

# Knowledge and Perceived Stigma Towards Tuberculosis among Tuberculosis Suspect by Gender in Community in Indonesia

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## Abstract

**Objective:** This study aims to description knowledge and perceived stigma towards tuberculosis among tuberculosis suspect.

**Background:** Knowledge and TB-related stigma constitutes ones of the major social factors causing delayed diagnosis and treatment.

**Methods:** This study is a further analysis of the Indonesia 2013-2014 national TB prevalence survey. Eligible population age  $\geq 15$  was interviewed to find TB symptoms and was screened with thorax x-ray for suspects to be tested MTB with microscopy, LJ culture and X-pert MTB/RIF. All positively screened participants also were interviewed about knowledge, attitude and stigma. Descriptive analysis was done using STATA.

**Results:** Total sample: 8.466. The proportion of TB suspect participants reported the way of TB transmission namely black magic, genetic and through food/drink were 18%, 47% and 59% respectively and high for males who living in rural and Sumatera. The proportion of the TB suspect participants mention hiding family member who has TB was 13% and high for males living in rural. Only 20% of participants mentioned that TB treatment was free. However, the participant reported they knew TB can be cured was 75%.

**Conclusion:** TB-related stigma was still high among TB suspects especially in rural Indonesia. Interventions concentrating on reducing TB patients' stigma should focus on improving patients' knowledge about TB.

**Keywords:** Tuberculosis, stigma, knowledge, gender, knowledge

## Introduction

Tuberculosis remains the leading cause of death from an infectious disease among adults worldwide. The World Health Organization (WHO) reported Globally,

the best estimate is that about 10 million people (range, 9.0–11.1 million) developed TB disease in 2018. Among the three countries with the highest estimated TB incidence rates were contributed from India (27%), China (9%) and Indonesia (8%)<sup>1</sup>.

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Indonesia, in 2017, the national inventory study found that about 80% of new cases were detected, 41% of these cases were not reported and the rest almost 20% were undetected or under-diagnosis<sup>2</sup>. The Directly Observed Treatment Short course (DOTS), the internationally recommended strategy for TB control, was adopted in 1995. DOTS comprises five components of which case detection by sputum smear microscopy

and some by molecular rapid test and standardized treatment with supervision and patient support are the major ones (Ministry of Health, 2011).

TB stigma and knowledge can be a barrier to early diagnosis and a deterrent to treatment adherence. Some studies found that no knowledge of TB and TB-related stigma constitutes one of the major social factors causing delayed diagnosis (Ali et al., 2017)<sup>5</sup> and factors accounted for treatment non-adherence<sup>6</sup> among TB patients. TB stigma and low knowledge of TB can lead people to feel discriminated and stigmatized for instant rejection and emotional problems because of misconceptions<sup>7</sup>. These fears lead many TB patients to hide their symptoms and it may contribute to delayed healthcare seeking, poor treatment adherence, and poor prognosis<sup>8</sup>.

Stigma defines as existing 'when a person is identified by a label that sets the person apart and links the person to undesirable stereotypes that result in unfair treatment and discrimination'<sup>6</sup>. Different propositions have been propounded concerning the etiology of stigma and fear of being infected is an obvious cause of discrimination<sup>9</sup>. While scientifically unfounded beliefs about the transmission of the disease have been found to be significant predictors of stigma<sup>10</sup>. Stigma and discrimination may affect the extent to which the patient is able to obtain, maintain and complete treatment<sup>11</sup>.

One pulmonary TB patient with smear positive is estimated to transmit an average of 10 other people per year<sup>12</sup>. From these infected individuals, 10-12% will develop TB after a few weeks or decades<sup>13</sup>. Without treatment, about 70% of patients with positive smear and 20% of patients with negative smear will experience death over a 3-year period<sup>14</sup>. Thus, stigma toward TB is a complex and multifaceted behavioral issue that needs to be understood better. However, few studies have examined TB-related stigma and its associated factors among TB patients in Indonesia. Therefore, we conducted further analysis to know magnitude of the problem on knowledge and stigma toward TB among pulmonary tuberculosis suspects in the community in Indonesia based on the Indonesia 2013-2014 national TB prevalence survey. Our goal was to provide policy-makers with recommendation for more organized TB control program to improve TB knowledge.

## **Material and Methods**

This cross-sectional survey with national coverage carried out from 2013-2014 with stratified multi-stage cluster sampling. Stratification was done by regions and urban/rural status. Indonesia was divided into three regions: Sumatera (46 clusters), Java-Bali (64), and other regions (outside Java-Bali and Sumatera) (46). The 156 clusters were distributed in 136 districts/cities throughout 33 provinces. The inclusion criteria were that residents who should have lived in the selected cluster for a minimum of one month and be aged 15 years and above.

All participants were interviewed about TB symptoms and received direct digital chest radiography (CXR). Participants were considered presumptive TB cases if they reported a cough for two weeks or more and/or hemoptysis and/or had abnormality in lungs or pleura based on the CXR. The presumptive TB cases were asked to submit spot and morning sputum specimens for direct microscopy examination with Ziehl-Neelsen staining and Lowenstein Jensen culture. X-pert MTB/RIF was carried out if the smear was positive or decisive culture results were not available. For knowledge, attitude and stigma information, all positively screened participants were interviewed for KAP and TB related stigma.

In this study, analyzed is using STATA 14.0 (College Station, TX, USA). Suspect TB participants. Participant were asked about how can TB be transmitted including variables: because of black magic, inherited genetically, through food/drink, after eating and drinking together with TB a patient, using the same eating utensil of a TB patient, through common use of public facilities and through hand shaking with a TB patient. Some questions were asked the main TB symptoms, whether TB treatment curable and free TB treatment. Attitude toward TB related stigma were also available on hide a family member who has TB.

## **Ethical Statement**

The National TB prevalence survey 2013-2014 was approved by ethical committee of National Institute of Health Research and Development. Participant was voluntary and all participants gave written informed consent before being involved in the study. All identity details of the survey participants were kept confidential.

## Result

A total of 8.466 participants completed the survey questionnaire. The number of suspected TB is the most male than female and most live in rural areas. Most of the suspects aged 15-54 years were 5.633 (66.53%)

and had a high school education up to university level of 6.666 (78.73%). The number of suspects originating from the Sumatra region is almost the same as in Java Bali ranging from 38-40%. Most of the suspects came from other provinces such as the provinces of Sulawesi, Kalimantan, Papua, Ambon and others (43%).(table 1)

**Table 1. Number and Percentage of Samples by Age, Education in Residence and Region**

No	Indicator	Male		Female		Male+ Female	
		n	%	n	%	n	%
	Age group						
1	15-54	3353	59.52	2280	40.48	5633	100
2	55 +	1670	58.95	1165	41.05	2833	100
	Level of education						
3	<= Junior High school	1176	65.48	620	34.52	1796	100
4	Senior High School+	3843	57.68	2823	42.32	6666	100
	Residence						
5	urban	1893	60.34	1244	39.66	3137	100
6	rural	3130	58.34	2199	41.26	5329	100
	Region						
7	Sumatera	1575	61,98	966	38.02	2541	100
8	Java-Bali	1654	59.93	1106	40.07	2760	100
9	Other	1794	56.68	1371	43.32	3165	100

Majority 65% of suspects of men and women already know that TB transmission through sputum splashes from coughing TB sufferers. However, there are still 18.5% of suspects who still believe that TB is caused by magic blows and 28.44% believe that TB is caused by blows / obstacles and this believe is more common in men than women. Approximately 60-65% of suspected men and women know that TB transmission can be

through eating and drinking together with sick people and using the same eating utensils with sick people and this is more common in men than women. Only 20% suspect know that TB treatment is free and the majority of men know that treatment is free compared to women. There are still around 13% of the suspect kept a secret if a family member is exposed to TB and this is also done more by men (62%) than women (38%)(Table 2).

**Table 2. Overview of Knowledge about the Mode of Transmission and Causes of TB and the Respondents' Attitudes to TB by Gender**

No	Knowledge of how transmission and causes of TB	Male				Female				Male + female			
		yes		no		yes		no		yes		no	
		n	%	n	%	n	%	n	%	n	%	n	%
1	Because of the blow / blow to the chest	1497	62.17	3526	58.2	911	37.83	2532	41.8	2408	28.44	6058	71.56
2	Black magic	1005	64.18	4018	58.23	561	35.82	2882	41.77	1566	18.5	6900	81.50
3	Inherited genetically	2442	61.37	2581	57.52	1537	58.63	1096	42.48	3979	47.00	4487	53.00
4	Through food/drink	3090	61.39	1933	56.31	1943	38.61	1500	43.69	5033	59.45	3433	40.55
5	Through sputum sparks from coughs of TB sufferers	3385	61.00	1638	56.15	2164	39.00	1279	43.85	5549	65.54	2917	34.46
6	Using the same eating / drinking utensil	3480	60.8	1975	57.52	1965	39.02	1478	42.08	5013	59.21	3453	40.79
7	Through the same food	3352	60.9	1671	56.41	2152	39.1	1291	49.59	5504	65.01	2962	34.99
8	Through communions of public facilities	1949	63.67	3074	56.87	1112	36.33	2331	43.13	3061	36.16	5405	63.84
9	Trough Hand shaking	1415	63.71	3608	57.77	806	36.29	2637	42.23	2221	26.23	6245	73.77
11	know main TB Symptom	3897	60.63	1126	55.00	2530	39.37	913	45.00	6427	75.92	2039	24.08
12	TB can be cured	3894	60.73	1129	54.97	2518	39.27	925	45.03	6412	75.74	2054	24.26
13	TB drug free	931	54.16	4092	60.65	788	45.84	2655	39.35	1719	20.03	6747	79.7
14	Would hide family member who has TB	703	62.32	4320	85.87	425	37.68	3018	41.13	1128	13.32	7338	86.68

The men in rural areas more than 50% still know the cause of TB is due to blunt magic. In addition, they also know that TB can be transmitted through food and drink and hereditary diseases. Men are more likely to know the cause of TB due to magical blah, and how TB is transmitted through food and drink and eating together with TB sufferers in Sumatra and Java Bali compared to other regions. Men who answered yes, kept it a secret that there were more TB family members compared to women in both urban and rural areas in

Sumatra and Java, while in other areas there were more women. Presentation male who answered yes, free TB treatment was almost the same as women in urban and rural areas in Sumatra and Java, while in other areas it was more on women. As many as 60% of men in rural areas say yes, knowing the main symptoms of TB and can be cured. In other areas the presentation said yes, knowing the main symptoms of TB and can be cured only at most women (43%) compared to men, while in Sumatra, Java Bali more in men at 30%. Table 3

**Table 3: Overview of TB Suspect Stigma in Urban and Rural Areas and in the Three Regions According to Gender and Region**

No	TB transmission Stigma	District								Region										
		Urban				Rural				Sumatera				Jawa Bali			Other			
		male		female		male		female		male		female		male	Female		male		female	
		n	%	n	%	n	%	n	%	n	%	n	%	%	n	%	n	%	n	%
1	Yes, blackmagic	319	31.71	179	31.91	686	68.26	382	68.9	392	39.00	212	37.79	28.26	140	24.96	329	32.74	209	37.25
2	Yes, trough food/ drink	1273	41.2	800	41.17	1817	58.8	1143	58.83	1067	34.53	619	31.86	29.71	568	29.23	1105	35.76	756	38.91
3	yes, Trought inherited genetically	1011	41.4	632	41.12	1431	58.6	905	58.88	850	34.81	467	30.38	29.65	436	28.37	868	35.54	634	41.25
4	yes, know main TB Simtom	1549	39.75	1025	40.51	2348	60.25	1505	59.49	1313	33.69	779	30.79	30.23	747	29.53	1406	36.08	1004	39.68
5	yes, woud hide family member who has TB	268	38.12	134	31.53	435	61.88	207	29.45	207	29.45	117	27.53	32.29	112	26.35	269	38.26	196	46.12
6	yes, Tb can be cured	1557	39.98	1016	40.35	2337	60.02	1502	59.65	1219	31.30	717	28.47	33.56	842	33.44	1368	35.13	959	38.09
7	yes, tb drug free	406	43.61	350	44.42	525	56.39	438	55.58	290	31.15	209	26.52	30.40	239	30.33	358	38.45	340	43.15

(see below the reference)

## Discussion

Findings from this study demonstrate the community's knowledge and attitudes towards TB etiology in Indonesia. Although most participants were aware of TB and knew its symptoms, the belief that TB is witchcraft, hereditary and trough food transmission still dominantly. Basic knowledge about the cause and mode of transmission is needed to reduce the stigma caused by traditional beliefs and negative attitudes towards TB<sup>15</sup>.

Various studies have highlighted the importance of knowledge and misconceptions about TB transmission. Misconceptions may include notions such as transmission through food/drink or sharing utensils etc. that it will be a tendency to discrimination and stigmatization<sup>16</sup>. In Pakistan, contaminated food was considered the source of infection by considered emotional trauma/stress the causative agent of TB<sup>17</sup>. While in Malaysia only of the respondents knew that genetic, sexual intercourse, sharing clothes, using the same toilet, using the same tooth-brush and shaking hands do not spread

TB infection<sup>18</sup>. Misconceptions and false beliefs or myths among TB patients have turned TB into a social stigma. This stigmatization can play an important role in reluctance of patients in seeking treatment. Such stigmatization of TB patients in the society can lead to reluctance in seeking treatment<sup>19</sup>

This current study shows that some participants admitted still belief that black magic and genetic can cause TB particularly males living in rural. The belief that TB is black magic and hereditary may be caused by witchcraft is similar to findings in other studies. In rural Uganda, many TB patients mentioned that causes of TB were through included sharing utensils, heavy labor, smoking, witchcraft or black magic and hereditary transmission. This perceived may effect TB patients were to seek care late or to avoid care<sup>20 21</sup>.

The level of knowledge and stigma is to some extent a barometer indicating the success of programs and the effective TB control to help patients and communities rethink the nature of TB and use clinical services more effectively<sup>22</sup>. Some studied identified features of TB-related stigma that respondents isolated themselves from friends was to hid their TB from other members of the community. It can cause of self-discrimination identified included fear of transmitting TB, and avoiding gossip and potential discrimination<sup>9</sup>. Stigma and consequent discrimination have an impact on TB control, concerns about being identified as a person with TB make them delaying seeking care and continuing with care<sup>23</sup>. This can lead to drugs resistant TB and increase transmission.

## Conclusion

Our findings suggest that public health interventions designed to improve knowledge on TB should include consideration of the individual patient's cultural and social context and the role that stigmatization may have in health-seeking behaviors. The study of TB stigma needs to be conducted in a socio-cultural context, and associations with knowledge, attitudes and health responses need to be further explored. A successful stigma intervention may need to be sensitive to the cultural context of TB patients and their families and communities.

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**Ethical Clearance :** Taken from Ethic committee of National Institute of Health Research and Development, Ministry of Health Indonesia

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