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ORIGINAL RESEARCH

# Tuberculosis literacy and stigma: female activists in five areas with the lowest treatment success rate in Semarang, Indonesia

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**Abstract**

**Background**: The Case Detection Rate of Tuberculosis (TB) in Semarang city increased from 2014 to 2018, while the Treatment Success Rate declined. Low literacy can trigger stigma in society, especially among women, resulting in low awareness of suspect TB for treatment.

**Objectives**: The aims are to analyze the correlation between TB literacy and stigma expressed among female health and social activists.

**Methods**: Cross-sectional research was conducted in five public health centers with the lowest Treatment Success Rate (TSR). A valid and reliable self-administered online questionnaire collected data that involved 391 respondents predominantly in the urban areas. Rank Spearman test was used to analyze the data with a confidence interval of 95%.

**Results**: The respondents were mostly elderly (>45 years; 61.6%), health activists with high school graduation, didn't have a family with a health background and did not work. Most of them showed low TB literacy (Me:60; SD±6.62) and high stigma (Me: 76; SD±10.36). They were also difficult to access, understand, assess, and apply information about TB. Age (p.0.03; r.-0.110), being health activist (p.0.081; r.-0.088), and TB literacy (p.0.001; r.0.165) correlated significantly with stigma.

**Conclusions**: Public Health Center's officers require inserting literacy education materials related to stigma to form a comfortable support system for persons with TB.

**Keywords**: literacy, stigma, tuberculosis.

**Conflicts of interest**: None declared.

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## Introduction

Case Notification Rate (CNR) per 100,000 population in Indonesia from 2015- 2018 shows an increase from year to year. Over the past four years, 130 cases (2015) have increased to 139 (2016), 161 (2017), and 193 cases (2018) (1). This high CNR is one of the indicators of program success because of many cases of TB that can be identified and treated immediately. Unfortunately, the Treatment Success Rate (TSR) decreased during that period: From 85.8% in 2015 to 85.0% in 2016, 85.1% in 2017, and 80.12% in 2018 (1). This situation can impact the accumulation of people with TB, both who are still in the treatment process and those who have not started treatment. This means the general community's risk of exposure to mycobacterium tuberculosis increases even if they are disciplined and use masks. Central Java is one of the provinces with an increase in CNR from 118 in 2016 to 115.4 per 100,000 population in 2018 (2), whereas, at the same time, the TSR decreased from 86.0% (2016) to 83.7% (2018), far from the target of achieving a treatment success rate of 90%. Among 37 public health centers in Semarang City, the five with the lowest treatment success rate were Kedungmundu, Bangetayu, Pegandan, Ngemplak Simongan, and Purwoyoso (3). In addition to the high rates of treatment dropout due to inadequate knowledge of drug side effects, this decrease in TSR shows the inability and unwillingness of patients and suspects regarding TB due to the high stigma in the surrounding community (4). Low social support emerges from stigma associated with low literacy (5). “Women in the Urban Village” (PKK) is a voluntary organization active in the empowerment and welfare of families (PKK). As one of the leading programs of the PKK, they have an essential role in the field of health (6). In TB prevention, they should have good TB literacy to provide social support for the community in the region, especially for TB patients. Health literacy is a person's ability to access, understand, assess and apply information (7). Literacy is one factor that influences the occurrence of stigma in society. Common public domains are social distance, traditional prejudice, exclusionary sentiments, negative affect, treatment carryover, disclosure carryover, perceptions of dangerousness (8). Some of these terms need an explanation: Social distance describes that someone tries to avoid a person with TB (PWTB). It is a traditional stereotype and prejudice believing all people with TB are less valuable. Exclusionary sentiments tend to separate PWTB from everyone else or deny them their rights. Negative affects refer to emotional reactions such as disgust or hatred toward PWTB. Treatment carryover means being afraid of people knowing they were treated for TB in the past. The perceived need for secrecy may linger after a person recovers. Disclosure carryover is when people are afraid of their reactions if known to have TB. Perceptions of dangerousness are the idea that PWTB somehow represents a risk to society (8).

## Materials and Methods

A total of 391 respondents filled out valid and reliable online questionnaires (see Annex) containing questions about demographic variables, TB literacy (20 questions), and stigma (20 questions). Respondents were the total number of women active in PKK in 5 public health centers. These primary data are bivariate and analyzed by the Rank Spearman Test (95% CI). The cross-sectional design of

the study was conducted with the permission of the ethics commission No: 417/KEPK-FKM/UNIMUS/2020.

## Results

Respondents of this study are divided as 24% of Bangetayu, 6.1% of Ngemplak Simongan, 23.5% of Kedungmundu, 9.2% of Purwoyoso, and 36.8% of Pegandan. Most of the respondents were elderly (>=45 years old, 61.6%) and with high school graduation (70.6%). A majority (80.1%) were health activists and didn't have a family with a health background (71.1%). Only a small percentage of the respondents were teachers (11.0%), the majority housewives (71.1%), for details, see Table 1.

**Table 1. Demographic summary of respondents (n = 391)**

| Variable | Frequency | Percent (%) | Mean; SD |
|---|---|---|---|
| **Age** | | | 47.8; 9.06 |
| Middle age | 150 | 38.4 | |
| Elderly | 241 | 61.6 | |
| **Education Level** | | | |
| < Senior High School | 276 | 70.6 | |
| Diploma | 41 | 10.5 | |
| Bachelor | 74 | 18.9 | |
| **Type of Work** | | | |
| Health Activist (Cadre) | 313 | 80.1 | |
| Non-Health Activist | 78 | 19.9 | |
| **Field Background** | | | |
| Health | 113 | 28.9 | |
| Non-Health | 278 | 71.1 | |
| **Occupation** | | | |
| Housewife | 278 | 71.1 | |
| Private Employee | 70 | 17.9 | |
| Teacher | 43 | 11.0 | |

Good literacy is more owned by respondents with health background (43%; p=0,621) and health activists (41.5%, p=0.935). However, the health activists had low specific Tb literacy (58.5%) and high stigma (56.5%). Respondents with a health background had low Tb literacy (56.6%) and high stigma (64.6%). The group of respondents with stigma was more elderly (59.3%; p=0.028). Most of them were health activists (56.5%; p=0.214) and had high school education (51.1%; p=0.274).Housewives made up for 56.1% (p=0.763). Stigma was related to low TB literacy and dominated by not health activist respondents. Some of the scores on TB literacy variables were low, especially in providing an assessment of littering and coughing behavior, able to spread pulmonary TB. For details, see Table 2.

**Table 2. Percent item distribution of TB literacy**

| Item | % very difficult | % quite difficult | % quite easy | % very easy |
|---|---|---|---|---|
| 1. Find information about pulmonary TB | 1.2 | 8.2 | 67.8 | 22.8 |
| 2. Find out how to prevent pulmonary TB | 0.8 | 9.2 | 73.7 | 16.3 |
| 3. Finding out where to get pulmonary TB treatment | 0.3 | 2 | 74.4 | 23.3 |
| 4. Get information about the risks of smoking against pulmonary TB | 2 | 5.1 | 72.4 | 20.5 |
| 5. Find a place to have a TB screening | 0 | 1.8 | 74.2 | 24 |
| 6. Understand information about pulmonary TB from the media | 0 | 5.6 | 77.2 | 17.2 |
| 7. Understand information about the symptoms of pulmonary TB from health Workers | 0 | 3.8 | 79.8 | 16.4 |
| 8. Understand health warning information about the dangers of smoking | 0 | 4.3 | 73.7 | 22 |
| 9. Understand that pulmonary TB requires complete treatment | 1.3 | 7.2 | 71.6 | 19.9 |
| 10. Providing an assessment of the home/ living environment can help you stay healthy (e.g. keeping it damp, getting sunlight and fresh air in and clean) | 0 | 4.6 | 79.3 | 16.1 |
| 11. Provide an assessment of why immunization is necessary to prevent pulmonary TB | 0.3 | 7.9 | 76.7 | 15.1 |
| 12. Providing an assessment of littering & coughing behavior can spread pulmonary TB | 1 | 21.5 | 65.2 | 12.3 |
| 13. Provide an assessment of the signs or symptoms of pulmonary TB which requires examination at a health service | 1 | 18.7 | 70.3 | 10 |
| 14. Self-examination to confirm diagnosis of TB if needed | 2.2 | 20.5 | 67.8 | 9.5 |
| 15. Treatment for TB if needed | 0.3 | 12 | 75.2 | 12.5 |
| 16. Make the decision not to smoke | 12.3 | 32.7 | 36.6 | 18.4 |
| 17. Doing exercise regularly | 2.3 | 16.4 | 63.9 | 17.4 |
| 18. Eating nutritious foods with attention to diversity, including eating fruits and vegetables | 0.5 | 4.6 | 70.3 | 24.6 |
| 19. Maintain the living conditions (room, boarding house, cottage or house) with sufficient light, adequate ventilation and not damp | 0 | 6.6 | 67 | 26.4 |

| | | | | |
|---|---|---|---|---|
| 20. Drying the bedding to avoid humid conditions | 0.3 | 4.3 | 70.3 | 25.1 |
| (n: 391; total score's range: 43-80; Me: 60; SD: 6.618) | | | | |

**Table 3. Percent Item Distribution of Stigma**

| Item | % SA | % Ag | % Nt | % DA | % SD |
|---|---|---|---|---|---|
| 1. Some people do not want to eat/drink with TB patients. | 17.6 | 40.2 | 6.4 | 31.2 | 4.6 |
| 2. Some people stay away from TB patients. | 5.7 | 16.6 | 7.4 | 62.9 | 7.4 |
| 3. Some people feel uncomfortable around TB patients. | 5.9 | 42.2 | 6.4 | 40.9 | 4.6 |
| 4. Some people do not want to come into contact with TB patients. | 2.3 | 21.5 | 6.4 | 63.4 | 6.4 |
| 5. Some people do not want to talk to people with TB. | 2.3 | 11.8 | 6.9 | 72.1 | 6.9 |
| 6. Some people do not want TB patients to live around them. | 2.3 | 9.5 | 7.2 | 70 | 11 |
| 7. If someone has TB, some people will treat others differently for the rest of their lives. | 0.5 | 6.2 | 7.2 | 73.1 | 13 |
| 8. Some people do not want their children to play around with TB patients. | 5.4 | 46 | 4.4 | 37.3 | 6.9 |
| 9. Some people think that TB patients are disgusting. | 0.5 | 4.9 | 7.2 | 73.4 | 14 |
| 10. Some people are afraid of TB patients. | 0.8 | 29.2 | 7.7 | 55.2 | 7.1 |
| 11. Some people do not want to eat/drink with family with TB. | 2.3 | 24.3 | 7.7 | 59.5 | 6.2 |
| 12. TB patients are dirty. | 0.5 | 2.6 | 6.4 | 73.1 | 17.4 |
| 13. TB patients are a curse. | 0.3 | 0.5 | 3.6 | 58.3 | 37.3 |
| 14. TB patients are embarrassing. | 0.3 | 0.5 | 4.1 | 69.6 | 25.5 |
| 15. People with TB must have their freedom limited. | 0.3 | 9.5 | 4.1 | 72.5 | 13.6 |
| 16. TB patients are the result of wrong behavior and deserve punishment. | 0.3 | 0.8 | 2.6 | 66.2 | 30.1 |
| 17. The TB patients must be isolated/locked up. | 0.8 | 5.6 | 2.8 | 73.4 | 17.4 |
| 18. I do not want to be friends with people with TB. | 0.8 | 5.3 | 2.6 | 72.6 | 18.7 |
| 19. TB patients are not allowed to mingle with the community. | 0.3 | 2.3 | 4.4 | 75.4 | 17.6 |

| | | | | | |
|---|---|---|---|---|---|
| 20. TB patients should not be able to work. | 0.3 | 26.1 | 4.6 | 74.9 | 14.1 |

(n: 391; total score's range: 31-100; Me: 76; SD: 10.36)

SA: Strongly Agree; Ag: Agree; Nt: Neutral; DA: Don't Agree; SD: Strongly Disagree

The stigma shown is relatively high in some items. Most respondents did not want to eat/ drink with TB patients (8%), they stayed away from TB patients (22.3%), they felt uncomfortable around TB patients (48.1%), they did not want their children to play around with TB patients (51.4%).

**Table 4. Result of rank Spearman bivariate test summary between variables (n = 391)**

| Variables | P *value* | cc | CI |
|---|---|---|---|
| Age | 0.030 | -0.110 | |
| Cadre Status | 0.081 | -0.088 | |
| Education level | 0.986 | -0.001 | 95% |
| Occupation | 0.925 | 0.005 | |
| Field background | 0.059 | -0.096 | |
| TB Literacy | 0.001 | 0.165 | |

Based on the Spearman rank test there is an association between TB literacy and stigma (p.0.001; r.0,165). Age is also positively correlated with stigma. (p.0,03; r.- 0,110).

## Discussion

Stigma against tuberculosis is a social determinant of health (9). Stigma has a potential impact on the health-seeking behavior of persons with TB, reducing the level of mask use, reducing the cure rate or increasing treatment dropouts, and rising patient stress so that the recovery rate also decreases (8). The number of elderly respondents who stigmatize a person with TB can be due to elderly's characteristics. In old age, they often experience mental problems such as patterns and attitudes to life, feeling lonely, worthless, and increasing emotions in the elderly (10). They also have more leisure time because they usually no longer work at this age. So they tend to spend time with their neighbors to talk about various issues, including a person with TB around them. A cadre is a community member who voluntarily assists in implementing health programs in the community. Cadres are more active in health programs than other members of the community. According to the Indonesian health department, cadres are local citizens selected and reviewed by the community and work voluntarily (6). In fact, they have a significant role in creating a supportive atmosphere for people with TB. However, this study shows that some cadre/health activists still stigmatize persons with TB. The cadre/ health activist can discover TB suspects, be drug swallow supervisors, even act as educators improving literacy and public knowledge about tuberculosis. For example, some previous studies increased knowledge significantly in homemakers with high school education (11). Stigma against TB in some

areas still shows a reasonably high score, even up to 32 and more. Factors significantly associated with stigma are age and married status (12). Our research shows thatrespondents had difficulties finding and using information about TB. Similar to the previous study (12), where most workers in Semarang city found it more challenging to find information than to understand and to apply (13). Today's society lives in the era of technology where everyone has a device. Various information, including health information, becomes effortless to find through websites, social media, chat rooms, etc. Unfortunately, this flood of information makes it difficult for the public to judge whether specific data is fact or a hoax (14). Thus, health literacy is necessary to make judgments and decide in daily life regarding health care, disease prevention, and health promotion to maintain or improve the quality of life (15). The stigma by the environment ofpersons with TB, especially by their families, can affect the healing process. Patients need motivation, social support, and low stigma to complete treatment (4,16). Public Health Centers are advised to improve the TB literacy of female activists in socialgroups like PKK so that community stigma can be controlled. If activists have adequate literacy, they will jointly influence the general public to remove the stigma against persons with TB. Moreover, counseling can accompanypersons with TB during treatment to stabilize their psychological condition (17).Meanwhile, community leaders and religious leaders need to provide direction so that the community can have a positive atmosphere, provide a supportive social environment for persons with TB and decrease Multi-Drug Resistance.

## Conclusions

The stigma shown towards persons with-Tuberculosis (TB) needs to be reduced and even eliminated to support TB patient treatment. Women activists in a social group called “Women in the Urban Village” (PKK) with adequate literacy will influence the wider community not to stigmatize persons with TB. Also, counseling TB patients themselves is needed to overcome psychological pressure due to stigma in society. With the intervention from these two sides, the success of TB treatment will be faster and easier to achieve.

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## Annex: Tuberculosis Literacy and Stigma Questionnaire

### A. Demographic Variables

1. Public Health Center :
2. Community Health Activist : Yes/ No
3. Sub Sub District :
4. Address :
5. Name :
6. Gender : Male/ Female/ Other
7. Date Birth :
8. Age :
9. Education level :
10. Job status :
11. Social Media Type :
12. Health background of family :
13. If Yes, Who are they? : Father/ Mother/ sibling/ another, Mention please……..

### B. Source of Information about TB

1. I've heard information about TB Yes/ No
2. Where do you get this information?
    1. Poster
    2. PHC
    3. Social Media
    4. Magazine
    5. Newspaper
    6. Television
    7. Radio
    8. Health Provider
    9. Subdistrict Government
    10. Website
    11. Billboard
    12. College
    13. Others, Mention please…….....

### C. TB LITERACY

1. Find information about pulmonary TB
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
2. Find out how to prevent pulmonary TB
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
3. Find out where to get pulmonary TB treatment
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
4. Get information about the risks of smoking against pulmonary TB
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
5. Find a place to have a TB screening
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
6. Understand information about pulmonary TB from the media
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
7. Understand information about the symptoms of pulmonary TB from health workers
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
8. Understand health warning information about the dangers of smoking

1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy

9. Understand that pulmonary TB requires complete treatment
   1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
10. Providing an assessment of the home/ living environment can help you stay healthy (e.g. keeping it damp, getting sunlight and fresh air in and clean)
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
11. Provide an assessment of why immunization is necessary to prevent pulmonary TB
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
12. Providing an assessment of littering & coughing behaviour can spread pulmonary TB
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
13. Provide an assessment of the signs or symptoms of pulmonary TB which requires examination at a health service
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
14. Self-examination to confirm diagnosis of TB if needed
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
15. Make the decision not to smoke
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
16. Treatment for TB if needed
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
17. Doing exercise regularly
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
18. Eating nutritious foods with attention to diversity, including eating fruits and vegetables
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
19. Maintain the living conditions (room, boarding house, cottage or house) with sufficient light, adequate ventilation and not damp
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy
20. Drying the bedding to avoid humid conditions
    1. Very Difficult 2. Quite Difficult 3.Quite Easy 4. Very Easy

**D. STIGMA**

**(**SA : Strongly Agree ; Ag : Agree; Nt : Neutral; DA : Don't Agree; SD : Strongly Disagree)

1. Some people do not want to eat/drink with TB patients
   1. SA 2. Ag 3.Nt 4. DA 5. SD
2. Some people stay away from TB patients
   1. SA 2. Ag 3.Nt 4. DA 5. SD
3. Some people feel uncomfortable around TB patients
   1. SA 2. Ag 3.Nt 4. DA 5. SD
4. Some people do not want to come into contact with TB patients
   1. SA 2. Ag 3.Nt 4. DA 5. SD
5. Some people do not want to talk to people with TB
   1. SA 2. Ag 3.Nt 4. DA 5. SD
6. Some people do not want TB patients to live around them
   1. SA 2. Ag 3.Nt 4. DA 5. SD
7. If someone has TB, some people will treat others differently for the rest of their lives
   1. SA 2. Ag 3.Nt 4. DA 5. SD
8. Some people do not want their children to play around with TB patients
   1. SA 2. Ag 3.Nt 4. DA 5. SD

9. Some people think that TB patients are disgusting children to play around with TB patients
   1. SA 2. Ag 3.Nt 4. DA 5. SD
10. Some people are afraid of TB patients
   1. SA 2. Ag 3.Nt 4. DA 5. SD
11. Some people do not want to eat/drink with a family with TB
   1. SA 2. Ag 3.Nt 4. DA 5. SD
12. TB patients are dirty
   1. SA 2. Ag 3.Nt 4. DA 5. SD
13. TB patients are a curse
   1. SA 2. Ag 3.Nt 4. DA 5. SD
14. TB patients are embarrassing
   1. SA 2. Ag 3.Nt 4. DA 5. SD
15. People with TB must have their freedom limited
   1. SA 2. Ag 3.Nt 4. DA 5. SD
16. TB patients are the result of wrong behavior and deserve punishment
   1. SA 2. Ag 3.Nt 4. DA 5. SD
17. The TB patients must be isolated/locked up
   1. SA 2. Ag 3.Nt 4. DA 5. SD
18. I do not want to be friends with people with TB
   1. SA 2. Ag 3.Nt 4. DA 5. SD
19. TB patients are not allowed to mingle with the community
   1. SA 2. Ag 3.Nt 4. DA 5. SD
20. TB patients should not be able to work
   1. SA 2. Ag 3.Nt 4. DA 5. SD