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Introducing *Jaga-rasa Jaga-tangga*: A Community Program that Can Reduce Tuberculosis Stigma in Sleman, Indonesia

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ABSTRACT

The low number of cases found compared to the incidence of Tuberculosis (TB) shows that the control of this disease becomes a serious problem. The stigma is suspected to be one of the obstacles to solving the TB problem in Indonesia. This study aims to analyze the ability of the *Jaga-rasa Jaga-tangga* program to decrease TB stigma in two Public Health Centers (PHCs) in Sleman Regency, Indonesia. This is a quasi-experimental study design with a control method. Both intervention and control groups get health education about TB stigma. The intervention group also gets an education about the *Jaga rasa Jaga tangga* (take care of your neighbors as well as take care of their feelings) program. The outcome measure was the TB stigma scale that measure before and after the intervention. Data were analyzed using paired t-tests and independent t-tests. 106 respondents were involved in this study divided into intervention and control groups. Age (p=0.006) and social status (p=0.015) are associated with TB stigma in the community. There were significant changes in the TB stigma scale after the intervention (paired =0.305; p=0.001). The *Jaga-rasa Jaga-tangga* program along with health education reduces TB stigma more effectively than health education only. Further studies are needed to confirm this result.

Keywords:

Community, Local wisdom, Public Health Center, Stigma, Tuberculosis

1. INTRODUCTION

Pulmonary tuberculosis (TB) is an infectious disease that is currently a public health problem because of its impact on individuals and families. The health burden of this disease causes morbidity and mortality for sufferers. The potential for this disease in people with HIV will aggravate the disease [1]. The incidence of TB patients with DM is very large in various countries with a double disease burden and the potential to cause death [2]. Both risk factors become severe if exposed to Covid-19. TB will aggravate HIV sufferers with kidney failure [3].

National data shows an increase in cases every year followed by a decrease in treatment efforts for TB sufferers in both adult and child age groups, but the development of childhood TB increased progressively due to a lack of parental awareness and limited access to health services for children TB sufferers (Health Ministry of Republic of Indonesia, 2020). Meanwhile, data on TB patients in Sleman Regency shows a low number of case findings compared

to the incidence of TB patients (Case Detection Rate 35.54%) with a mortality rate of 5.4% [5], [6]. The low number of cases that are found compared to the actual cases is an important concern in TB disease control.

Negative impacts for TB sufferers from several studies show patients experiencing drug withdrawal, irregular treatment, and exclusion from the environment. Such conditions require the government to make various efforts to suppress the development of TB in the community through various programs ranging from assistance in taking medicine, to ease access for patients in health services, and also sputum taking with personal selling (*jemput bola*) effort [7].

Case Detection Rate (CDR) is one of the indicators of TB control in case discovery. Case discovery is the first step in TB treatment and is a priority for TB control which acts as a preventive effort to stop TB transmission in the community [6]. Investigation of close contacts in the same house and interaction with the environment is a priority in determining the risk of contracting TB disease [8]. Case finding is influenced by family support, socio-economic, support from doctors and nurses, availability of access to health services, social stigma, psychological stress, and knowledge are significant factors in the success of tuberculosis treatment [9].

The stigma experienced by people with or affected by tuberculosis (TB) hereinafter referred to as TB stigma remains one of the main challenges in the control of TB [10], [11]. TB stigma can hinder the discovery of new cases due to social exclusion, irregular treatment, ridicule by others, and lack of change in treatment. Stigma is a factor in strengthening the difficulty of finding TB cases and drug resistance due to treatment withdrawal [12], [13]. Therefore, an approach is needed to overcome these hurdles by identifying challenges to TB service quality, data on barriers to access to services, strengthening health service responses and creating a friendly environment for patients, educating the public about TB to remove stereotypes, strengthening TB communities and task forces to create an environment without TB stigma and discrimination [12], [14]. There is a relationship between stigma and the discovery of cases of TB patients in the community [15]. Specific interventions are needed to overcome the discovery of TB cases. One of these interventions is developing networks to stop stigma to improve case investigations with a local wisdom approach.

We introduce a program to overcome TB stigma with a local wisdom approach. The program is called *Jaga rasa Jaga-tangga* or take care of your neighbors as well as take care of their feelings. This is a community-based program equipped with a direct connection to a wide range of Public Health Center (PHC) tracking program applications as well as its reporting and monitoring program. The *Jaga rasa Jaga-tangga* program aims to reduce the stigma of TB sufferers, improve treatment adherence, and increase the finding of new cases in the community. This program is expected to accelerate case tracking and mapping the demographic distribution of TB patients in the community. This research aims to analyze the ability of *the Jaga rasa Jaga-tangga* program to decrease TB stigma in two Public Health Centers (PHCs) in Sleman, Indonesia.

2. METHOD

The study used a quasi-experimental approach with pre-post design with control. The location of this study was in two PHC areas in Sleman Regency. The sample size is determined based on the WHO application formula, with the alpha (α) significance level usually set at 0.05 and the beta (β) strength level usually set at 0.80. The calculation results are 106 samples. The sample criteria for this study are communities where there are TB sufferers. The community respondents consisted of community leaders, religious leaders, health cadres, and members of a youth organization.

Respondents were divided into two groups of 53 people each. Respondents' demographic data including age, gender, education level, social status, marital status, and distance from home to PHC were recorded. The health education was carried out in six stages consisting of 1) an explanation of TB; 2) psychosocial and economic impacts on sufferers; 3) TB stigma and its impact on TB sufferers; 4) sharing experiences from TB survivors; 5) social participation with local wisdom *Jaga rasa Jaga-tangga* (for the intervention group), and 6) anti-stigma-TB campaign. In the control group, respondents were given health education only without step number five (the social participation of the *Jaga rasa Jaga-tangga* program).

The *Jaga rasa Jaga-tangga* program or take care of your neighbors as well as take care of their feelings is a community program designed to reduce the stigma of TB sufferers, improve treatment adherence, and increase the finding of new cases in the community. The *Jaga rasa Jaga-tangga* program is a community-based program equipped with a direct connection to a wide range of Public Health Center (PHCs) tracking program applications. This program also connects to PHC's reporting and monitoring program.

TB Stigma of all respondents was measured before and after the intervention using the TB Stigma Scale by Van Rie, which has been tested for validity and reliability with the Indonesian version [16], [17]. This scale is a questionnaire-based measurement that is filled out based on the level of respondents' agreement with a statement related to their attitude toward TB sufferers around them. The higher the score, the higher the TB stigma of respondents. The data obtained were then analyzed using univariate and bivariate analysis using paired t-tests and independent t-tests to see the significance of TB stigma scale changes before and after the intervention and the significance of differences between the intervention and control groups.

Before data collection, this study had obtained permission from the Institutional Health Research Ethics Commission No.DP.04.03/e-KEPK.2/840/2023. All respondents in this study were informed about the research and signed informed consent.

3. RESULTS AND DISCUSSION

3.1. Result

A total of 106 participants were involved. Both groups had an average age of 55.67 ± 9.02 years, with an average home-to-PHC distance of 2.26 ± 0.69 km. In the intervention group, most respondents were women (41/51.2%), had a high school education level (28/63.6%), were the general public (41/51.2%), and had a TB Stigma score of 31.72+8.01. While in the control group most respondents were women (39/48.8%), had a primary school education level (22/88.0%), were the general public (39/48.8), and had a TB stigma value of 33.92 ± 4.44. The data shows that there is no difference in TB stigma in the intervention and control groups. The complete demographic data analysis is presented in Table 1.

Table 1. Correlation of Demographic Data with Predictors with TB-Stigma

Variable	Group		Mean ± SD	Pearson Correlation	Sig α
	Intervention n (%)	Control n (%)			
Age (year)			55.67 ± 9.02	-0.263	0.006*
Gender				-0.138	0.158
Male	12 (46.2)	14 (53.8)			
Female	41 (51.2)	39 (48,8)			
Education level				-0.114	0.245
Elementary School	3 (12.0)	22 (88.0)			
Junior High School	7 (46.7)	8 (53.3)			
Senior High School	28 (63.6)	16 (36.4)			
University/College	15 (68.2)	7 (31.8)			
Social Status				-0.236	0.015*
Religious figures	1 (25.0)	3 (75.0)			
Community figures	2 (40.0)	3 (60.0)			
Youth figures	4 (100)	0 (0.0)			
Health cadres	5 (38.5)	8 (61.5)			
Community	41 (51.2)	39 (48.8)			
Marital Status				-0.125	0.203
Married	45 (47.9)	49 (52.1)			
Widower/widow	4 (100)	0 (0.0)			
Not Married	4 (30.0)	4 (50.0)			
House-PHC distance (km)			2.26 ± 0.69	-0.035	0.725
Initial TB-Stigma scale					
Intervention			31.72 ± 8.01	0.170	0.082
Control			33.92 ± 4.44		

*) *Sig α <0.05; significant*

Table 1 shows the relationship between respondents' demographics and people's behavior toward TB stigma. The variables that show the relationship are social status and age. While the variables of gender, education, and distance from home to PHC are not related to stigmatizing behavior in the community. Social status in the community helps prevent stigmatizing behavior in society. Stigma can also be controlled based on the age of the participant.

Before being analyzed using parametric tests, data normality tests were carried out using Kolmogorov-Smirnov and it was found that stigma TB scores were normally distributed. Likewise, the results of the homogeneity test found that the data obtained were homogeneous. Parametric tests were carried out using paired t-tests and independent t-tests. The results are presented in Table 2 and Table 3.

Table 2. TB-Stigma Analysis in the Intervention Group using paired T-tests

Variable	Mean ± SD	Std Error Mean	95% CI		Paired Correlation	df	Sig α
			Lower	Upper			
Stigma TB *pre-post*	5.698 ± 8.923	0.867	3.980	7.417	0.305	106	0.001*

*Sig α<0.05 significant

The paired t-test results to distinguish TB-stigma values before the intervention compared to after the intervention. The analysis showed statistically significant changes (Table 2). This means that the anti-stigma TB intervention program, *jaga rasa jaga-tangga.* had a significant influence on the intervention group in lowering TB stigma.

Furthermore, the researcher wanted to know if the intervention group compared to the control group had significant changes. The researcher continued the independent t-test (Table 3).

Table 3. Post-test Analysis Using Independent T-tests in Intervention Group Compared to Control Groups

Variable	Group		*t-test*	*Sig α*	*95% CI*	
	Intervention *Mean ± SD*	**Control** *Mean ± SD*			*Lower*	*Upper*
TB-Stigma	0.38 ± 14.06	4.66 ± 6.13	-2.033	0.045	-8.461	-0.105

**Sig α<0.05; significant*

Table 3 shows that there were significant differences between the intervention and control groups in reducing TB stigma. The intervention group was more effective in reducing TB stigma than the control group.

3.2. Discussion

The results showed a relationship between age and social status with TB stigma in the community. Age will show maturity in digesting information and sorting out information that hurts others [18]. Meanwhile social status helps influence negative information so that it can be neutralized and become the basis for the discovery of new concepts that can be applied in the community [19].

TB stigma arises and develops due to inaccurate information about tuberculosis. The lack of information about treatment programs, especially the duration of treatment and side effects, makes people perceive that the disease is dangerous and must be avoided [20]. In addition, TB disease also accompanies other chronic diseases such as HIV / AIDS [17]. Although this disease appears preceded by HIV / AIDS, sufferers who experience this disease, will worsen their condition even to death [21].

The stigma of TB sufferers leads to feelings of discrimination, isolation, danger, lack of support, shame, and stress [22], [23]. One of these conditions is caused by the behavior of health workers who handle TB due to different interpretations of infection control, lack of ability to provide psychosocial assistance for patients, perceptions of stigmatizing attitudes and behaviors of colleagues in charge of TB disease health services as well as self-awareness of the main role of stigma modifiers [18], [23], [24]. Thus, the role of health workers is very important in participating in reducing the stigma of TB sufferers other than community members where TB sufferers are located.

Health workers also have difficulty tracing members in close contact with TB sufferers for screening. The lack of information about TB disease and the barrier between health workers and the community due to lack of communication and understanding cause difficulties in close contact tracing [10], [25], [26]. In addition, this barrier is caused by the lack of regular visits by health workers to sufferers, the lack of community understanding in responding to TB sufferers, and the fear that the patient's family will be ostracized by residents [27].

The stigma that arises due to the bad perception of TB sufferers is mainly fear of transmission and lack of understanding about treatment programs [28]. Another factor is discrimination against sufferers in social activities such as neighborhood meetings or other social activities [29]. Victims generally feel stigmatized and frightened due to the social impact of stigmatizing [30]. Conditions like this worsen the mental health condition of sufferers [24]. Psychosocial illness is experienced by sufferers in the form of depression, anxiety, and excessive fear related to a lack of knowledge about the disease and its impact on themselves and others. Other studies show fear of the length of treatment and cure rates from treatment programs [28], [31].

People with active and latent TB are both potentially depressed [21]. The difference between them, especially in people with latent TB, is that there are feelings of fear and distrust of suffering from latent TB and worry about the reactivation of TB, thus causing unwanted stress in their lives [30]. People with chronic diseases such as HIV also experience stigma in the community environment which causes internalized stigma as a result of opportunistic diseases such as TB disease [32]. TB stigma that has been internalized in TB sufferers as a complication of other diseases can

be prevented by anti-stigma programs along with TB treatment treatment [33]. Thus, stigma will converge on TB sufferers if the main cause of the disease cannot be eliminated.

Stigma TB sufferers need to get social support from the surrounding community. The construction of social support by maintaining paradigms and beliefs about TB treatment is part of the TB disease treatment and cure system [34]. This construction is used by utilizing the local wisdom of *Jaga rasa Jaga-tangga* which maintains social support by maintaining the feelings of those undergoing TB treatment and supports all efforts to screen without fear. Nurturing beliefs and social values in the face of TB stigma can encourage togetherness in facing health problems by fostering feelings of empathy and moral support [35].

TB stigma that has been internalized in TB sufferers as a complication of other diseases can be prevented by anti-stigma programs along with TB treatment treatment [33]. Anti-stigma programs with a local wisdom approach *Jaga rasa Jaga-tangga* can reduce perceptions about the stigma of TB sufferers because of the close approach to culture in the community. Health interventions with a local wisdom approach can absorb aspirations and focus more on the fundamental problems experienced by the community. The implementation of anti-stigma interventions involving various elements in the community will help effectively increase community knowledge and perceptions in encouraging stigma reduction [36]. TB sufferers will experience a decrease in stigma, in addition to through anti-stigma programs in the community, the inclusion of stigma handlers when treated by health workers will greatly help reduce stigma internalization [2].

TB stigma in communities can be reduced when they have a shared commitment to prevent and end TB disease with environmental support including the environment at home, community, and health service level [37]. The support of the patient's family will build perceptions of local wisdom support in helping strengthen the commitment to end TB disease simultaneously [38]. Social strengthening can be encouraged by mutual respect, good communication, and mutual assistance in the division of roles [39]. The use of local wisdom helps strengthen community joints in building a strong social order [40].

3.3 Limitation

The study had limitations on a sample that was not randomized and did not distinguish by villages and cities. Differences in location indicate representativeness and characteristics of the population.

4. CONCLUSION

The *Jaga-rasa Jaga-tangga* program can effectively reduce the community's TB stigma scale in the TB sufferer's living environment than health education only. In the future, this is also expected to be used for other health problems that are connected with TB (like Diabetes Mellitus and HIV) and other community health problems. Further studies are needed to confirm this result.

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