was lower than support through other mechanisms such as home visits and individual counselling. This may relate to the TB-stigma score findings specifically relating to fear of disclosure and a lack of trust in others, especially outside of the household, some of which may be due to feelings of isolation and marginalization from the surrounding community or, if being retreated, previous experiences during TB illness and care-seeking. This supposition appears to be supported by the finding of high unmet needs for peer group meetings and group counselling, which was highest amongst those experiencing higher levels of TB-Stigma. One study has identified cultural and religious belief approaches that act as a health communication channel to reduce TB-Stigma, which may be affected by peer solidarity. Developing a more robust conceptualization, design, and delivery of peer group support (including both meetings and mutual-support counselling sessions) with a standardized package, effective training, and structured evaluation of feasibility, acceptability, effectiveness, and cost-effectiveness will be critical to consider whether scale-up and integration into routine TB services is locally appropriate.

This study has several limitations. First, Indonesia has diverse geography and cultures, which may affect the perceptions of TB-Stigma, depression, and the need for social support. We recruited 612 participants across seven purposively selected study provinces of Indonesia because they represented areas with diverse TB burdens, geographical topography, and socio-cultural norms. Nevertheless, our results may not be generalisable to Indonesia at national level or the SEARO region more broadly. Second, we only captured TB-Stigma, depression, and the need for social support among people with drug-susceptible TB and ruled out those with DR-TB, who have been found in other settings to be at a higher risk of TB-Stigma and depression. Third, using PHQ-9, we measured only depression, which may have underestimated the prevalence of other manifestations of mental illness, including anxiety, and their association with TB-Stigma. Fourth, the grouping of TB-Stigma Scale (no stigmatisation, low, moderate, and high) using quartile cut-off was not previously validated. The grouping would

help practical policy interpretation, but any future studies need to validate the cut-off for better interpretation.

In Indonesia, people with TB have high rates of intersecting TB-Stigma and depression. Being male, of younger working age, receiving TB treatment at private healthcare facilities, and losing work due to TB were the factors most strongly associated with higher TB-stigma levels. There was a large unmet need for social support through peer-led mutual support groups. These findings emphasise the importance of using locally-validated tools to measure the psychosocial impact of TB. Evidence-based, standardized but adaptable training and intervention packages, including peer-led mutual support groups, should be developed to defray the psychosocial impact of TB by reducing TB-Stigma and depression, and improving QoL among people with TB.

Supporting information

S1 Checklist. STROBE checklist.
(DOC)

S1 Appendix. Culturally adapted and validated TB-Stigma scale.
(DOCX)

S2 Appendix. Patient Health Questionnaire-9 (PHQ-9).
(DOCX)

S3 Appendix. Instrument to measure social support received and needed by people with TB.
(DOCX)

S1 Fig. Correlation between TB-Stigma and PHQ scores, and TB-Stigma score between depression groups. White horizontal lines in the boxplot are the median values.
(DOCX)

S2 Fig. TB-Stigma, depression, and quality of life between groups.
(DOCX)

S1 Table. TB-Stigma and depression symptoms.
(DOCX)

S2 Table. TB-Stigma, depression, and quality of life between groups.
(DOCX)

S3 Table. Unmet need of psychosocial support and TB-Stigma.
(DOCX)

Acknowledgments

Author Contributions

Conceptualization: Ahmad Fuady, Muchtaruddin Mansyur, Tom Wingfield.

Data curation: Ahmad Fuady, Bustanul Arifin, Ferdiana Yunita, Saidah Rauf, Agus Fitriangga, Agus Sugiharto, Finny Fitry Yani, Helmi Suryani Nasution, I. Wayan Gede Artawan Eka Putra.

Formal analysis: Ahmad Fuady, Ferdiana Yunita.

Funding acquisition: Ahmad Fuady, Agus Sugiharto, Tom Wingfield.

Investigation: Bustanul Arifin, Ferdiana Yunita, Saidah Rauf, Agus Fitriangga, Finny Fitry Yani, Helmi Suryani Nasution, I. Wayan Gede Artawan Eka Putra.

Methodology: Ahmad Fuady, Tom Wingfield.

Project administration: Ferdiana Yunita, Saidah Rauf, Agus Fitriangga, Agus Sugiharto.

Resources: Ahmad Fuady, Finny Fitry Yani, Helmi Suryani Nasution, I. Wayan Gede Artawan Eka Putra.

Software: Ahmad Fuady.

Supervision: Ahmad Fuady, Muchtaruddin Mansyur, Tom Wingfield.

Validation: Ahmad Fuady, Muchtaruddin Mansyur, Tom Wingfield.

Visualization: Ahmad Fuady.

Writing – original draft: Ahmad Fuady.

Writing – review & editing: Ahmad Fuady, Bustanul Arifin, Ferdiana Yunita, Saidah Rauf, Agus Fitriangga, Agus Sugiharto, Finny Fitry Yani, Helmi Suryani Nasution, I. Wayan Gede Artawan Eka Putra, Muchtaruddin Mansyur, Tom Wingfield.

References

1. World Health Organization. Global tuberculosis report 2022. Geneva: World Health Organization; 2022.

2. World Health Organization. The end TB strategy. Geneva: World Health Organization; 2015.

3. Macintyre K, Bakker MI, Bergson S, Bhavaraju R, Bond V, Chikovore J, et al. Defining the research agenda to measure and reduce tuberculosis stigmas. The International Journal of Tuberculosis and Lung Disease. 2017 //; 21(11):S87–S96. https://doi.org/10.5588/ijtld.17.0151 PMID: 29025490

4. Daftary A, Mitchell EMH, Reid MJA, Fekadu E, Goosby E. To End TB, First-Ever High-Level Meeting on Tuberculosis Must Address Stigma. Am J Trop Med Hyg. 2018 11; 99(5):1114–6. https://doi.org/10.4269/ajtmh.18-0591 PMID: 30226149. PMCID: PMC6221214.

5. Soemarko DS, Halim FA, Kekalih A, Yunus F, Werdhani RA, Sugiharto A, et al. Developing a tool to measure tuberculosis-related stigma in workplaces in Indonesia: An internal validation study. SSM—Population Health. 2023 2023/03/01/; 21:101337. https://doi.org/10.1016/j.ssmph.2023.101337 PMID: 36660173

6. Nuttall C, Fuady A, Nuttall H, Dixit K, Mansyur M, Wingfield T. Interventions pathways to reduce tuberculosis-related stigma: a literature review and conceptual framework. Infectious Diseases of Poverty. 2022 2022/09/23; 11(1):101. https://doi.org/10.1186/s40249-022-01021-8 PMID: 36138434

7. Chen X, Du L, Wu R, Xu J, Ji H, Zhang Y, et al. Tuberculosis-related stigma and its determinants in Dalian, Northeast China: a cross-sectional study. BMC Public Health. 2021 Jan 04; 21(1):6. https://doi.org/10.1186/s12889-020-10055-2 PMID: 33397334. PMCID: PMC7780403. Epub 20210104.

8. Challenge TB. TB stigma measurement guidance. Den Haag: KNCV; 2018.

9. The Global Fund. Tuberculosis and human right. The UN General Assembly high-level meeting on ending TB; 24 September 2018. New York: The Global Fund; 2018.

10. United Nations. United Nations high-level meeting on the fight against tuberculosis. New York: United Nations; 2018 26 September 2018.

11. World Health Organization. Global tuberculosis report 2021. Geneva: World Health Organization; 2021.

12. Datiko DG, Jerene D, Suarez P. Stigma matters in ending tuberculosis: Nationwide survey of stigma in Ethiopia. BMC Public Health. 2020 2020/02/06; 20(1):190. https://doi.org/10.1186/s12889-019-7915-6 PMID: 32028914

13. Daftary A, Frick M, Venkatesan N, Pai M. Fighting TB stigma: we need to apply lessons learnt from HIV activism. BMJ Glob Health. 2017; 2(4):e000515. https://doi.org/10.1136/bmjgh-2017-000515 PMID: 29225954. PMCID: PMC5717927. Epub 20171031.

14. Van Rie A, Sengupta S, Pungrassami P, Balthip Q, Choonuan S, Kasetjaroen Y, et al. Measuring stigma associated with tuberculosis and HIV/AIDS in southern Thailand: exploratory and confirmatory factor analyses of two new scales. Trop Med Int Health. 2008 Jan; 13(1):21–30. https://doi.org/10.1111/j.1365-3156.2007.01971.x PMID: 18290998.

15. Teo AKJ, Singh SR, Prem K, Hsu LY, Yi S. Duration and determinants of delayed tuberculosis diagnosis and treatment in high-burden countries: a mixed-methods systematic review and meta-analysis. Respir Res. 2021 Sep 23; 22(1):251. https://doi.org/10.1186/s12931-021-01841-6 PMID: 34556113.

16. Chang SH, Cataldo JK. A systematic review of global cultural variations in knowledge, attitudes and health responses to tuberculosis stigma. IJTLD. 2014; 18(2):168–73. https://doi.org/10.5588/ijtld.13.0181 PMID: 24429308

17. Zimmerman E, Smith J, Banay R, Kau M, Garfin AMCG. Behavioural barriers and perceived trade-offs to care-seeking for tuberculosis in the Philippines. Glob Public Health. 2022 02; 17(2):210–22. https://doi.org/10.1080/17441692.2020.1855460 PMID: 33275865. Epub 20201204.

18. Lee LY, Tung HH, Chen SC, Fu CH. Perceived stigma and depression in initially diagnosed pulmonary tuberculosis patients. J Clin Nurs. 2017 Dec; 26(23–24):4813–21. https://doi.org/10.1111/jocn.13837 PMID: 28370819. Epub 20170517.

19. Chen X, Xu J, Chen Y, Wu R, Ji H, Pan Y, et al. The relationship among social support, experienced stigma, psychological distress, and quality of life among tuberculosis patients in China. Sci Rep. 2021 Dec 20; 11(1):24236. https://doi.org/10.1038/s41598-021-03811-w PMID: 34931006. PMCID: PMC8688519. Epub 20211220.

20. Qiu L, Tong Y, Lu Z, Gong Y, Yin X. Depressive symptoms mediate the associations of stigma with medication adherence and quality of life in tuberculosis patients in China. Am J Trop Med Hyg. 2019 Jan; 100(1):31–6. https://doi.org/10.4269/ajtmh.18-0324 PMID: 30398139. PMCID: PMC6335886.

21. Atre S, Kudale A, Morankar S, Gosoniu D, Weiss MG. Gender and community views of stigma and tuberculosis in rural Maharashtra, India. Glob Public Health. 2011; 6(1):56–71. https://doi.org/10.1080/17441690903334240 PMID: 21509994.

22. Chan PL, Le LV, Ishikawa N, Easterbrook P. Regional progress towards hepatitis C elimination in the Western Pacific Region, 2015–2020. Glob Health Med. 2021 Oct 31; 3(5):253–61. https://doi.org/10.35772/ghm.2021.01065 PMID: 34782866.

23. Kane JC, Elafros MA, Murray SM, Mitchell EMH, Augustinavicius JL, Causevic S, et al. A scoping review of health-related stigma outcomes for high-burden diseases in low- and middle-income countries. BMC Med. 2019 Feb 15; 17(1):17. https://doi.org/10.1186/s12916-019-1250-8 PMID: 30764819. PMCID: PMC6376728. Epub 20190215.

24. Rakhmawati W, Nilmanat K, Hatthakit U. Living with stigma: the experience of tuberculosis patients and family caregivers in Indonesia. Indian Journal of Public Health Research & Development. 2019; 10(10).

25. Rakhmawati W, Nilmanat K, Hatthakit U. Moving from fear to realization: Family engagement in tuberculosis prevention in children living in tuberculosis Sundanese households in Indonesia. International Journal of Nursing Sciences. 2019 2019/07/10/; 6(3):272–7. https://doi.org/10.1016/j.ijnss.2019.06.002 PMID: 31508446

26. Artawan Eka Putra IWG, Purnama Dewi NPE, Probandari AN, Notobroto HB, Wahyuni C. The implementation of comprehensive health education to improve household contacts' participation in early detection of tuberculosis. Health Educ Behav. 2021 Apr 08:10901981211001829. https://doi.org/10.1177/10901981211001829 PMID: 33829894. Epub 20210408.

27. Fuady A, Fitriangga A, Sugiharto A, Arifin B, Yunita F, Yani FF, et al. Characterising and Addressing the Psychosocial Impact of Tuberculosis in Indonesia (CAPITA). [Preliminary report]; 2022.

28. Cremers AL, de Laat MM, Kapata N, Gerrets R, Klipstein-Grobusch K, Grobusch MP. Assessing the Consequences of Stigma for Tuberculosis Patients in Urban Zambia. PLOS ONE. 2015; 10(3): e0119861. https://doi.org/10.1371/journal.pone.0119861 PMID: 25806955

29. Ayana TM, Roba KT, Mabalhin MO. Prevalence of psychological distress and associated factors among adult tuberculosis patients attending public health institutions in Dire Dawa and Harar cities, Eastern Ethiopia. BMC Public Health. 2019 2019/10/28; 19(1):1392. https://doi.org/10.1186/s12889-019-7684-2 PMID: 31660912

30. Fuady A, Houweling TAJ, Mansyur M, Burhan E, Richardus JH. Cost of seeking care for tuberculosis since the implementation of universal health coverage in Indonesia. BMC Health Serv Res. 2020 Jun 03; 20(1):502. https://doi.org/10.1186/s12913-020-05350-y PMID: 32493313. PMCID: PMC7271484. Epub 20200603.

31. Lestari BW, McAllister S, Hadisoemarto PF, Afifah N, Jani ID, Murray M, et al. Patient pathways and delays to diagnosis and treatment of tuberculosis in an urban setting in Indonesia. Lancet Reg Health West Pac. 2020 Dec; 5:100059. https://doi.org/10.1016/j.lanwpc.2020.100059 PMID: 34327397. PMCID: PMC8315599. Epub 20201128.

32. Pradipta IS, Idrus LR, Probandari A, Lestari BW, Diantini A, Alffenaar JC, et al. Barriers and strategies to successful tuberculosis treatment in a high-burden tuberculosis setting: a qualitative study from the patient's perspective. BMC Public Health. 2021 Oct 21; 21(1):1903. https://doi.org/10.1186/s12889-021-12005-y PMID: 34670527. PMCID: PMC 8529853. Epub 20211021.

33. Munro SA, Lewin SA, Smith HJ, Engel ME, Fretheim A, Volmink J. Patient Adherence to Tuberculosis Treatment: A Systematic Review of Qualitative Research. PLOS Medicine. 2007; 4(7):e238. https://doi.org/10.1371/journal.pmed.0040238 PMID: 17676945

34. Morris MD, Quezada L, Bhat P, Moser K, Smith J, Perez H, et al. Social, economic, and psychological impacts of MDR-TB treatment in Tijuana, Mexico: a patient's perspective. Int J Tuberc Lung Dis. 2013 Jul; 17(7):954–60. https://doi.org/10.5588/ijtld.12.0480 PMID: 23743315. PMCID: PMC3769163.

35. Thomas BE, Shanmugam P, Malaisamy M, Ovung S, Suresh C, Subbaraman R, et al. Psycho-Socio-Economic issues challenging multidrug resistant tuberculosis patients: A systematic review. PLoS One. 2016 Jan 25; 11(1):e0147397. https://doi.org/10.1371/journal.pone.0147397 PMID: 26807933; PMCID: PMC4726571.

36. Franck C, Seddon JA, Hesseling AC, Schaaf HS, Skinner D, Reynolds L. Assessing the impact of multi-drug-resistant tuberculosis in children: an exploratory qualitative study. BMC Infect Dis. 2014 Aug 01; 14:426. https://doi.org/10.1186/1471-2334-14-426 PMID: 25084990. PMCID: PMC4127187. Epub 20140801.

37. Iskandar D, Suwantika AA, Pradipta IS, Postma MJ, van Boven JFM. Clinical and economic burden of drug-susceptible tuberculosis in Indonesia: national trends 2017–19. The Lancet Global Health. 2023; 11(1):e117–e25. https://doi.org/10.1016/S2214-109X(22)00455-7 PMID: 36435182

38. Fuady A, Arifin B, Yunita F, Rauf S, Fitriangga A, Sugiharto A, et al. Stigma towards people with tuberculosis: a cross-cultural adaptation and validation of a scale in Indonesia. BMC Psychology. 2023 2023/04/13; 11(1):112. https://doi.org/10.1186/s40359-023-01161-y PMID: 37055814

39. Stop TB Partnership. TB stigma assessment—implementation handbook. Geneva: Stop TB Partnership; 2019.

40. Mohammedhussein M, Hajure M, Shifa JE, Hassen TA. Perceived stigma among patient with pulmonary tuberculosis at public health facilities in southwest Ethiopia: A cross-sectional study. PLoS One. 2020; 15(12):e0243433. https://doi.org/10.1371/journal.pone.0243433 PMID: 33290413. PMCID: PMC7731994. Epub 20201208.

41. Redwood L, Mitchell EMH, Viney K, Snow K, Nguyen TA, Dung LAT, et al. Depression, stigma and quality of life in people with drug-susceptible TB and drug-resistant TB in Vietnam. Int J Tuberc Lung Dis. 2021 Jun 01; 25(6):461–7. https://doi.org/10.5588/ijtld.20.0952 PMID: 34049608.

42. Chandra M, Rana P, Chandra K, Arora VK. Tuberculosis—Depression syndemic: A public health challenge. Indian J Tuberc. 2019 Jan; 66(1):197–202. https://doi.org/10.1016/j.ijtb.2019.02.007 PMID: 30878069. Epub 20190226.

43. van der Linden A. Cross-cultural validation of the PHQ-9 in Bahasa Indonesia to measure depression among persons affected by leprosy. Amsterdam: Vrije Universiteit Amsterdam; 2019.

44. EuroQol Research Foundation. EQ-5D-5L user guide. Rotterdam, The Netherlands: EuroQoL; 2019.

45. Purba FD, Hunfeld JAM, Iskandarsyah A, Fitriana TS, Sadarjoen SS, Ramos-Goñi JM, et al. The Indonesian EQ-5D-5L Value Set. Pharmacoeconomics. 2017 Nov; 35(11):1153–65. https://doi.org/10.1007/s40273-017-0538-9 PMID: 28695543. PMCID: PMC5656740.

46. Cai T, Huang Q, Yuan C. Emotional, informational and instrumental support needs in patients with breast cancer who have undergone surgery: a cross-sectional study. BMJ Open. 2021 Aug 09; 11(8):e048515. https://doi.org/10.1136/bmjopen-2020-048515 PMID: 34373305. PMCID: PMC8354258. Epub 20210809.

47. Teo AKJ, Tan RKJ, Smyth C, Soltan V, Eng S, Ork C, et al. Characterizing and Measuring tuberculosis stigma in the community: A Mixed-Methods Study in Cambodia. Open Forum Infect Dis. 2020 Oct; 7

(10):ofaa422. https://doi.org/10.1093/ofid/ofaa422 PMID: 33134412. PMCID: PMC7585330. Epub 20200916.

48. Redwood L, Mitchell EMH, Nguyen TA, Viney K, Duong L, Phạm HT, et al. Adaptation and validation of the Van Rie tuberculosis stigma scale in Vietnam. Int J Infect Dis. 2022 Jan; 114:97–104. https://doi.org/10.1016/j.ijid.2021.10.040 PMID: 34715359. Epub 20211029.

49. The Consortium Community Penabulu—STPI. Indonesia TB stigma assessment. Jakarta: The Consortium Community Penabulu—STPI; 2022.

50. Mukerji R, Turan JM. Exploring manifestations of TB-related stigma experienced by women in Kolkata, India. Ann Glob Health. 2018 Nov 05; 84(4):727–35. https://doi.org/10.9204/aogh.2383 PMID: 30779523. PMCID: PMC6748300. Epub 20181105.

51. Junaid SA, Kanma-Okafor OJ, Olufunlayo TF, Odugbemi BA, Ozoh OB. Tuberculosis stigma: Assessing tuberculosis knowledge, attitude and preventive practices in surulere, Lagos, Nigeria. Ann Afr Med. 2021; 20(3):184–92. https://doi.org/10.4103/aam.aam_40_20 PMID: 34558447. PMCID: PMC8477276.

52. Courtwright A, Turner AN. Tuberculosis and stigmatization: pathways and interventions. Public Health Rep. 2010; 125 Suppl 4(Suppl 4):34–42. https://doi.org/10.1177/00333549101250S407 PMID: 20626191. PMCID: PMC2882973.

53. Sagbakken M, Frich JC, Bjune GA. Perception and management of tuberculosis symptoms in Addis Ababa, Ethiopia. Qual Health Res. 2008 Oct; 18(10):1356–66. https://doi.org/10.1177/1049732308322596 PMID: 18703818. Epub 20080814.

54. Stallworthy G, Dias HM, Pai M. Quality of tuberculosis care in the private health sector. J Clin Tuberc Other Mycobact Dis. 2020 Aug; 20:100171. https://doi.org/10.1016/j.jctube.2020.100171 PMID: 32642560. PMCID: PMC7332523. Epub 20200613.

55. Daniels B, Shah D, Kwan AT, Das R, Das V, Puri V, et al. Tuberculosis diagnosis and management in the public versus private sector: a standardised patients study in Mumbai, India. BMJ Glob Health. 2022 Oct; 7(10). https://doi.org/10.1136/bmjgh-2022-009657 PMID: 36261230. PMCID: PMC9582305.

56. Fuady A, Houweling TAJ, Mansyur M, Richardus JH. Catastrophic total costs in tuberculosis-affected households and their determinants since Indonesia's implementation of universal health coverage. Infectious Diseases of Poverty. 2018 2018/01/12; 7(1):3. https://doi.org/10.1186/s40249-017-0382-3 PMID: 29325589

57. Duan W, Zhang W, Wu C, Wang Q, Yu Y, Lin H, et al. Extent and determinants of catastrophic health expenditure for tuberculosis care in Chongqing municipality, China: a cross-sectional study. BMJ Open. 2019 Apr 11; 9(4):e026638. https://doi.org/10.1136/bmjopen-2018-026638 PMID: 30975682. PMCID: PMC6500361. Epub 20190411.

58. Timire C, Ngwenya M, Chirenda J, Metcalfe JZ, Kranzer K, Pedrazzoli D, et al. Catastrophic costs among tuberculosis-affected households in Zimbabwe: A national health facility-based survey. Trop Med Int Health. 2021 Oct; 26(10):1248–55. https://doi.org/10.1111/tmi.13647 PMID: 34192392. PMCID: PMC8519355. Epub 20210803.

59. Citro B, Soltan V, Malar J, Katlholo T, Smyth C, Sari AH, et al. Building the evidence for a rights-based, people-centered, gender-transformative tuberculosis response: An analysis of the Stop TB Partnership community, rights, and gender tuberculosis assessment. Health Hum Rights. 2021 Dec; 23(2):253–67. PMID: 34966240. PMCID: PMC8694305.

60. Zhang K, Wang X, Tu J, Rong H, Werz O, Chen X. The interplay between depression and tuberculosis. J Leukoc Biol. 2019 Sep; 106(3):749–57. https://doi.org/10.1002/JLB.MR0119-023R PMID: 31254317. Epub 20190628.

61. Molebatsi K, Wang Q, Dima M, Ho-Foster A, Modongo C, Zetola N, et al. Depression and delayed tuberculosis treatment initiation among newly diagnosed patients in Botswana. Glob Public Health. 2021 Jul; 16(7):1088–98. https://doi.org/10.1080/17441692.2020.1826049 PMID: 32991275. PMCID: PMC8005506. Epub 20200929.

62. Ambaw F, Mayston R, Hanlon C, Medhin G, Alem A. Untreated depression and tuberculosis treatment outcomes, quality of life and disability, Ethiopia. Bull World Health Organ. 2018 Apr 01; 96(4):243–55. https://doi.org/10.2471/BLT.17.192658 PMID: 29695881. PMCID: PMC5872008. Epub 20180205.

63. Sweetland AC, Galea J, Shin SS, Driver C, Dlodlo RA, Karpati A, et al. Integrating tuberculosis and mental health services: global receptivity of national tuberculosis program directors. Int J Tuberc Lung Dis. 2019 May 01; 23(5):600–5. https://doi.org/10.5588/ijtld.18.0530 PMID: 31097069. PMCID: PMC6558966.

64. Sweetland A, Oquendo M, Wickramaratne P, Weissman M, Wainberg M. Depression: a silent driver of the global tuberculosis epidemic. World Psychiatry. 2014 Oct; 13(3):325–6. https://doi.org/10.1002/wps.20134 PMID: 25273311. PMCID: PMC4219079.

65. Sweetland AC, Jaramillo E, Wainberg ML, Chowdhary N, Oquendo MA, Medina-Marino A, et al. Tuberculosis: an opportunity to integrate mental health services in primary care in low-resource settings. Lancet Psychiatry. 2018 Dec; 5(12):952–4. https://doi.org/10.1016/S2215-0366(18)30347-X PMID: 30241700. PMCID: PMC6489124. Epub 20180918.

66. Wingfield T, Tovar MA, Huff D, Boccia D, Montoya R, Ramos E, et al. A randomized controlled study of socioeconomic support to enhance tuberculosis prevention and treatment, Peru. Bull World Health Organ. 2017 Apr 01; 95(4):270–80. https://doi.org/10.2471/BLT.16.170167 PMID: 28479622. PMCID: PMC5407248. Epub 20170209.