INFORMAL WORKERS' PULMONARY TUBERCULOSIS STIGMA IN KEDIRI REGENCY, EAST JAVA, INDONESIA

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Abstract. Tuberculosis (TB) patients face unfavorable reception from the community, their surroundings, and their workplace, including resistance, ostracism, complaints, and even dismissal. This negative stigma is related to the fact that public education of tuberculosis is still inadequate, therefore people have the erroneous perception of tuberculosis sufferers. This study aimed to analyze TB stigma and its impact on informal workers. Inclusion criteria were those who registered as informal workers in Kediri Regency at the time the research was conducted. Exclusion criteria included having a mental disorder or other conditions that prevent them from an interview. Out of 215 informal workers in Kediri Regency, Indonesia, 175 met the inclusion criteria and were recruited as research participants. The research employed descriptive research design with a cross-sectional study and data were collected via online surveys. Data analysis was performed by frequency distribution and t-test. Based on the results of this study, social support had an influence on stigmatizing behavior (p-value = 0.004. Respondents emphasized the importance of social support throughout their illness and recovery. Even though neighbors, and in some cases friends, abandon the patient, the unconditional love of family members remains the main source of social support for some people. Stigma matters in TB prevention, care, and treatment and warrants stigma reduction interventions. Family members' compassion encourages patients to adhere to treatment and helps them overcome the stigma associated with TB.

Keywords: informal workers, pulmonary tuberculosis, stigma

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INTRODUCTION

Pulmonary tuberculosis (TB) is a chronic infectious illness that causes global health effects. TB is caused by the microorganism Mycobacterium tuberculosis, which can be transmitted through the air and infect people. Every year, more than eight million people fall ill with contagious tuberculosis, and over 250,000 children die {Formatting Citation}. The majority of persons with tuberculosis live in Asia's densely populated countries, including Bangladesh, China, Indonesia, India, and Pakistan (Dye, 2006). The incidence of tuberculosis varies greatly. In some African nations, for example, the prevalence of tuberculosis is greater than 1000 per 100,000 populations (WHO, 2008). In Western countries such as the United Kingdom, the United States, Canada, and Australia, the frequency is 20 per 100,000 (WHO, 2008). One of the main problems that persists in efforts to reduce the number of TB cases is a lack of community knowledge; there are still many people who lack information, causing people to have the false perception of pulmonary TB patients. According to Ashaba *et al* (2021), tuberculosis causes a decline in immunity and physical weakness, resulting in limitations in daily activities, which can damage society's financial, social, and physical well-being and social isolation. Stigma is a negative perception or view of someone who will be formed by the distance between the social environment and have feelings of shame and isolation (Edginton *et al*,

2002; Macq *et al*, 2006). Stigma is something related to the label given by a group or society to a disgraceful person or group. Stigma can be specified for a person or persons with a disease such as an infected person full term Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) (Cremers *et al*, 2015; Mbuthia *et al*, 2020). Stigma can arise in the family and society and it can be in the form of social support or a stigma against TB cases (Bresenham *et al*, 2020).

Based on the 2022 Global TB Report, the highest number of TB cases occurs in the productive age group, especially those aged 25 to 34 years (WHO, 2022). In Indonesia, the largest number of TB cases occurs in the productive age group, especially those aged 45 to 54 years (World Health Organization, 2021). This age is the age at which the majority of people work. Kediri is one of the districts and cities in East Java and is an area that has an industrial center. Based on Kediri city master data,2022 the number of TB sufferers in Kediri City in 2020 was 554 people with 162 bacteriologically positive. TB is declared an occupational health hazard and therefore requires health services, namely prevention and treatment as well as support in the workplace. The government focuses on controlling TB in workers through Minister of Health's regulation number 67 of 2016 concerning TB Control (Ministry of Health, 2016) and Minister of Manpower's regulation number 13 of 2022 concerning control of TB in the workplace (Ministry of Manpower, 2022). Based on a preliminary study in 2 workplaces (rattan industry and corn seed industry), it was found that conditions that could lead to TB infection were poor ventilation, absence of infection prevention in the workplace, non-optimal use of PPE and high smoking habits. Workplace policy support is needed to overcome stigma and discrimination. There is increasing interest in the social impact of TB, which is reflected in the increasing number of published studies. However, research in Indonesia has not

specifically found a population of informal workers. This quantitative method was initiated to produce an overview and understanding of the factors that influence TB stigma among informal workers.

MATERIALS AND METHODS

Study design

We conducted a cross-sectional survey with informal workers.

Setting and study population

The study design was cross sectional using quantitative methods and was conducted between September and November 2021. Kediri, an area of industrial center, is one of the districts and cities in East Java. This research was conducted on informal workers from two industries, including the corn seed industry and the rattan industry. The sample size was calculated using a simple population proportion formula based on the assumption of a confidence level of 95%, marginal error of 5%.

The formula used to calculate the sample size in this study was:

$$n = \frac{N}{1+N(e)^2}$$

where n = Sample size

N = Population (in this case, number of informal workers in Kediri was 275; therefore, N = 275)

e = Percentage of allowance for sampling error accuracy that can still be tolerated (in this case, e = 0.05)

When putting N = 275 and e = 0.05 in the equation above, the calculation resulted in the sample size is 163. Considering, a non-response rate of 5%, a final sample size of 175 participants was obtained.

Research participants were recruited using a systematic random sampling method and taken at every 2nd interval of the research population sampling frame. The number of informal workers participating in this study was allocated proportionally and a systematic random sampling technique was applied to select study participants who met the eligibility criteria. The study sample was drawn from all the were registered as employees at the time the research was conducted. Workers having a mental disorder or other conditions prevent them from being interviewed were excluded.

A semi-structured questionnaire was designed based on a literature review. It included information regarding socio-demographic characteristics such as gender, age, marital status, education level as well as questions regarding factors related to TB stigma. Research assistants who had experience conducting previous investigations were trained for appropriate data collection techniques, and were supervised to ensure compliance with study protocols. The research equipment was pre-tested in the lumber industry, and then refined before actual data collection. All informal workers who met the inclusion criteria were sequentially included in the research until the sample size was reached. Participants who withdrew consent or were too ill to provide consent were excluded from the study.

Data collection

An online survey questionnaire previously pre-tested with informal workers separately from the target group, was used to collect the data.

The questionnaire covered the elements that may contribute to TB stigma among informal workers, including social support. Data collection was done during January to March 2023.

Data analysis

We used frequencies and percentages to describe and show categorical and continuous data, as well as mean and standard deviation (SD). We compared variables in univariate studies using t-test. All statistical calculations were analyzed using Statistical Package for the Social Sciences (SPSS) version 22 (IBM, Armonk, NY). *p*-value of less than 0.05 was considered statistically significant.

Ethical consideration

The research protocol was approved by the Health Research Ethics Committee (KEPK) Faculty of Medicine, Sebelas Maret University, Surakarta No.EC/Protocol ID: 01/02/12/127.

RESULTS

Characteristics general population

A total of 175 informal workers were involved in this research. An overview of the characteristics of the general population of informal workers is presented in Table 1, differentiated by age, gender, level of education, income, health insurance ownership and insurance. According to age, the majority of the subjects (68 participants, 38.9%) aged between 18-25 years. Most of respondents were male (127, 72.6%), completed high school (122, 69.7%). About half (91, 52%) earned a monthly income

Table 1

Characteristic of research participants (N = 175)

Characteristic	Frequency *n* (%)
Age (years)	
18-25	68 (38.9)
26-35	55 (31.4)
36-45	34 (19.4)
46-55	16 (9.1)
56-65	2 (1.1)
Gender	
Male	127 (72.6)
Female	48 (27.4)
Level of education	
Secondary	8 (4.6)
High school	122 (69.7)
College/higher (above)	45 (25.7)
Monthly income	
USD <63	34 (19.4)
USD 63-130	91 (52)
USD 131-189	32 (18.2)
USD 190- 255	18 (10.2)
Health insurance ownership	
Had it	147 (84)
Did not have	28 (16)

Table 1 (cont)

Characteristic	Frequency *n* (%)
Insurance based on 147 people	
BPJS health insurance	(93.1)
KIS guarantee	6 (3.4)
Other	4 (2.3)

BPJS: Badan Penyelenggara Jaminan Sosial, a government agency responsible for managing social security programs; KIS: Kartu Indonesia Sehat, an agency providing access to healthcare services at participating healthcare facilities across Indonesia; USD: US Dollar

between USD 63-130. Majority of the respondents (147, 84%) had health insurance it; among them 137 (93.1%) had BPJS health insurance.

Information on sources and types of social support that influence stigma among informal workers is presented in Table 2. The act of encouraging positive thoughts while listening to concerns and empathizing with the circumstances being experienced is known as emotional support. The majority of respondents (90.3%), who gave positive ratings for the workplace's ability to give emotional support, believe that TB patients will be able to find employment there. The workplace offers support for carrying out ordinary job (89.7%), as well as support for costs/ health insurance and sick leave (93.7%). From the research results, it was also found that family support that can be given to workers with TB is by providing motivation to undergo treatment and treatment until completion and providing support to accompany them to health facilities (92.6%). Real support is given in the form of taking patients to medical facilities, assisting with everyday tasks, providing transportation, and

Table 2

Assessment of the social support variables (N = 175)

Variable and sub-variable	Frequency *n* (%)	Mean ± SD (min - max)
Emotional support		5.50 ± 0.44 (0 - 6)
People with TB have the possibility to work in the workplace.	158 (90.3)	
The workplace offers an assistance for work performing.	157 (89.7)	
The company offers financial assistance for care.	157 (89.7)	
The company offers days off for illnesses.	164 (93.7)	
The support system from the family encourages further treatment.	165 (94.3)	
Families support their need for transportation to medical facilities.	162 (92.6)	
Informational support		1.80 ± 0.83 (0 - 2)
Workers are given accurate TB education.	166 (94.9)	
Promote workers' understanding about TB to lessen their negative perceptions of it.	165 (94.3)	

Table 2 (cont)

Variable and sub-variable	Frequency *n* (%)	Mean ± SD (min - max)
Instrumental support		1.90 ± 0.87 (0 - 2)
Workers with TB symptoms are supported at work to begin treatment.	163 (93.1)	
For employees with TB symptoms, the workplace offers a chance for time off from treatment.	171 (97.7)	
Assessment support		2.82 ± 0.42 (0 - 3)
By giving accurate information about TB, the workplace aids in reducing societal stigma.	164 (93.7)	
For cured TB patients, the workplace provides the opportunity to participate in community events	165 (93.7)	

max: Maximum; min: Minimum; SD: standard deviation; TB: tuberculosis

even providing care. For employees who were experiencing symptoms, the workplace provided instrumental support in the form of support to begin treatment (93.1%) and timely opportunity support (97.7%) to recover from treatment. Informational support is assistance in the form of giving accurate information in the form of ideas and guidance regarding tuberculosis. As much as 94.9% of those who evaluated informational support for workers said it would give accurate knowledge about TB; 94.3% provided insight to reduce negative perceptions about TB. A total of 164 respondents (93.7%) indicated their commitment to providing accurate information, while 165 respondents (94.3%) expressed their willingness to support families affected by TB to access further treatment. Additionally, they acknowledged the crucial role of family support in TB treatment, particularly emphasizing the pivotal role of family members at home in providing care to individuals suffering from TB. This can help family members affected by TB reduce the risk of transmission by preparing a special room to temporarily limit direct contact, using masks, supporting the treatment process, and listening to complaints. Those with treated TB are able to participate in communal activities.

In this study, there is a significant relationship between social support and stigma behavior (p-value = 0.004). This means that changes in levels of social support are statistically associated with changes in levels of stigmatizing behavior.

DISCUSSION

The stigma associated with tuberculosis is brought on by a fear of contracting the disease, which makes the illness more stigmatized than infection can be prevented (Christodoulou, 2011; Hatzenbuehler *et al*, 2013; Juniarti and Evans, 2011). Labeling, stereotyping, purging, and

discrimination all contribute to the damaging societal process known as stigma (Abebe *et al*, 2010; Ahmedani, 2011; Duko *et al*, 2019). According to Hatzenbuehler *et al* (2013) and Stangl *et al* (2019), stigma can have an impact on health issues and lead to gaps in society. People with TB may face stigma and opposition because to their exclusion from the community, including the workplace and medical services. Workplace stigma and discrimination take many different forms, including reducing staff owing to frequent sick days, denying promotions, and being stigmatized and shunned by coworkers or management out of concern about infection (Siegel *et al*, 2015; World Economic Forum, 2008). Programs for TB prevention must be implemented by encouraging community involvement, early identification, and prevention, as well as the support and commitment of stakeholders (Li *et al*, 2017). Threats come in a variety of forms, but societal stigma happens when society adopts prejudices and treats those who are ill unfairly. According to Corrigan *et al* (2009); Kolte *et al* (2020), internal stigma (self-stigma) refers to the negative sensations of stigmatization and expectation in the form of family rejection and isolation from the community that are internalized to affect self-esteem. Lack of knowledge about TB in the community might contribute to stigmatization by making those who experience its symptoms reluctant to report about their sickness for fear of encountering prejudice and stigma from others.

Physically, intellectually, and socially related to one's health behavior, social support has a favorable impact. According to (Glanz *et al*, 2002); Putra and Toonsiri (2019), social support consists of emotional support, instrumental support, informational support, and appraisal support. Social support is a type of interaction between society and individual characteristics in the community. Social support for individuals affects health behavior and, in turn, indirectly affects how

people perceive the health issues they face. The damaging effects of stigma can be overcome by social support, which also boosts a person's self-esteem. According to Hatzenbuehler *et al* (2013), social support is employed in TB treatment to directly improve adherence to treatment, boost confidence, and boost self-efficacy.

The study of Datiko *et al* (2020) indicated that low educational attainment, poverty, and a lack of public awareness about TB are all factors in the stigma associated with the disease. Intervention is required to guarantee that TB sufferers can be welcomed and supported to seek care (Jugdoyal, 2018). Additionally, better health education on TB is needed, as well as community support for TB sufferers (Meo *et al*, 2020). Stigma is significant and a challenge in TB prevention and control (Datiko *et al*, 2020; Myburgh *et al*, 2023). The success of TB programs and the ability of the community to support TB patients can both be positively or negatively impacted by how the community views TB (Cohen *et al*, 2018). Knowledge of the illness, the ability to seek treatment, and the circumstances affecting it all influence perception. According to the results of a qualitative study conducted in Nigeria, patients are not permitted to cohabitate and disease is viewed as a misfortune and a source of shame (Mbuthia *et al*, 2020).

Tuberculosis also impacts on the person's ability to work because of their reduced capacity to undertake physical work and because of their isolation. For some, the costs associated with TB treatment and these work challenges were a heavy burden. These financial problems are reflected in reports of people having to borrow money to overcome these difficulties (Atre *et al*, 2004; Demissie *et al*, 2003; Long *et al*, 2001). Many research studies found that fear was a common theme. A portion of this anxiety was attributed to the dangers of having a major illness and the possibility of dying. From this perspective, the fear related to the view of TB being a 'death penalty' and an 'incurable disease'. However, for

some people, their dread was a result of the shame and stigma associated with having TB as well as the possibility that others would learn they had contracted the illness.

In Summary, the findings of this research provide valuable insights into the challenges faced by informal workers in Kediri Regency regarding pulmonary tuberculosis stigma. By understanding the root causes and manifestations of stigma, policymakers, healthcare professionals, and community leaders can develop targeted strategies to promote TB awareness, reduce stigma, and improve access to care for all individuals affected by this disease.

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CONFLICT OF INTEREST DISCLOSURE

The authors declare no conflict of interest.

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