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Stigma and health-related quality of life (HRQoL) among people with multidrug-resistant tuberculosis (MDR-TB): A cross-sectional study in Indonesia

Bustanul Arifin[1,2,a*], Muhamad G. Sarwadan[1,a], Elly Wahyudin[1], Latifah M. Sarifah[3], Ahmad Fuady[4,5], Fredrick D. Purba[6], Sylmina D. Alkaff[7], Akhmad Ardiansyah[8] and Jamaluddin Madolangan[3,9,10]

[1]Department of Pharmacy, Faculty of Pharmacy, Universitas Hasanuddin, Makassar, Indonesia; [2]Department of Health Sciences, University Medical Center Groningen (UMCG), University of Groningen, Groningen, the Netherlands; [3]Labuang Baji Hospital, Makassar, Indonesia; [4]Department of Community Medicine, Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia; [5]Primary Health Care Research and Innovation Center, Indonesian Medical Education and Research Institute, Faculty of Medicine, Universitas Indonesia, Jakarta, Indonesia; [6]Faculty of Psychology, Universitas Padjadjaran, Jatinangor, Indonesia; [7]Robotics and Artificial Intelligence, Department of Engineering, Faculty of Advanced Technology and Multidiscipline, Universitas Airlangga, Surabaya, Indonesia; [8]Department of Pharmacy, Universitas Sembilanbelas November Kolaka, Kolaka, Indonesia; [9]Department of Tuberculosis Disease, Labuang Baji Hospital, Makassar, Indonesia; [10]Departement of Pulmonology and Respiratory Medicine, Faculty of Medicine, Universitas Hasanuddin, Makassar, Indonesia

[a]Both authors contributed equally to this article

*Corresponding author: bustanul.arifin.ury@unhas.ac.id

Abstract

Stigma often accompanies people with multidrug-resistant tuberculosis (MDR-TB) and potentially affects their health-related quality of life (HRQoL). The aim of this study was to investigate the stigma faced by patients with MDR-TB, both from the patients' and community's perspective, and its relationship with HRQoL. Data was gathered at the provincial hospital in Makassar, South Sulawesi, Indonesia. The instrument employed in this research was the Indonesian version of the tuberculosis (TB) stigma instrument to assess MDR-TB stigma from the patient and community perspectives. The patient perspective represents how individuals with TB perceive and experience stigma, including the fear of disclosure, isolation, and guilt (feeling responsible for the burden on their family or their own risky behaviors). Meanwhile, the community perspective reflects how individuals with TB perceive societal attitudes towards them, such as social distancing, avoidance, and reluctance to interact. HRQoL was measured using the European quality of life-5 dimensions-5 level version (EQ-5D-5L) instrument. Notably, the evaluation of anxiety and depression is centered on the fifth dimension of the EQ-5D-5L instrument. A total of 210 patients with MDR-TB were included in the study, all of whom reported experiencing stigma. Most participants perceived stigma at a moderate level, with 76% from the patient perspective and 71% from the community perspective. The average EQ-5D-5L index score was 0.72 (95% confidence interval (95%CI): 0.68–0.76). Measurements from both perspectives show similar scores. There is a substantial negative association between the level of stigma and HRQoL, both from the patient's perspective (R^2=-0.33; F=102.52; p<0.001) and the community's (R^2=-0.32; F=96.76; p<0.001). The study highlights that the stigma of MDR-TB significantly affects the HRQoL from the patient and community perspective.

Keywords: EQ-5D-5L index scores, HRQoL, Indonesia, MDR-TB, stigma

Introduction

Tuberculosis (TB) is a chronic infectious illness that continues to be a global public health issue. The estimated number of people diagnosed with TB globally in 2024, according to the World

Health Organization, was 10.8 million cases [1]. Indonesia ranked second with 969,000 cases, which is 17% in 2020 [1]. People with the highest incidence of TB were found in the productive age group of 15–50 years [2]. TB treatment requires a prolonged and continuous regimen of at least six months, distinguishing it from the management of other bacterial infections [3]. One of the most serious consequences of poor adherence is the development of multidrug-resistant TB (MDR-TB), which occurs when the TB bacteria become resistant to the first-line anti-TB medication. MDR-TB not only compromises treatment effectiveness but also contributes to the spread of resistant strains, thereby increasing the complexity of disease management. In the more severe case, inadequate treatment adherence can further lead to extensively drug-resistant TB (XDR-TB), which is resistant to both first-line and several second-line drugs, posing a significant challenge to TB control efforts [3,4]. The growing prevalence of MDR-TB presents significant challenges to global TB control efforts due to its longer treatment duration, lower success rates, and increased toxicity of second-line drugs compared to drug-susceptible TB (DS-TB) [5].

Treatment for MDR-TB now includes both short-term regimens (STR) and Bedaquiline, Pretomanid, and Linezolid (BPaL) regimens, which can be completed within six months, as well as long-term treatment (≥20 months) with potentially toxic second-line anti-TB medications for more complex cases [6]. MDR-TB can be considered the most severe disease of all TB diseases, and its treatment is more difficult than the disease itself [7]. In 2021, the total number of MDR-TB patients in Indonesia reached 8,268 cases, with only 5,234 patients having started treatment [1]. In 2021, South Sulawesi reported 381 cases of MDR-TB, which rose to 496 cases in 2022 [2]. MDR-TB is closely linked to poverty, vulnerability, and various social risks, including stigma [8]. Patients with MDR-TB often face significant social discrimination, which further isolates them from their communities [9,10]. Existing research has highlighted that stigma is particularly prevalent among TB patients, especially in countries with a high burden [11-13]. Studies conducted across different regions have reported that between 42% and 48% of TB patients experience stigma related to their condition, underscoring the widespread nature of this issue [12,14].

Stigmatization is a critical social determinant of health, significantly impacting individuals' well-being and access to medical care. It stems from societal and institutional norms that label certain behaviors or characteristics as undesirable or devalued. When a disease is associated with stigma, individuals may fear the social and economic repercussions of their diagnosis, leading to reluctance to seek medical attention or adhere to treatment. This reluctance ultimately hinders effective disease management and public health efforts [15-17]. For instance, patients undergoing MDR-TB treatment often face significant challenges due to stigma, which negatively affects their mental health and treatment outcomes [18]. Furthermore, stigma adversely impacts the health-related quality of life (HRQoL) of MDR-TB patients. Individuals with a limited understanding of stigmatization are more likely to experience poor HRQoL, low self-esteem, and depression. Conversely, satisfactory knowledge about stigmatization is associated with more favourable HRQoL outcomes [19]. Therefore, enhancing understanding of the impact of treatment, along with addressing other factors such as age and education, may reduce stigmatization and its adverse effects on patients' quality of life (QoL) and HRQoL [19].

QoL is a broad concept that encompasses physical, social, mental, economic, and other aspects. It specifies how an individual experiences satisfaction and measures the patient's self-perception of their overall health state, function, and well-being [20]. Meanwhile, HRQoL is defined as the degree to which the patient's subjective assessment of physical health, mental health, and social standing is affected by the condition and its daily care [21]. Research in Yemen and South Africa revealed that although MDR-TB treatment yielded promising results, there was a decrease in the HRQoL of patients undergoing treatment, especially their mental health, even after treatment was completed [22,23]. Low HRQoL is more pronounced in MDR-TB patients with comorbid diseases such as diabetes mellitus [9]. MDR-TB has a negative impact on all HRQoL domains, from physical, economic, and social stress to psychological stress due to stigmatization and discrimination received by the patients [24].

Various instruments are available to measure HRQoL, including the Short Form Health Survey (SF-36), which evaluates eight health domains to provide a comprehensive profile of a patient's health status [25], and the Health Utilities Index (HUI), designed to assess general

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health status and generate utility scores for economic evaluations [26]. However, the European quality of life-5 dimensions-5 level version (EQ-5D-5L) is the most widely used tool for measuring HRQoL due to its simplicity, validity, and adaptability across various health conditions and populations [27]. EQ-5D is particularly valuable for assessing changes in patients' health status over time and allows for cross-country comparisons, making it a key instrument in epidemiological studies, clinical trials, and health policy research. Furthermore, its ability to generate utility scores enables its widespread application in health economics, particularly in cost-utility analysis (CUA) and quality-adjusted life year (QALY) calculations, which are essential for decision-making in healthcare resource allocation [28]. Studies have also shown that EQ-5D is frequently used beyond economic evaluations, as it provides a standardized and efficient method for assessing patient-reported outcomes in various medical and public health settings [29,30].

Stigma and HRQoL studies in MDR-TB patients in Indonesia are scarce. The research carried out mainly explores only MDR-TB knowledge and drug compliance [31,32], with few studies evaluating HRQoL and stigma. A study in Jambi, Indonesia, found that MDR-TB patients have low HRQoL, especially those with accompanying diseases such as diabetes mellitus, compliance, and drug monitoring, which are considered risk factors [9]. Research in Gresik, Indonesia, shows that MDR-TB patients with high self-stigma have a higher chance of developing depression than patients with low self-stigma, so promotional efforts by providing support and education to the public should be made to help eliminate the stigma and reduce the incidence of depression in MDR-TB patients [33]. There were only a few studies that measured the impact of stigma on HRQoL, particularly in terms of changes in the EQ-5D-5L index score. Therefore, the aim of this study was to assess the stigma among MDR-TB patients from both patient and community perspectives, as well as its association with the EQ-5D-5L index score.

Methods

Study design and setting
The cross-sectional study was conducted in Makassar, South Sulawesi, Indonesia, from August to December 2023. The study involved outpatients receiving care at a provincial hospital, which serves as one of the primary MDR-TB reference centers in Eastern Indonesia. This hospital is a key referral facility for MDR-TB cases in the region, providing specialized treatment and care for patients from various districts.

Participants
Participants in this study were patients diagnosed with MDR-TB by a pulmonologist, aged 18 years or older, who provided written informed consent. Participants who had difficulty comprehending the study instruments were assisted by their caregivers during data collection. The sample size was calculated using the formula for determining sample size in descriptive studies by Isaac and Michael (1995) [34]:

$$\eta = \frac{\chi^2 \cdot N \cdot \rho \cdot (1-\rho)}{d^2(N-1) + \chi^2 \cdot \rho \cdot (1-\rho)} = \eta = \frac{3.841 \cdot 496 \cdot 0.5 \cdot (1-0.5)}{0.05^2(496-1) + 3.841 \cdot 0.5 \cdot (1-0.5)} = \eta = 210$$

The required sample size (η) for this study was determined using a standard sample size formula incorporating several key parameters [34]. The chi-square value (χ^2) for a 95% confidence level at one degree of freedom was set at 3.841. The total population (N) consisted of 496 MDR-TB patients, as recorded in the *Sistem Informasi* Tuberculosis (SiTB), a digital platform developed by the Indonesian Ministry of Health for TB case tracking, treatment management, and program evaluation across the country. Given the absence of prior data, the estimated population proportion (ρ) was conservatively assumed to be 0.5. Additionally, a margin of error (d) of 0.05, representing a 5% error rate, was applied to ensure statistical reliability in the sample size calculation. Thus, the minimum required sample size was determined to be 210 participants. The sample was selected using a purposive sampling technique to ensure representation of the target population.

Instrument

This study used the culturally adapted Indonesian version of Van Rie's TB stigma instrument [35], which measures TB stigmatization through two main parts: part A (patient perspective) and part B (community perspective). Participants in this study completed an instrument consisting of these two sections to assess TB stigma. Part A consists of 11 items assessing the personal experiences and feelings of MDR-TB patients regarding their diagnosis, including fear of disclosing their TB status, feelings of exclusion, and emotional impacts such as guilt and social isolation. Meanwhile, part B includes ten items capturing the patients' perceptions of how their community (family, neighbors, or acquaintances) treats or views them due to their condition, such as whether people tend to avoid TB patients, are reluctant to talk or interact with them, and hold negative perceptions about TB sufferers [35,36]. Thus, patients not only assessed the stigma they personally experienced but also evaluated the stigma they perceived from their surrounding environment, providing a more comprehensive understanding of the impact of stigma on the QoL of TB patients. It is important to note that the community perspective is based on patient-reported data, and no separate recruitment of community members was conducted. This approach aligns with the validated Indonesian version of Van Rie's TB Stigma Scale, which has been widely used to measure TB-related stigma in Indonesia [35]. For each item, respondents were provided with four response options using a Likert scale: strongly disagree (0), disagree (1), agree (2), and strongly agree (3) [28]. Higher scores indicate greater levels of stigma experienced by the participants, with total scores ranging from 0 to 50 points [28]. To facilitate interpretation and policy considerations, the stigma scores were categorized into four levels: no stigma (no stigmatization in all questions), low (TB stigma score <16.67), moderate (TB stigma score: 16.68–33.33), and high TB stigmatization (TB stigma score >33.33) [37]. The relationship between MDR-TB stigma scores and HRQoL was analyzed in this study, as these two factors are inherently interrelated [22,38].

To measure the HRQoL, the EQ-5D-5L instrument was used, a generic two-page tool widely used for assessing HRQoL [39]. The first page of the instrument includes the EQ-5D descriptive system, which evaluates five dimensions: mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. Each dimension is rated on five levels of severity: no problems, slight problems, moderate problems, severe problems, and extreme problems/unable to perform. A one-digit number represents the selected level for each dimension, resulting in a five-digit code that describes the respondent's health state. For example, the code '11111' indicates no problems in any dimension, while '13242' reflects no problems in mobility, moderate problems in self-care, slight problems in usual activities, severe problems in pain or discomfort, and slight problems in anxiety or depression. Each EQ-5D health state is converted into a single index score based on population preference weights. In this study, the Indonesian value set was used for the conversion [39]. For instance, the health state '11111' corresponds to the maximum index score of 1.00 (indicating perfect health), while '13242' yields a score of 0.49. The second page of the instrument features a visual analog scale (EQ-VAS), which resembles a thermometer ranging from 0 ("worst imaginable health") to 100 ("best imaginable health"). The EQ-VAS provides a more holistic measure of the patient's overall health perception, complementing the EQ-5D-5L index score [39].

Additionally, participants' demographic data were collected using a structured questionnaire. The questionnaire included information on sex, age, marital status, education level, occupation, income status, smoking history, and duration of MDR-TB treatment. Treatment duration was categorized as "early treatment" (≤6 months since starting treatment at the time of data collection) or "advanced treatment" (>6 months).

Data collection procedure and data sources

Participants were recruited using purposive sampling at the hospital's MDR-TB clinic. Eligible participants were adults (aged 18 years or older) diagnosed with MDR-TB, proficient in Bahasa Indonesia, and without severe comorbidities or cognitive impairments. The sampling strategy aimed to achieve a minimum sample size of 210 participants while capturing diverse sociocultural experiences related to TB stigma, psychological distress, and social support needs. The recruitment process involved identifying eligible patients during their routine visits to the MDR-

TB clinic. Clinic staff assisted in screening potential participants based on the inclusion criteria. The research team then approached eligible patients, explained the study's objectives, procedures, and ethical considerations, and obtained written informed consent from those who agreed to participate. Recruitment continued until the target sample size was achieved. Once consent was obtained, participants were guided to the waiting room, where they completed the self-administered instruments. Data collection was conducted using structured, paper-based tools, including a TB stigma instrument and the EQ-5D-5L instrument for measuring HRQoL. Participants were provided with clear instructions on how to complete the instruments, and trained research assistants were available to assist those who required clarification or had difficulty understanding the questions. On average, participants took 10–20 minutes to complete the instruments. The use of self-administered tools minimized bias and ensured confidentiality of responses.

To ensure safety and compliance with hospital protocols, all participants and researchers were required to wear face masks. Participants who did not have a mask were provided with one by the clinic's TB nurses. All patients had previously received education on the importance of mask-wearing to prevent TB transmission, and full compliance was observed during data collection. The data collection phase lasted approximately four weeks, ensuring sufficient participation to meet the study's objectives. Completed instruments were collected, checked for completeness, and securely stored in a locked cabinet to maintain confidentiality. Data were subsequently entered into a password-protected electronic database for analysis.

Statistical analysis

In this study, the data analysis described participants' sociodemographic characteristics, which were presented in a frequency distribution table (n) and percentage. Additionally, MDR-TB stigma scores were evaluated using standard deviation (SD) and range. For descriptive analysis, responses for each item were divided into two categories: the options of very disagreeable (0) and disagree (1) were combined into "disagree", while options of agree (2) and fully agree (3) were combined into "agree". The percentage of respondents who agreed on each item was calculated. The general linear model (GLM) was applied to estimate the value of B and the 95% confidence interval (95%CI) to identify sociodemographic factors associated with MDR-TB stigmatization. A further statistical descriptive analysis compared the EQ-5D-5L index score between subgroups based on sociodemographic characteristics, with mean calculations and a 95%CI [40,41].

The association between MDR-TB stigma and HRQoL, as quantified by the EQ-5D-5L index score (r_s), was analyzed using Spearman's correlation coefficient. This statistical approach was adopted due to its suitability for evaluating both the strength and direction of associations in datasets with non-normal distributions, as was the case in this study. This analysis treats the factors affecting the interaction between HRQoL and stigma as dependent variables, while stigma and HRQoL are considered independent variables. The complete statistical analysis was performed on IBM SPSS Statistics version 25 (IBM Corp., New York, USA). Relationships that exhibit statistical significance were established with a *p*-value of less than 0.05.

Results

Participant characteristic

The demographic and clinical characteristics of the 210 study participants are presented in **Table 1**. Males comprised 60% of the participants, while females comprised 40%. Most were aged 18–60, with the smallest proportion (10.5%) being over 60 years old. Marital status showed 63.3% were married, 23.3% unmarried, and 13.3% widowed. The highest education level was senior high school (38.1%), followed by college/university (26.2%), while 6.2% had no formal education. Employment data indicated that 60% were employed, 21.9% were homemakers, and 18.1% were unemployed, with 75.7% earning below the minimum wage. Most participants (96.2%) had no smoking history. Regarding treatment, 80.5% had been on therapy for over six months, while 19.5% were in the early phase (≤6 months).

MDR-TB stigma score

This study found that the average TB stigma score in part A (patient perspective) was 23.46 (SD: 7.26). The majority of participants (76.2%) experienced moderate TB stigma, which was mostly

associated with feelings of guilt for having TB, among other things: being a family burden (61%), engaging in lifestyle activities that were thought to contribute to their TB diseases, such as smoking or drinking alcohol (54.8%), and being anxious about being infected with HIV/AIDS (35.7%). Furthermore, 49.6% felt lonely, and 42.5% had lost many acquaintances when their MDR-TB diagnosis was revealed (**Table 2**).

Table 1. Participants' characteristics (n=210)

Characteristics	n (%)
Sex	
Male	126 (60.0)
Female	84 (40.0)
Age, years old	
18–30	50 (23.8)
31–40	49 (23.3)
41–50	49 (23.3)
51–60	40 (19.1)
>60	22 (10.5)
Marital status	
Not married	49 (23.3)
Married	133 (63.4)
Widowed	28 (13.3)
Highest educational level attained	
No education	13 (6.2)
Primary school	22 (10.5)
Junior high school	40 (19.0)
Senior high school	80 (38.1)
College/university	55 (26.2)
Occupation	
Unemployed	38 (18.1)
Active employment	126 (60.0)
Homemakers	46 (21.9)
Having income	
Under minimum wage	159 (75.7)
Minimum wage/more	51 (24.3)
Smoking history	
No smoking	202 (96.2)
Smoking	8 (3.8)
Duration of treatment	
Started treatment (≤6 months)	41 (19.5)
Advanced treatment regimen (>6 months)	169 (80.5)

The average TB stigma score in part B (community perspective) was 25.8 (SD: 7.87; range: 8.3–50). There were 71.4% of participants who reported moderate TB stigma from a community standpoint, including a sense of isolation from and by people in their neighborhoods (37.7–78.1%). Almost 70% of others were terrified of them, and 33.3% felt disgusted with TB patients (**Table 2**).

Table 2. Health-related quality of life (HRQoL) report categorized by problem severity (n=210)

Part A patient perspective (n=210)				
MDR-TB stigma category	Mean	SD; min-max	n	%
Stigma total	23.46	7.26; 1.5–43.9	210	100
No stigma	0	0	0	0
Low	12.58	4.17; 1.5–16.7	36	17.1
Moderate	24.64	4.28; 18.2–33.3	160	76.2
High	37.88	2.85; 34.8–43.9	14	6.7
Domain: Disclosure			n agree*	% agree*
P5. I am afraid to tell people outside my family that I have TB			88	42.0
P6. I am afraid to tell others that I have TB because others may think that I also have HIV/AIDS			97	46.2
P8. I choose carefully who I tell about having TB			126	60.0
P11. I am afraid of other people to tell my family that I have TB			51	24.3
Domain: Isolation				
P1. I feel hurt by how others react to knowing that I have TB			87	41.4
P2. I have lost friends when I shared with them that I have TB			95	42.5
P3. I feel lonely			104	49.6

Part A patient perspective (n=210)				
MDR-TB stigma category	Mean	SD; min-max	n	%
P4. I am afraid of going to TB clinics because other people may see me there			65	31.0
Domain: Guilty				
P7. I feel guilty because my family has the burden of caring for me			128	61.0
P9. I feel guilty for getting TB because of my smoking, drinking, or other lifestyle behaviours			115	54.8
P10. I am worried about having HIV/AIDS			75	35.7
Part B community perspective (n=210)				
MDR-TB stigma category	Mean	SD; min-max	n	%
Stigma total	25.79	7.87; 8.3–50	210	100
No stigma	0	0	0	0
Low	14.22	2.76; 8.3–16.7	30	13.4
Moderate	25.23	3.99; 18.3–33.3	148	71.4
High	39.27	4.04; 35–50	32	15.2
Domain: Isolation			n agreed*	% agreed*
C12. Some people may not want to eat or drink with friends who have TB			157	74.8
C13. Some people feel uncomfortable about being near those with TB			139	66.2
C14. If a person has TB, some community members will behave differently towards that person for the rest of his/her life have HIV/AIDS			79	37.7
C15. Some people do not want those with TB playing with their children			145	69.0
C16. Some people keep their distance from people with TB			131	62.4
C21. Some people may not want to eat or drink with relatives who have TB			164	78.1
Domain: Distancing				
C17. Some people think that those with TB are disgusting			70	33.3
C18. Some people do not want to talk to others with TB			56	26.7
C19. Some people are afraid of those with TB			143	68.1
C20. Some people try not to touch others with TB			68	32.4

MDR-TB: multidrug-resistant tuberculosis; SD: standard deviation
*Number and percentages of respondents who agreed to the corresponding item

HRQoL based on the problem level, measured using the EQ-5D-5L

The majority of participants indicated that they experienced no problem across the five dimensions: mobility (54.8%), self-care (76.2%), usual activities (51%), pain or discomfort (42.4%), and anxiety or depression (55.2%). In the anxiety or depression dimension, the second most frequently reported outcome was a severe problem (16.2%), in contrast to the other four dimensions, where the second most reported outcome was the slight problems (**Table 3**).

Table 3. Distribution of health-related quality of life (HRQoL) responses categorized by problem severity level across EQ-5D-5L dimensions

Problem Level	Mobility		Self-care		Usual activities		Pain/ discomfort		Anxiety/ depression	
	n	%	n	%	n	%	n	%	n	%
No problem	115	54.8	160	76.2	107	51.0	89	42.4	116	55.2
Slight problem	73	34.7	30	14.3	67	31.9	76	36.2	33	15.7
Moderate problem	20	9.5	19	9.0	28	13.3	30	14.2	24	11.5
Severe problem	1	0.5	0	0	7	3.3	14	6.7	34	16.2
Unable	1	0.5	1	0.5	1	0.5	1	0.5	3	1.4

Factor associated with MDR-TB stigma and HRQoL

MDR-TB stigma scores in both the patient and community perspectives indicated a moderate level of stigma, with the highest mean score observed in the community perspective. The utility score for MDR-TB was 0.72 (95%CI: 0.68–0.76) based on the total number of participants. Participants in the advanced treatment regimen had higher utility score of 0.82 (95%CI: 0.78–0.84), while those in the started treatment had lower utility score of 0.34 (95%CI: 0.28–0.40). Male participants had significantly lower stigma scores in the community perspective. Age did not show a significant difference in stigma scores; however, across all age categories, stigma scores were higher than those in the reference group (age >60 years). Marital status did not show a significant difference in stigma scores in either patient or community perspectives. Stigma scores were significantly higher among patients with elementary and junior high school education in patient perspective. However, in the community perspective, there was no significant difference in stigma scores based on education level.

Regarding occupation, there were no significant differences in stigma scores in either the patient or community perspectives. The mean stigma scores were lower across all occupations compared to homemakers. Participants with an income under the minimum wage exhibited significantly higher stigma scores in both the patient and community perspectives compared to those with a minimum wage/more. For smoking history, in the patient perspective, stigma scores were lower among non-smokers than smokers. Conversely, in the community perspective, stigma scores were higher among non-smokers than smokers. However, neither difference was statistically significant. Regarding treatment duration, in both patient and community perspectives, participants who had started treatment exhibited significantly higher stigma scores compared to those in the advanced treatment regimen (**Table 4**). Although conventionally a 95%CI that includes the null value (0 for differences or 1 for ratios) is interpreted as non-significant (corresponding to a *p*-value>0.05), minor discrepancies—such as a 95%CI slightly including the null—may occur due to rounding, scale transformations, or differences in computational methods [42]. In our analysis, the reported *p*-values confirmed statistical significance despite any minimal inclusion of the null value in the 95%CI [42]. Furthermore, our study found significant variations in EQ-5D-5L index scores across demographic and clinical groups. Females had lower scores (EQ-5D index scores: 0.68; 95%CI: 0.62–0.75) than males (EQ-5D index scores: 0.74; 95%CI: 0.69–0.79). Employed individuals (EQ-5D index scores: 0.74; 95%CI: 0.69–0.79) and those earning at least the minimum wage (EQ-5D index scores: 0.78; 95%CI: 0.71–0.85) scored higher. When stratified by age, participants aged >60 years achieved the highest scores (EQ-5D index scores: 0.76; 95%CI: 0.65–0.88), followed by those in the 31–40 age group (EQ-5D index scores: 0.75; 95%CI: 0.67–0.84). Married participants scored slightly higher (EQ-5D index scores: 0.73; 95%CI: 0.68–0.78) than unmarried ones (EQ-5D index scores: 0.72; 95%CI: 0.63–0.81), while widowed individuals recorded the lowest scores (EQ-5D index scores: 0.65; 95%CI: 0.57–0.73). Regarding education, senior high school graduates scored 0.75 (95%CI: 0.69–0.81), university graduates scored 0.74 (95%CI: 0.67–0.81), and those without formal education scored the lowest (EQ-5D index scores: 0.62; 95%CI: 0.35–0.88). Clinically, newly diagnosed patients initiating treatment had the lowest scores (EQ-5D index scores: 0.34; 95%CI: 0.28–0.40), while patients on advanced treatment regimens scored the highest (EQ-5D index scores: 0.81; 95%CI: 0.78–0.84) (**Table 4**).

Correlation between stigma and HRQoL among MDR-TB patients

The correlation analysis between MDR-TB stigma and HRQoL, which has been adjusted to age, sex, duration of treatment, history of smoking, income, and employment, resulted in significant regression equations. From the patient's perspective, the results showed R^2=-0.330, F=102.52, and $p<0.001$, whereas from the community perspective R^2=-0.318, F=96.762, and $p<0.001$ (**Table 5**). The results showed a lower negative relationship between MDR-TB stigma ratings and HRQoL. This indicates that higher stigma ratings were strongly linked to a lower HRQoL. Patients who had recently begun treatment had a lower EQ-5D-5L index score of 0.34 (95%CI: 0.28–0.40), indicating poorer HRQoL than those on an advanced treatment regimen (EQ-5D-5L index score: 0.81; 95%CI: 0.78–0.84) (**Table 4**).

Discussion

The present study demonstrates a substantial burden of MDR-TB stigma among adults, adversely affecting HRQoL. From a community perspective, the MDR-TB stigma score was lower in men compared to women, while from a patient perspective, it was higher among individuals with elementary and junior high school education levels. The MDR-TB stigma score was elevated among those with incomes below the minimum wage and those who have recently commenced MDR-TB therapy, from both patient and community perpectives. The mean EQ-5D-5L index score for MDR-TB participants in this study was 0.72, which is inferior to the general population score in Indonesia (0.91) [41]. This study found that women, individuals with primary school education, unemployed, and those newly commencing MDR-TB treatment exhibited lower EQ-5D-5L index scores. Although the correlation results in this study are limited, it is possible to infer that stigma can have a substantial impact on HRQoL due to its substantial value. Furthermore, the correlation implies a negative direction, indicating that the HRQoL decreases as the stigma score increases.

Table 4. Factors related to multidrug-resistant tuberculosis (MDR-TB) stigma and health-related quality of life (HRQoL)

Characteristics	n (%)	Patient perspective			Community perspective			Health-related quality of life
		Mean	SD	β (95%CI)	Mean	SD	β (95%CI)	EQ-5D index score (95%CI)
Total participants	210 (100)	23.48	7.34	-	26.06	7.79	-	0.72 (0.68–0.76)
Sex								
Male	126 (60.0)	23.39	6.89	-0.17 (-2.19–1.85)	24.74	7.75	-2.646 (-4.81–(-0.48))*	0.74 (0.69–0.79)
Female	84 (40.0)	23.56	7.82	REF	27.38	7.83	REF	0.68 (0.62–0.75)
Age, years old								
18–30	50 (23.9)	22.70	8.62	1.49 (-2.18–5.15)	26.00	7.84	1.15 (-2.85–5.16)	0.69 (0.62–0.77)
31–40	49 (23.3)	24.18	6.99	2.97 (-0.71–6.65)	25.88	8.40	1.04 (-2.98–5.05)	0.75 (0.67–0.84)
41–50	49 (23.3)	24.15	7.01	2.94 (-0.74–6.61)	25.82	8.18	0.97 (-3.05–4.99)	0.72 (0.64–0.80)
51–60	40 (19.0)	23.90	6.59	2.69 (-1.11–6.49)	25.92	6.82	1.07 (-3.09–5.22)	0.68 (0.58–0.78)
>60	22 (10.5)	21.21	6.08	REF	24.85	8.45	REF	0.76 (0.65–0.88)
Marital status								
Not married	49 (23.3)	23.19	8.47	-0.24 (-3.65–3.17)	27.45	8.62	1.50 (-2.17–5.16)	0.72 (0.63–0.81)
Married	133 (63.3)	23.56	7.05	0.13 (-2.86–3.12)	25.15	7.64	-0.80 (-4.02–2.42)	0.73 (0.68–0.78)
Widowed	28 (13.3)	23.43	6.09	REF	25.95	7.42	REF	0.65 (0.57–0.73)
Highest education level attained								
No schooling	13 (6.2)	21.68	9.06	0.03 (-4.35–4.40)	24.36	6.55	0.27 (-4.51–5.04)	0.62 (0.35–0.88)
Elementary school	22 (10.5)	25.89	6.22	4.24 (0.67–7.82)*	27.58	7.68	3.49 (-0.42–7.39)	0.61 (0.50–0.72)
Junior high school	40 (19.0)	24.77	6.69	3.12 (0.17–6.07)*	26.17	6.11	2.08 (-1.14–5.29)	0.71 (0.63–0.79)
Senior high school	80 (38.1)	23.66	6.77	2.00 (-0.48–4.49)	26.52	7.37	2.43 (-0.28–5.14)	0.75 (0.69–0.81)
College/university	55 (26.2)	21.65	7.97	REF	24.09	9.76	REF	0.74 (0.67–0.81)
Occupation								
Unemployed	38 (18.1)	22.57	7.73	-2.17 (-5.31–0.97)	25.88	7.21	-1.22 (-4.63–2.18)	0.66 (0.56–0.77)
Active employment	126 (60.0)	23.26	7.38	-1.48 (-3.95–0.99)	25.29	8.26	-1.81 (-4.49–0.86)	0.74 (0.69–0.79)
Housewife	46 (21.9)	24.74	6.47	REF	27.10	7.29	REF	0.69 (0.61–0.77)
Having income								
Under minimum wage	159 (75.7)	24.19	7.28	3.04 (0.77–5.31)*	26.76	7.56	3.98 (1.54–6.43)*	0.70 (0.65–0.74)
Minimum wage/more	51 (24.3)	21.15	6.78	REF	22.78	8.14	REF	0.78 (0.71–0.85)
Smoking history								
No smoking	202 (96.2)	23.36	7.12	-2.59 (-7.75–2.57)	25.81	7.89	0.39 (-5.22–5.99)	0.72 (0.68–0.76)
Smoking	8 (3.8)	25.95	10.48	REF	25.42	7.91	REF	0.69 (0.46–0.92)
Duration of treatment								
Started treatment	41 (19.5)	30.52	5.71	8.78 (6.59–10.97)*	34.47	6.83	10.78 (8.51–13.06)*	0.34 (0.28–0.40)
Advanced treatment regimen	169 (80.5)	21.74	6.53	REF	23.69	6.57	REF	0.81 (0.78–0.84)

EQ-5D: EuroQoL-5 dimension; SD: standard deviation
General linear model (GLM) was used to estimate β and 95%CI for sociodemographic factors associated with MDR-TB stigma and HRQoL. EQ-5D-5L scores were compared between subgroups using mean and 95%CI. Spearman's correlation analyzed the relationship between MDR-TB stigma and HRQoL due to non-normal data distribution
*Statistically significant at $p<0.05$

Table 5. Spearman correlation of multidrug-resistant tuberculosis (MDR-TB) stigma and health-related quality of life (HRQoL) (n=210)

Stigma category	Health-related quality of life (HRQoL)		
	R^2	F	p-value
Patient	-0.330	102.52	0.001
Community	-0.318	96.76	0.001

R^2: coefficient of determination

In this study, the high rate of MDR-TB stigma stems from participants' reluctance to reveal their disease status and their profound sense of guilt regarding their MDR-TB diagnosis. The majority of participants demonstrated selective disclosure, carefully choosing confidants within their immediate family circle. Their hesitancy to inform others was primarily driven by fears of being associated with HIV/AIDS. This self-imposed isolation resulted in feelings of loneliness and deterioration of social relationships upon disclosure of their illness. Furthermore, participants expressed significant regret over their previous engagement in activities that heightened their MDR-TB exposure risk, such as smoking, poor adherence to previous TB treatment regimens, delayed health-seeking behavior, frequent exposure to crowded, and poorly ventilated environments. These risk-associated behaviors, coupled with their current health status, intensified their sense of guilt about becoming a burden to their families. The fear experienced by MDR-TB patients is influenced by community perspectives, as they often feel guilty for being perceived as a source of infection [43]. As a result, they may be considered repulsive [44,45], become subjects of social gossip [45], lose social status [46], face dismissal from work, and encounter difficulties getting their job back [44,47]. This aligns with our findings, where participants reported avoiding social activities, keeping their distance, and isolating themselves more frequently. This behavior is an anomaly in the social patterns of MDR-TB patients and is likely due to their misunderstandings about the disease [48]. In this study, the MDR-TB stigma score was higher than that of MDR-TB patients in Vietnam and China [38,49]. In general, stigma against TB patients persists in Indonesia, Vietnam, and China, albeit in different forms and with varying impacts. In all three countries, this stigma leads to social isolation, delayed treatment, and psychological consequences such as anxiety, depression, and reduced HRQoL [36,41,49].

In Indonesia, TB stigma is primarily influenced by economic and social factors, including workplace discrimination. Additionally, while the Indonesian National Health Insurance (*Jaminan Kesehatan Nasional* or JKN) program provides free treatment, stigma remains high due to insufficient public education [37,50]. In Vietnam, stigma is more socially and internally driven; patients often feel ashamed to disclose their condition due to fears of damaging their family's reputation. Some patients prefer using the term "*lao lực*" (TB caused by overwork) instead of "*lao phổi*" (pulmonary TB) to gain greater social acceptance [49]. In China, stigma has a more pronounced impact on mental health due to discrimination from both the general public and healthcare workers. This discourages patients from seeking treatment and exacerbates feelings of isolation [38,51]. Unlike Indonesia and Vietnam, China has focused more on educating healthcare workers and providing social support, although workplace protection policies remain weak [51]. Briefly, the forms and impacts of TB stigma vary across countries, depending on social, cultural, and healthcare system factors. Therefore, solutions must be tailored to each context, emphasizing education, psychosocial support, and stronger policies to protect TB patients.

The MDR-TB stigma is higher among economically productive young adults and housewives. Although the stigma among male MDR-TB is slightly lower than that of females, one of the main factors contributing to high MDR-TB stigmatization is poor economic status. In some developing countries, males are often considered the backbone of the family. Moreover, MDR-TB patients must visit healthcare centers weekly for medication, not only risking job loss, but also having to cover their own transportation costs during a long period of treatment. It is not surprising that in TB patients, related studies from LMICs have shown that men feel concerned about TB and TB-related stigma, as it can severely affect their primary livelihood status as well as social standing [44,48,52].

Stigma negatively correlates with HRQoL for MDR-TB patients. A greater stigma score correlates with a diminished perception of HRQoL among individuals. The modest link indicates that the stigma associated with MDR-TB considerably impacts the deterioration of HRQoL,

particularly in patients who have recently commenced therapy. The modest correlation is affected by the moderately elevated stigma value; however, certain persons exhibit no decline in the EQ-5D-5L index score, and conversely. In the cohort of patients initiating therapy, there exists a significant stigma value alongside a low EQ-5D-5L index score. The assessment of MDR-TB stigma that affects HRQoL produces a new perspective on the evaluation of MDR-TB programs, and in order to improve effective treatment strategies where mortality can be suppressed, one thing that needs to be improved is that MDR-TB management should shift to decreasing disease-related morbidity. The role of the government is vital in raising awareness of MDR-TB in the community to reduce misperceptions about MDR-TB disease and its transmission in the workplace and to strengthen social protection and employment laws, so it is expected that these rules can contribute to preventing job loss or at least prolonged hours of inability to work (permission) [52]. This economic problem will also shape the patient's behavior in self-stigmatization, which tends not to give information to others about their illness so that they feel safe at work.

High stigma can lead to depression and can have a major impact on low HRQoL [53]. Someone with little understanding of stigmatization is less likely to have poor HRQoL, low self-esteem, and depression. On the other hand, if the patient is knowledgeable about stigma, it will benefit them [54]. To minimize stigma and boost self-esteem, increasing access to accurate and empathetic information about the disease is essential. High stigma can lead to emotional changes such as depression, behavioral changes related to obtaining appropriate treatment, lack of motivation for health services, and even drug misuse [54].

HRQoL goes in the opposite direction of the stigma of MDR-TB patients. The low HRQoL in MDR-TB patients is due to the length of time and side effects of therapy, physical and social restrictions, and anxiety about the disease. Patients newly treated for MDR-TB have a very low HRQoL due to the extended treatment duration, the amount of medication required, and the side effects of hallucinations and physical weakness [22,23,55]. The findings are also consistent with research in South Africa, which reported that MDR-TB patients complain of excessive drug use and the side effects of physical weakness [55]. Over time, HRQoL in MDR-TB patients can increase as they become more accustomed to their condition and remain motivated to recover. HRQoL is often missed in the treatment of MDR-TB patients [22]. HRQoL assessments can be used to discriminate, evaluate, and forecast difficulties, as well as provide solutions for the treatment of physical and mental elements in MDR-TB patients during the treatment stage, in order to promote treatment therapy, healing processes, and risk reduction. These results provide preliminary evidence that the assessment of mental and physical components serves as an additional integrative measure in the later stages of treatment, thereby promoting treatment success [55].

A previous study reported that among MDR-TB patients undergoing cycloserine therapy, 13.3% experienced depression, 12% suffered from anxiety, and another 12% developed psychosis [56]. Nevertheless, most patients were able to continue therapy under strict monitoring by healthcare professionals to manage their mental health conditions. Clinical guidelines [57], published in the American Journal of Respiratory and Critical Care Medicine, emphasized the importance of rigorous monitoring of cycloserine-induced neuropsychiatric side effects. Additionally, healthcare providers are advised not only to oversee this therapy but also to provide adequate psychological support for MDR-TB patients. Furthermore, another study in The Lancet reported that MDR-TB treatment often faces challenges in managing adverse drug reactions, including mental health disorders associated with second-line medications such as cycloserine [58]. Therefore, mitigation strategies such as early screening for mental health disorders, regular monitoring throughout therapy, patient education, and psychological support are essential to minimize the adverse effects. Notably, although cycloserine remains a crucial component of MDR-TB therapy, healthcare professionals must ensure strict monitoring of adverse effects, comprehensive patient education on neuropsychiatric risks, and the provision of psychological support to prevent complications during treatment.

The EQ-5D scoring index as a representation of HRQoL in the present study has proven to be a good measure of HRQoL in MDR-TB patients in South Sulawesi. While our research focuses on the correlation between stigma and HRQoL in MDR-TB patients, depression is also another

factor that needs to be closely observed. MDR-TB-related stigma and depression can synergistically interact, significantly reducing HRQoL. Research indicates that MDR-TB stigma substantially diminishes HRQoL, particularly among patients newly initiated on therapy [59,60]. Patients beginning MDR-TB treatment require specialized care to manage the adverse effects of medication and the demanding dosage regimen [61]. Furthermore, psychological support is crucial to stabilize the patient's mental health and reduce the impact of depression [62,63].

This study possesses several notable strengths and limitations. A primary strength lies in its conduct within a major referral hospital specializing in TB care, offering critical insights into the experiences of MDR-TB patients in a high-burden setting. Notably, this study represents the first of its kind in South Sulawesi, thereby contributing novel evidence to the limited body of literature on TB-related stigma and its impact on HRQoL in this region. The study enrolled 210 participants, a sample size that, while not representative of the entire provincial MDR-TB population, provides meaningful and context-specific findings within the hospital setting. Furthermore, the research underscores the role of sociocultural factors in shaping patient experiences, although cultural diversity was not explicitly examined as a study variable. These findings establish a foundational basis for future investigations into the interplay between TB stigma, psychological distress, and social determinants of health in Indonesia.

However, the study also has limitations. First, it was conducted in a single hospital, which may limit the generalizability of the findings to the entire Indonesian population or other geographical areas. Despite this, the hospital's status as a referral center for East Indonesia provides valuable insights into the experiences of patients in this region. Second, while the study aimed to account for cultural diversity, it did not explicitly detail the specific cultural groups included in the sample. Future research should clarify the cultural demographics of participants to better understand how cultural factors, such as traditional health practices or community stigma, influence TB-related outcomes. Third, the study utilized a stigma questionnaire specifically developed for TB patients, which is a strength as it allowed for the inclusion of context-specific values relevant to MDR-TB patients. For instance, the questionnaire addressed issues such as fear of transmission, social exclusion, and internalized shame, which are particularly salient in the context of TB in Indonesia. However, this also means that the findings may not be directly comparable to studies using generic stigma instruments, limiting the ability to draw broader conclusions across different health conditions or populations.

Based on these findings, a qualitative study on stigma and HRQoL in MDR-TB patients is recommended to provide a more comprehensive understanding of these issues. Qualitative methods, such as in-depth interviews or focus group discussions, could uncover deeper insights into the lived experiences of patients, including how cultural and social factors shape their perceptions of stigma and their coping mechanisms. Furthermore, similar research in Western Indonesia is encouraged to validate and expand these results, ensuring a broader representation of the Indonesian population. For example, studies in other regions of Indonesia, such as Java or Sumatra, could investigate how differences in healthcare infrastructure, community attitudes, or cultural practices influence TB-related stigma and patient outcomes. Such comparative research would strengthen the generalizability of findings and inform more targeted interventions across diverse settings.

Conclusion

Participants suffering from MDR-TB experienced significant stigma, which negatively impacted their HRQoL. Based on self-reported data from MDR-TB patients, stigma was particularly higher among women, individuals of working age, smokers, unemployed TB patients, and those who had recently started MDR-TB treatment. The primary factor contributing to the high level of stigma was the nature of the disease itself. A better understanding of these patient-reported experiences may support the development of more effective intervention strategies to reduce stigma and depression while improving HRQoL. Addressing this issue requires the implementation of stigma reduction programs that integrate community-based education, psychological support, and targeted social interventions to promote public awareness and enhance patient resilience. Moreover, the integration of stigma-sensitive approaches into MDR-TB treatment protocols could effectively mitigate the detrimental effects of stigma on patients' well-being.

Ethics approval

The study was approved by the Faculty of Public Health Ethics Committee of Hasanuddin University, Makassar, South Sulawesi, Indonesia (4631/UN4.14.1/TP.01.02/2023, August 1, 2023).

Competing interests

There were no identified potential conflicts of interest related to this article.

Underlying data

On request, the first and corresponding author will provide derived data to support this work's findings. The research instrument utilized in this study is publicly accessible via the link: 10.6084/m9.figshare.28293089.

Declaration of artificial intelligence use

This manuscript was developed through the strategic integration of artificial intelligence (AI) tools and techniques, with the authors systematically leveraging insights from advanced AI models, such as ChatGPT, DeepSeek, Claude, and QuillBot. These tools were employed to: (a) elevate language quality through improvements in grammar, sentence structure, and readability; (b) facilitate content summarization by enabling concise presentation and comparison of prior research findings; and (c) enhance technical writing by providing structured guidance on articulating complex technical descriptions and formulating robust conclusions. It is critical to note that the final authority over the manuscript's content, structure, and conclusions rests entirely with the authors, with the lead author responsible for coordinating and synthesizing contributions from all co-authors.

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