



A recent of tuberculosis's burden and under-notification in Indonesia: A scoping review

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Abstract

Tuberculosis (TB), an age-old infectious ailment triggered by *Mycobacterium tuberculosis*, spreads through airborne droplets expelled during coughing, sneezing, or talking. Despite being ancient, TB remains a formidable threat, surpassing even HIV-AIDS before the COVID-19 era. The escalating burden of TB partly due to significant underreporting, skewing the documented count of new cases. This underreporting hamper control efforts by obscuring the whereabouts and health status of index cases, thereby facilitating TB transmission within communities. Indonesia, among the top 30 nations grappling with TB, ranks third in incidence and second in underreporting. Various factors, such as smoking, malnutrition, diabetes mellitus, HIV, and underreporting, exacerbate TB prevalence in Indonesia. Inadequate reporting leads to increased TB transmission, elevated morbidity and mortality rates, and a surge in drug-resistant TB. The Indonesia Inventory Study of Tuberculosis conducted from 2016 to 2017 revealed a 41% underreporting rate, notably 96% from the private health sector. Indonesia has implemented several initiatives, including Public-Private Mix programs, mandatory notification, and TB reporting system enhancements, to bolster case identification and notification rates.

Keywords: Burden; Under Notification; Tuberculosis; Indonesia

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1. Introduction

Tuberculosis (TB) is an ancient infectious disease caused by *Mycobacterium tuberculosis*, which is spread through droplets produced by TB patients when coughing, sneezing, or talking. As one of the oldest infectious diseases on earth, tuberculosis is still one of the most deadly diseases, even more than HIV-AIDS before the COVID-19 pandemic emerged. In 2021, TB was responsible for approximately 1.6 million people's deaths, marking a rise of 0.1 million deaths compared to the previous year. Indonesia held the second position globally in terms of pulmonary TB cases, with India leading the list, followed by Indonesia and China. The World Health Organization (WHO) projected that approximately 10.6 million individuals contracted TB in 2021, reflecting a 4.5% increase from the preceding year. In the absence of adequate treatment, the mortality rate for TB is estimated to be around 50% within the first year [1]. The incidence of TB continues to rise, partly attributable to a significant disparity between the documented number of new cases and those that go unreported (under-notification) [2].

The substantial impact of underreporting TB is impairing TB control efforts. This is mainly because the whereabouts and health status of index cases become

uncertain, making it challenging to determine whether they are present in their homes, schools, workplaces, hostels, or other locations. An active TB state contributes significantly to uncontrolled TB transmission in the broader community. Individuals with smear-positive (+) TB have the potential to infect 10-15 others per year. Untreated patients with smear-positive (+) TB face a mortality risk of less than 8 years [3-4]. According to the World Health Organization (WHO) report, Indonesia is recognized as one of the 30 countries facing a substantial tuberculosis burden globally, ranking third-highest in terms of tuberculosis incidence. In 2018, the documented tuberculosis incidence in Indonesia was 316 cases per 100,000 population, indicating an estimated 845,000 people were affected by tuberculosis during that year. The report also estimates that the tuberculosis mortality rate in Indonesia was around 35 per 100,000 population, leading to the loss of approximately 93,000 lives to tuberculosis in 2018 [1].

2. Materials and Methods

This study employs a scoping review methodology to identify and analyze relevant literature on the topic. A scoping review is a systematic approach designed to map key

concepts, types of evidence, and research gaps within a particular field. The articles included in this review were identified through a comprehensive literature search in electronic databases such as PubMed, Google Scholar, and Science Direct, using the keywords "underreporting," "tuberculosis," and "private sector." We excluded studies whose abstracts did not relate to the context, were non-English, or published more than five years ago. This process involved defining clear research questions, systematically searching and selecting literature based on predefined inclusion and exclusion criteria, extracting data using standardized forms, and synthesizing the findings to highlight major themes and implications. This method ensures a thorough understanding of the topic, offering a robust contribution to the existing body of knowledge.

3. Results and discussion

After deduction replications, we identified 95 studies related to our context. We excluded 59 articles after the abstract screening, leaving 36 articles for further evaluation. We included observational (26), experimental (9), and qualitative (4) studies in this scoping review.

3.1. Recent condition of the burden of tuberculosis in Indonesia

The high incidence of TB in Indonesia is closely related to various risk factors, specifically smoking, malnutrition, and diabetes mellitus (DM). It is estimated that over 152,000 cases of TB are associated with smoking habits, while malnutrition and DM are believed to contribute to over 120,000 and 25,000 cases of tuberculosis, respectively. According to the Tuberculosis Prevalence Survey (SPTB) conducted between 2013 and 2014, the proportion of tuberculosis cases was twice as high among individuals who reported a history of diabetes mellitus, smoking, or residing with a tuberculosis patient compared to those without these factors. Moreover, the proportion of tuberculosis cases among the population with a history of tuberculosis was seven times higher than among those without such a history [1-5]. Another factor that is closely related to the high incidence of TB in Indonesia is the increasing prevalence of HIV. Individuals with HIV face a significantly heightened 20-fold risk of developing TB. The pathogenesis of TB infection in those living with HIV is intricately tied to the degradation of the immune system, particularly the decline in CD4 T lymphocytes.

The onset of HIV infection leads to a reduction in CD4 T lymphocytes, impairing the immune response against *Mycobacterium tuberculosis*. Consequently, this diminished immune function paves the way for the reactivation of latent TB, transitioning it from a dormant phase to an active infection. HIV poses a significantly higher risk for the development of multidrug-resistant tuberculosis (MDR-TB). Individuals living with HIV face a 50% likelihood of contracting MDR-TB, in stark contrast to the 5-10% risk observed in those who are HIV-negative. The correlation between TB and HIV is mutually influential. Individuals with HIV are more prone to TB due to deficiencies in their cellular immune system. Simultaneously, TB stands out as the leading cause of mortality (30-50%) among those affected by HIV/AIDS. TB infection accelerates the progression of HIV/AIDS, leading to a quicker transition to fatal outcomes [6-7]. Beyond its impact on the healthcare sector, tuberculosis

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imposes a substantial economic burden. The greatest tuberculosis burden is projected to be in the age group of 25-34 years, with a prevalence rate of 753 per 100,000 population.

Findings from the 2013-2014 Tuberculosis Prevalence Survey (SPTB) in Indonesia revealed a higher prevalence of tuberculosis in men compared to women, with rates of 1,083 per 100,000 population for men and 461 per 100,000 population for women. Household costs associated with drug-sensitive tuberculosis amount to 133 USD, while those for multidrug-resistant TB (MDR-TB) reach 2,804 USD. About 36% of households, with a breakdown of 43% in impoverished households and 25% in non-poor households, face catastrophic costs due to drug-sensitive tuberculosis. The incidence of catastrophic costs rises significantly to 83% for MDR-TB. In economically disadvantaged households, these costs stem from factors such as the tuberculosis patient's role as the family's breadwinner, job loss, and a history of previous treatments [5-8]. In 2015, a survey conducted by the Ministry of Health indicated a higher incidence of tuberculosis in urban settings, with a rate of 846 per 100,000 population, in contrast to rural areas, where the rate was 674 per 100,000 population. Additionally, among individuals aged over 65 years, the tuberculosis incidence was notably elevated at 1,582 per 100,000 population [5].

3.2. Under-notification of tuberculosis cases in Indonesia

Tuberculosis notification is the formal process of reporting identified cases of TB to health authorities, followed by subsequent reporting to the National Tuberculosis Program (NTP). This essential step plays a pivotal role in the early stages of public health intervention. Recognizing and reporting TB cases is of utmost importance in effectively addressing the disease, lowering transmission rates, and preventing tuberculosis-related deaths [5-9-11]. Notification plays a crucial role in the planning, execution, and assessment of health promotion and intervention programs for tuberculosis by predicting of the disease burden. This process is vital for effective program management, enabling a comprehensive understanding of the scale of the tuberculosis issue and facilitating informed decision-making in the public health domain [12]. Underreporting of tuberculosis cases refers to not reporting diagnosed tuberculosis patients to local authorities and or the National Tuberculosis Program (NTP) by medical doctors or TB officers. The consequences of underreporting in tuberculosis can have detrimental effects on the effectiveness of TB prevention and control programs.

It may lead to the broader transmission of TB, heightened rates of morbidity and mortality associated with TB, and an escalation in drug-resistant tuberculosis (DR-TB) [2]. In the 2022 WHO report, Indonesia ranked as the second-highest country globally in terms of the significant disparity between officially reported tuberculosis cases and the estimated actual number of TB cases [1]. The decline in TB notifications during 2020 and 2021 implies a growth in the number of individuals with undiagnosed and untreated tuberculosis. This initially results in a rise in TB-related deaths and heightened community transmission. Subsequently, there is a delayed increase in the number of people developing tuberculosis. The decrease in notifications is attributed to various factors, including the reallocation of

healthcare resources to address the COVID-19 pandemic, restrictions on movement limiting access to healthcare, and individuals' reluctance to seek medical attention due to concerns about COVID-19 transmission in healthcare settings. Additionally, disruptions in the supply chain of TB medications and diagnostic tools may have contributed to the challenges in maintaining continuous TB care.

3.3. What Efforts Have Been Undertaken by Indonesia to Address Tuberculosis Underreporting?

Various efforts have been made by Indonesia, especially to increase the number of cases discovered and notification rates for tuberculosis, including:

1. Mandate the reporting of tuberculosis cases across all healthcare facilities.
2. Conduct proactive case identification, particularly among high-risk groups such as individuals with HIV/AIDS, diabetes mellitus patients, and those experiencing malnutrition.
3. Intensify efforts in contact tracing to identify and address potential tuberculosis cases.
4. Enhance the accuracy and completeness of record-keeping and reporting in all healthcare institutions.
5. Bolster the collaboration between government and private healthcare facilities for the identification, management, and treatment of tuberculosis.
6. Expand and reinforce diagnostic and treatment services for tuberculosis.
7. Optimize public awareness through effective communication, information dissemination, and educational campaigns about tuberculosis [5].

Points 1, 2, and 3 were put into effect through the enforcement of Minister of Health Regulation No. 67 of 2016, which mandates the notification of tuberculosis by all healthcare facilities. Additionally, to enhance the availability of high-quality tuberculosis services, the government has initiated a collaborative approach between the public and private sectors known as PPM (Public-Private Mix). The integration of the TB PPM is designed to motivate all healthcare facilities dealing with tuberculosis to engage in the network, ensuring that every tuberculosis patient is identified, treated by established standards, and documented in the National Tuberculosis Program information system [5-13]. Additionally, the Indonesian government has introduced the Integrated Tuberculosis Information System (SITT) and written documentation for the recording and reporting of drug-sensitive tuberculosis cases. Furthermore, for Independent Practicing Doctors to report tuberculosis cases, the government has developed WIFI TB, a mobile application program designed for this purpose. Nevertheless, the tuberculosis recording and reporting initiative has faced challenges in achieving optimal functionality. According to observations from JEMM [14] not utilize the Integrated Tuberculosis Information System (SITT), despite having access to computers.

The formats and forms for diagnostic referrals, treatment cards, and other documents have not consistently updated to align with the standards of the ongoing National Tuberculosis Program, leading many health centers to independently print and copy these forms. The issue of data completeness persists, particularly concerning incomplete information such as addresses and contact details at patients' residences. Furthermore, JEMM 2020 identified disparities

between the number of tuberculosis cases reported in the tuberculosis information system and those reported by health service facilities, with variations also noted in the number of cases recorded in medical records. Cases involving treatment with drugs other than those specified by the National TB Program were not consistently reported. Real-time reporting using SITT faced challenges, especially in community health centers where staff workload is notably high, and internet speed issues pose a challenge in certain areas. SITT is just one of approximately seven online data systems at community health centers, and TB program staff often juggle multiple responsibilities with other programs. Obtaining information on treatment outcomes for patients referred to other health facilities is a complex task. Similar challenges apply to the use of TB WIFI, where data sharing and review between SITT and SIHA are constrained due to SIHA's reliance on aggregate data [5-14].

A study conducted in Semarang in 2020, focusing on private sector doctors' utilization of WIFI TB, revealed that the reasons for non-adoption of the WIFI TB application included respondents' lack of familiarity with the application. Challenges in operating the application, particularly in tasks such as inputting, editing, and saving patient data within the app, were identified. Additionally, a stable internet connection was highlighted as a crucial factor influencing the application's usability. The approach implemented by the local City Health Service was also noted as a contributing factor to the reluctance to use the WIFI TB application [15]. Similar findings were derived from a research study involving 28 independent practicing doctors in Yogyakarta in 2019. Reasons for non-compliance with mandatory tuberculosis notifications included a lack of awareness regarding the regulations requiring mandatory notification, perceiving notification tasks as burdensome amidst routine responsibilities, ethical concerns related to potential leakage of patient personal data, fear of facing stigmatization, and a lack of a clear and practical mechanism for notification. Furthermore, the absence of both sanctions and incentives for notifications was identified as an influential factor [16].

4. Conclusions

Indonesia is acknowledged as one of the 30 nations grappling with a significant burden of tuberculosis globally, holding the third position in terms of tuberculosis incidence and the second position in underreporting. The elevated prevalence of TB in Indonesia is intricately linked to various factors, notably smoking, malnutrition, diabetes mellitus (DM), HIV, and underreporting. The repercussions of inadequate reporting in tuberculosis can have adverse impacts on the efficacy of TB prevention and control initiatives. This shortfall in reporting may contribute to the widespread transmission of TB, increased rates of morbidity and mortality associated with TB, and a surge in drug-resistant tuberculosis (DR-TB). Indonesia has implemented various initiatives aimed at improving the detection and reporting rates of tuberculosis cases. These efforts include: (1) Enforcing the mandatory reporting of tuberculosis cases across all healthcare facilities; (2) Proactively identifying cases, especially among high-risk groups such as individuals with HIV/AIDS, diabetes mellitus patients, and those experiencing malnutrition; (3) Strengthening efforts in contact tracing to promptly identify and address potential

tuberculosis cases. (4) Improving the accuracy and completeness of record-keeping and reporting in healthcare institutions to enhance overall data quality; (5) Fostering collaboration between government and private healthcare facilities to jointly identify, manage, and treat tuberculosis cases.; (6) Expanding and reinforcing diagnostic and treatment services for tuberculosis to ensure comprehensive coverage; and (7) Optimizing public awareness through effective communication, information dissemination, and educational campaigns to educate the public about tuberculosis.

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