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Original Article

Understanding delayed diagnosis and treatment of tuberculosis: a cross-sectional study in Semarang, Indonesia

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Abstract

Introduction: Tuberculosis (TB) is a major public health challenge worldwide. Despite the aspiration of the World Health Organization's 'End TB Strategy', Indonesia continues to struggle with adequate identification and diagnosis of TB cases, resulting in prolonged delays in accessing treatment. This study examined the factors influencing patients' delay and routes to accessing a reliable TB diagnosis.

Methodology: A cross-sectional survey design was employed, involving 179 TB patients receiving appropriate treatment from 10 primary healthcare services in Semarang, Indonesia. Data were collected through a questionnaire, analyzed using Chi square analysis, and binary logistic regression was used to predict the correlation and odds ratio variables related to the delayed diagnosis.

Results: Most participants were diagnosed by primary healthcare services (89%). Females experienced more delay compared to males (53% vs 47%). The median diagnostic delay was 19 days between the first onset of symptoms and receiving a reliable diagnosis. Education (p value: 0.040; adjusted odds ratio (AOR): 0.348; 95% confidence interval (CI): 0.127–0.951), and belief that TB is a hereditary disease (p value < 0.001; AOR: 1.671; 95% CI: 1.253–2.229) were identified as key factors associated with diagnostic delay.

Conclusions: Comprehensive community interventions targeting the factors identified in this study are needed to improve education with culturally sensitive strategies and greater engagement with both formal and informal care providers.

Key words: tuberculosis; HSB; delayed; diagnosis; treatment.

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Introduction

Tuberculosis (TB) remains a significant global health challenge, with an estimated 10.6 million people infected and 1.3 million deaths in 2022 alone [1]. In response, the World Health Organization (WHO) launched the 'End TB Strategy', which aims to reduce TB deaths by 95% and incidence by 90% by 2030 [2]. While some high TB-burden countries such as South Africa and India have made substantial progress toward these goals, Indonesia continues to face major hurdles [1].

Indonesia is among the countries with the highest TB burden globally. The WHO estimates that there were 969,000 TB cases in Indonesia in 2022, with only about 75% receiving appropriate treatment [3] and less than 20% of patients are diagnosed at the first healthcare service they seek care from [4]. Although the Indonesian Ministry of Health has implemented initiatives such as the Public–Private Mix (PPM) Program to reduce the number of missed TB cases, participation by medical professionals remains limited, reducing the program's overall impact [5]. Despite the expansion of TB services, early diagnosis and timely treatment initiation remain critical gaps. Delays in diagnosis contribute to prolonged infectiousness and increased risk of transmission within communities [6,7].

One of the key factors contributing to delayed TB diagnosis is the pattern of patients' health-seeking behavior (HSB). In Indonesia, this behavior is influenced by several determinants, including individual health literacy, sociocultural norms, and economic barriers [8]. Studies have shown that individuals often manage their initial symptoms through rest, self-medication, or alternative treatments before seeking care from formal health services [8–10]. However, the expression of these behaviors is not uniform across the country. Given Indonesia's vast cultural and ethnic diversity, local beliefs and customs play a significant role in shaping how people perceive illness and decide when and where to seek help. For example, in Aceh, TB has been associated with spiritual or supernatural causes, affecting treatment preferences [11].

In order to enhance the effectiveness of Indonesia's TB reduction programs, it is essential to understand how community beliefs and behaviors affect diagnostic timelines. Therefore, this study aims to explore the health-seeking behaviors and factors contributing to diagnostic delay among TB patients in Semarang, Indonesia.

Methodology

Study design and participants

A cross-sectional study was undertaken in 2022 in Semarang, the capital city of Central Java Province, to address this knowledge gap. Semarang has a population of 2 million people spread across 16 districts. The city has 20 general hospitals, 9 special hospitals, 37 primary healthcare services, and 246 clinics [12]. Ten primary healthcare services (Bangetayu, Bugangan, Genuk, Halmahera, Karangdoro, Lamper Tengah, Lebdosari, Srondol, Tambakaji, Tlogosari Kulon) were purposively chosen because they had the highest TB incidence in Semarang.

The individuals who were older than 15 years, were already recorded as TB patients residing in Semarang, and consented to participation in the study were included. Three patients were excluded because they were diagnosed with extrapulmonary TB. Data were collected by trained enumerators using a participant questionnaire. Data were collected at the participants' residences. The data needed to locate the residences were provided to the project team by their primary health service.

Survey instrument

The questionnaire included questions covering a variety of domains considered to be essential influences on patient pathways for accessing TB diagnoses, which included the following: how long since the first symptoms until being diagnosed with TB; knowledge of TB (2 questions with yes and no options), 15 questions with right, wrong and do not know options); attitudes towards TB symptoms (7 questions with Likert scale answer options); belief in the effectiveness of TB medication (4 questions with Likert scale answer options); health staff support (5 questions with Likert scale options); family support (5 questions with Likert scale options); and history of seeking treatment before being diagnosed. Questionnaire validity and reliability were initially tested among 30 patients from two primary healthcare services (Bulu Lor and Bandarharjo) before being more broadly implemented. The results indicated acceptable to good reliability across all scales: knowledge (0.706), attitudes (0.602), belief (0.625), health staff support (0.830), and family support (0.825).

Table 1. Demographic characteristics of the participants.

Variable	n (%)
Gender	
Male	84 (46.9)
Female	95 (53.1)
Marital Status	
Single	44 (24.6)
Widow	13 (7.3)
Marriage	122 (68.2)
Education	
No school	3 (1.7)
Primary school	23 (12.8)
Middle school	40 (22.3)
High school	89 (49.7)
University	24 (13.5)
Age (years)	
15–30	54 (30.16)
31–60	107 (59.78)
≥ 61	18 (10.06)
Income	
≤ 3,060,000 IDR (≤ 191 USD)	123 (68.7)
> 3,060,000 IDR (> 191 USD)	56 (31.3)

Data management

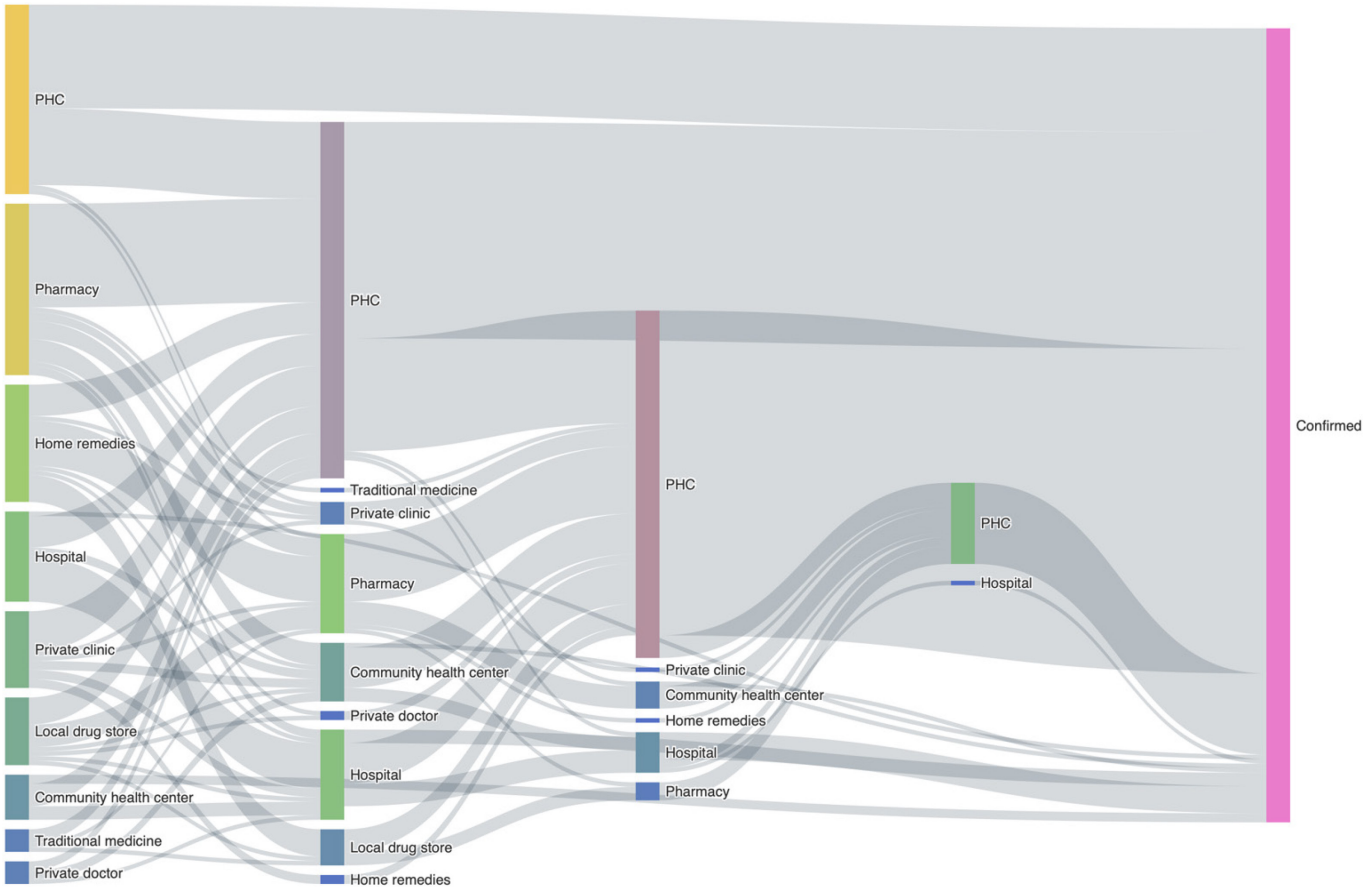
The resulting questionnaire data were analyzed with IBM SPSS statistics version 27 (IBM Corp, Armonk, NY, USA). The data was cleaned to remove duplicates and adjust incorrect details. The Chi square test was used to analyze factors related to TB patients' HSB. Binary logistic regression was used to assess factors associated with delayed diagnosis. Variables with $p < 0.25$ in bivariate analysis were included in the multivariable model. Sankey diagrams were used to visualize the HSB patterns identified to determine the association between categorical variables. The Sankey diagrams were selected as a visualization tool because they provide a clear and intuitive way to illustrate the flow of patients through different stages of the HSB process. For the purposes of this study, 'delay' was defined as patients receiving appropriate TB diagnosis more than 19 days after the onset of the symptoms, as this was the average identified among the sample participants. This study was approved by the Health Research Ethics Committee Faculty of Health Universitas Dian Nuswantoro No. 370/EA/KEPK-Fkes-UDINUS/III/2023.

Results

The demographic characteristics are presented in Table 1. The mean age was 41 years, the majority were female (53.1%), most had finished primary-high school education (85%), more than half had an income lower than the minimal income standard for Semarang (≤ 3,060,000 IDR equal to 191 USD), and 48% had experienced delayed diagnosis.

The pathways of patient HSB are shown in Figure

Figure 1. Pathways of patient health-seeking behavior.



1. Participants reported having sought different types of treatment for their symptoms before receiving a TB diagnosis. Almost half the participants (45.5%) were given a TB diagnosis on the third visit to obtain medication to address ongoing symptoms. Most participants were diagnosed by primary healthcare services (89%). As outlined in Table 2, 21% of the participants took medication from a pharmacy, 15% chose home remedies, 3% chose traditional remedies, and 41% chose government health services (acute, primary, or community health services) for the first point of care. Only 14.6% of participants received their diagnosis from the first health service where they sought care.

The median diagnostic delay was 19 days, with a minimum delay of 3 days and a maximum delay of 115 days (Table 2). Females experienced more delay compared to males (23 vs. 19 days). The median delay for participants who worked was shorter compared to those who were unemployed (22 vs. 23 days for females, 19 vs 24 days for males). The number of patients who engaged in self-treatment for TB symptoms was high (home remedies 14.5%; local drug store 8.9%; pharmacy 21.3%; traditional medicine 2.8%).

Table 3 shows several significant associations between patient characteristics and diagnostic delay. Although gen der, age, occupation, and income were not significantly associated with delay ($p > 0.05$), a slightly higher proportion of females experienced delays (50.5%) compared to males (45.2%). Education level was significantly associated with diagnostic delay

Table 2. Medication access of the participants.

Variable	n (%)
First medication access	
Community health center	10 (5.6)
Home remedies	26 (14.5)
Hospital	20 (11.2)
Local drug store	16 (8.9)
Pharmacy	38 (21.2)
PHC	42 (23.5)
Private clinic	17 (9.5)
Private doctor	5 (2.8)
Traditional medicine	5 (2.8)
The likelihood of being diagnosed based on the number of visits	
First visit	27 (15.1)
Second visit	52 (29.1)
Third visit	81 (45.2)
Fourth visit	19 (10.6)
Delay	
Median ± IQR	19 ± 14

Table 3. Factors correlated to diagnosis delay among participants.

Characteristics	Delay (> 19 days)	Non-delay (≤ 19 days)	*p* value (COR, CI 95%)
Gender			
Male	38 (45.2)	46 (54.8)	0.578
Female	48 (50.5)	47 (49.5)	(0.809; 0.449–1.457)
Education			
No-school	1 (33.3)	2 (66.7)	
Primary-high school	67 (44.1)	85 (55.9)	0.014*
University	18 (75)	6 (25.0)	
Age (years)			
15-30	23 (42.6)	31 (57.4)	
31-60	53 (49.5)	54 (50.5)	0.563
≥ 61	10 (55.6)	8 (44.4)	
Occupation			
No-work	32 (52.5)	29 (47.5)	0.489
Work	54 (45.8)	64 (54.2)	(0.765; 0.412–1.421)
Income			
≤ 3,060,000 IDR (≤ 191 USD)	54 (43.9)	69 (56.1)	0.100
> 3,061,000 IDR (> 191 USD)	32 (57.1)	24 (42.9)	(0.587; 0.310–1.111)
Knowledge			
Poor	77 (6.7)	88 (53.3)	0.323
Good	9 (64.3)	5 (35.7)	(0.486; 0.156–1.513)
Attitude			
Poor	73(52.9)	65(47.1)	0.027*
Good	13 (31.7)	28(68.3)	(2.419; 1.157–5.059)
Belief			
Poor	43(41.7)	60(58.3)	0.070
Good	43(56.6)	33(43.4)	(0.550; 0.302–1.001)
Health staff Support			
Poor	54 (52.9)	48 (47.1)	0.174
Good	32 (41.6)	45 (58.4)	(1.582; 0.871–2.874)
Family support			
Poor	45 (44.6)	56 (55.4)	0.361
Good	41(52.6)	37 (47.4)	(0.725; 0.401–1.132)
TB is a hereditary disease			
Totally agree	0(0)	17(100)	
Agree	18 (41.9)	25 (58.1)	> 0.001*
Not sure	5 (45.5)	6 (54.5)	
Disagree	57 (58.2)	41 (41.8)	
Totally disagree	6 (60)	4 (40)	
Traditional medicine is more effective for TB treatment			
Totally agree	1 (8.3)	11 (91.7)	
Agree	24 (42.1)	33 (57.9)	0.003*
Not sure	20 (66.7)	10 (33.3)	
Disagree	41 (51.9)	38 (48.1)	
Totally disagree	0 (0)	1 (100)	
Cough more than 2 weeks but still able to do daily activities no need to worry			
Totally agree	2 (14.3)	12 (85.7)	
Agree	46 (53.5)	40 (46.5)	0.033*
Not sure	10 (41.7)	14 (8.3)	
Disagree	28 (50.9)	27 (49.1)	
Totally disagree	0(0)	0(0)	

*Significant at 5% level.

(p = 0.014), with the highest delay observed among patients with university-level education (75.0%) compared to those with primary to high school education (44.1%) and those with no formal schooling (33.3%). Attitudes toward TB also showed a significant association (p = 0.027), where individuals with poor attitudes experienced more delays (52.9%) than those with good attitudes (31.7%).

While general knowledge, beliefs, and support from health staff or family did not show significant associations, several belief-related items were strongly linked to delay. Specific TB-related perceptions were significantly associated with delay. Respondents who believed that TB is a hereditary disease (p < 0.001), or who agreed that traditional medicine is more effective for TB treatment (p = 0.003), were significantly more likely to delay diagnosis. For example, 66.7% of those who were unsure about traditional medicine experienced delay, while only 8.3% of those who totally agreed did so. Similarly, individuals who believed that a cough lasting more than two weeks does not warrant concern if one can still carry out daily activities were significantly more likely to delay (p = 0.033).

Two variables were significantly associated with

diagnostic delay (Table 4). Education was a protective factor, with individuals who had higher education levels being significantly more likely to experience delay (adjusted odds ratio (AOR) = 0.348; 95% CI: 0.127–0.951; $p = 0.042$). Additionally, the belief that TB is a hereditary disease was significantly associated with increased odds of delay (AOR = 1.671; 95% CI: 1.253–2.229; $p = 0.045$).

Discussion

Timely diagnosis of tuberculosis (TB) is a critical determinant of treatment success and disease control, particularly in high-burden countries like Indonesia. This study revealed that nearly half of the TB patients in Semarang experienced a diagnostic delay of more than 19 days, despite the availability of free TB services at public health facilities. While the median delay observed in this study (19 days) is shorter than some previous reports from Indonesia [13], the proportion of delayed cases remains unacceptably high and reflects underlying barriers in the health system and community-level behavior. This proportion is higher than reported in some comparable settings, such as North Ethiopia (31.3%) [14]. This shorter delay may be due to the sample being drawn from patients already engaged with primary healthcare (PHC) services rather than from acute or hospital-based settings. These findings align with previous research in Indonesia showing that timely diagnosis is rare on first contact with the health system and is often affected by factors such as education level, insurance status, and the type of provider initially visited [13].

Gender-related disparities were also observed, with women experiencing longer delays than men. This may be influenced by socio-cultural factors in Indonesia that restrict women's autonomy and access to healthcare [15]. Prior studies have shown that women often de-prioritize their own health needs due to economic dependence, domestic responsibilities, or stigma associated with TB [15,16]. In India, for example, cultural expectations and fear of social consequences have been shown to result in underreporting and diagnostic delays among young women, with one study reporting only one female being diagnosed for every 2.4 males [17].

The very low percentage (15.1%) of patients who received a TB diagnosis at their first healthcare visit may reflect limitations in diagnostic capacity at initial points of care. Interestingly, the study found that PHC facilities in Indonesia were the most common diagnostic site. This contrasts with other countries, such as Ethiopia, where hospitals often serve as the primary diagnostic point and are associated with shorter diagnostic timelines [18]. Indonesia's national health insurance system requires patients to seek care through PHC before being referred to hospitals [19]. This requirement, combined with the availability of TB diagnostic laboratories at PHC level, likely contributes to earlier diagnosis in this context.

The findings of this study also confirm that cultural beliefs and perceptions about TB influence HSB. A substantial proportion of the patients initially pursued self-treatment or traditional remedies, and many believed that TB is a hereditary disease or that traditional medicine is more effective. These perceptions significantly delayed diagnosis. Similar patterns have been observed in Malawi and South Africa, where strong cultural and religious beliefs lead patients to seek help from traditional healers, even after receiving a formal TB diagnosis [20]. In Ethiopia, traditional medicine remains widely used, and patients often delay formal care due to low perceived severity of symptoms or high trust in alternative healers [21,22]. These findings of the high use of traditional and complementary medicine to treat TB symptoms align with the results of the present study.

The relationship between health literacy and the level of education is complex. Studies have shown that individuals with higher education are more likely to have better health literacy, but the correlation is not straightforward [23]. This highlights the need for further investigation into the nature of this association. It is also noteworthy that patients frequently seek healthcare from both private and traditional medicine

Table 4. Multivariate analysis of factors that influenced diagnosis delay.

Variables	*p* value	COR (CI 95%)	*p* value	AOR (CI 95%)
Education	0.042*	0.349 (0.121–1.753)	0.040*	0.348 (0.127–0.951)
Attitude	0.487	0.720 (0.285–1.818)		
Belief	0.939	0.953 (0.284–3.203)		
Health staff support	0.190	0.610 (0.291–1.277)		
TB is a hereditary disease	0.046*	1.557 (1.008–2.405)	< 0.001*	1.671 (1.253–2.229)
Traditional medicine is more effective for TB treatment	0.931	1.024 (0.598–1.753)		
Cough more than 2 weeks but still able to do daily activities; no need to worry to	0.934	1.023 (0.598–1.751)		
Nagelkerke R Square		0.172		0.152

*Significant at 5% level.

sectors due to the widely held perception that TB is a hereditary disease [13]. This cultural belief contributes to the delay in diagnosis, as evidenced by the study findings. Prior Indonesian research revealed that cultural and religious contexts significantly impact TB communication and education [24]. The views and information related to TB influence the behavior of seeking medical attention [25].

Interestingly, this study found that individuals with higher education were more likely to experience diagnostic delay, which contrasts with commonly held findings from other settings where education is typically associated with earlier health service utilization. One possible explanation is that individuals with higher education may initially attempt to self-manage symptoms, conduct online self-diagnosis, or delay care-seeking due to work commitments, perceived stigma, or the assumption that their symptoms are not serious. Some may prefer to consult private providers or pharmacies rather than public health centers, which may lead to fragmented care and delayed diagnosis [26,27].

However, this study also has limitations to be considered, as it was conducted in a higher-incidence TB area of Indonesia, and the results may not be generalizable to lower-incidence areas. This is because TB's prevalence and risk factors may differ in different settings. Therefore, it is important to conduct similar studies in other areas of Indonesia to confirm the findings. A second limitation was that HSB was measured based on patient recall. Patients may not accurately remember their symptoms or exposure to risk factors, which could lead to misclassification of HSB status. This status could affect the validity of the study's findings and make it difficult to draw definitive conclusions about the relationship between HSB and TB risk.

Conclusions

This study highlights that diagnostic delay in tuberculosis remains a significant challenge in Semarang, Indonesia, despite the availability of public health services. Nearly half of the patients experienced delays exceeding 19 days, influenced by a combination of sociocultural beliefs, HSB, and health system factors. Misconceptions, such as the belief that tuberculosis is a hereditary disease, were significantly associated with delayed diagnosis. Interestingly, individuals with higher education were more likely to postpone seeking care, suggesting that education does not always translate into timely health actions. Gender differences and the low proportion of patients diagnosed at their first visit further underscore the barriers to early detection. These findings indicate the need for culturally sensitive education strategies and greater engagement with both formal and informal care providers. Future studies should explore similar issues in other regions of Indonesia to better understand variations in delay and inform targeted interventions.

Availability of data and materials

The datasets are not publicly available but are available from the corresponding author upon reasonable request.

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Conflict of interest

No conflict of interest is declared.

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