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Penulis : Eppy Setiyowati, Erika Martining Wardani, Nur Ainiyah, Siti Damawiyah, Ni Njoman Juliasih

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Achmad Syafiuddin, Ph.D.

NPP. 20071300

**LPPM Universitas Nahdlatul Ulama Surabaya**

Website : [lppm.unusa.ac.id](http://lppm.unusa.ac.id)

Email : [lppm@unusa.ac.id](mailto:lppm@unusa.ac.id)

Hotline : 0838.5706.3867

# Relationship between stigma and quality of life in people with pulmonary tuberculosis in East Java, Indonesia

*by Eppy Setiyowati*

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# Relationship between stigma and quality of life in people with pulmonary tuberculosis in East Java, Indonesia

## Relación entre el estigma y la calidad de vida en personas con tuberculosis pulmonar en Java Oriental, Indonesia

Eppy Setiyowati<sup>1a\*</sup>, Erika Martining Wardani<sup>2a</sup>, Nur Ainiyah<sup>3a</sup>, Siti Damawiyah<sup>4a</sup>,  
Ni Njoman Juliasih<sup>5b</sup>

### SUMMARY

**Introduction:** The social experience makes rejection from society of people with pulmonary tuberculosis depressed and worsens their quality of life. Thus, it should be reducing the social stigma that exists in society, namely improving the pattern of quality of life and good self-perception in patients. The aim of this study was an overview of social stigma and quality of life in people with pulmonary tuberculosis in East Java, Indonesia.

**Methods:** This study used analytics with a cross-sectional approach design. The study population consisted of 2 groups of 65 tuberculosis patients, and 65 were families. A large sample of 2 groups consisted of tuberculosis patients, 55 respondents, and 55 families. The sampling technique used total sampling; data was

collected using a questionnaire sheet. The data were analyzed using the Chi-Square test with an  $\alpha = 0.05$ .

**Results:** The results showed that most (60 %) families have bad social stigma and most (58.2 %) tuberculosis patients have a poor quality of life. Chi-Square test results  $p$ -value = 0.007 and  $\alpha = 0.05$ , which means there is a relationship between stigma and social quality of life for tuberculosis patients in Indonesia.

**Conclusion:** The worse the social stigma in the family, the worse the quality of life for tuberculosis patients. It is expected that the family will provide full support to tuberculosis patients in terms of their quality of life so that the patient's physical health is improved.

**Keywords:** Pulmonary, quality of life, review, social stigma, tuberculosis.

### RESUMEN

**Introducción:** La experiencia social hace que el rechazo de la sociedad a las personas con tuberculosis pulmonar, lo que genera depresión y empeora la calidad de vida de los pacientes. Por ello, es necesario reducir el estigma social que existe en la sociedad, es decir, mejorar el patrón de calidad de vida y la buena autopercepción de los pacientes. El objetivo del estudio fue la descripción general del estigma social y la calidad de vida de las personas con tuberculosis pulmonar en Java Oriental, Indonesia.

**Métodos:** Este estudio utilizó análisis con un diseño de enfoque transversal. La población de estudio consistió en 2 grupos de 65 pacientes con tuberculosis, y 65 eran familias. La gran muestra de 2 grupos consistía en pacientes con tuberculosis, 55 encuestados y 55 familias. Se empleó la técnica de muestreo total, instrumento de recolección de datos mediante una hoja

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ORCID ID: 0000-0001-9930-6218<sup>1</sup>

ORCID ID: 0000-0002-0178-0024<sup>2</sup>

ORCID ID: 0000-0003-0390-186X<sup>3</sup>

ORCID ID: 0000-0003-2353-2096<sup>4</sup>

ORCID ID: 0000-0003-2142-7882<sup>5</sup>

<sup>a</sup>Faculty of Nursing and Midwifery, Universitas Nahdlatul Ulama Surabaya, Indonesia

<sup>b</sup>Departement of Public Health, School of Medicine, Universitas Ciputra Surabaya, Indonesia

\*Correspondent Author: Eppy Setiyowati  
E-mail: [eppy@unusa.ac.id](mailto:eppy@unusa.ac.id)

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de cuestionario. Los datos se analizaron mediante la prueba Chi-Cuadrado con un  $\alpha = 0,05$ .

**Resultados:** Los resultados mostraron que la mayoría (60%) de las familias tienen estigma social y la mayoría (58,2 %) de los pacientes tuberculosos tienen una mala calidad de vida. Los resultados de la prueba de Chi-cuadrado valor  $p = 0,007$  y  $\alpha = 0,05$ , lo que significa que existe una relación entre el estigma y la calidad de vida social de los pacientes con tuberculosis en Indonesia.

**Conclusión:** Cuanto mayor es el estigma social en la familia, peor es la calidad de vida de los pacientes tuberculosos. Se espera que la familia brinde todo el apoyo a los pacientes tuberculosos en cuanto a su calidad de vida para que la salud física del paciente mejore.

**Palabras clave:** Pulmonar, calidad de vida, revisión, estigma social, tuberculosis.

## INTRODUCTION

Tuberculosis is a global public health problem with the highest mortality rate among other people (1-6). One in 10 causes of death worldwide is tuberculosis, and 1.5 million people die (7,8). Indonesia ranks second in the world as the most significant contributor to tuberculosis patients after India (9,10). In 2015, the Case Detection Rate (CDR) of pulmonary tuberculosis in Indonesia was recorded at 125 cases per 100 000 population. In the last statistical data in 2018, there were 324 539 cases in Indonesia (6,11,12). In some countries, tuberculosis patients are spreading infectious diseases, which leads to a rejection of the presence of tuberculosis patients in the community over a very long time (13,14).

The social stigma that occurs in tuberculosis patients causes them to feel isolated from their family, friends, and people around them (15,16). This causes tuberculosis patients to experience prolonged fear and anxiety (17-19). Anxiety in tuberculosis patients due to social stigma causes psychological disorders associated with lower enjoyment of life and demotivation, which implies lower functional capacity and quality of life (20,21). Therefore, the **quality of life in tuberculosis patients** is essential because it will affect several aspects of life (22-25).

Social stigma for tuberculosis patients occurs in society caused by tuberculosis is a shameful

and frightening disease. It can be reduced by improving people's knowledge and perception of tuberculosis (17,22). The results of the study state that knowledge, attitudes, and behaviors indicate that 76 % of families have heard of tuberculosis, 26 % can mention two major signs and symptoms, and 51 % understand how it is a contagion. Only 19 % know tuberculosis control programs provide free medication (26).

The risk of developing tuberculosis appears to increase in some areas, indicating that the prevalence of tuberculosis in the community is also high (27,28). The increase in prevalence is often due to people's knowledge, attitudes, and behavior toward people with tuberculosis providing social stigma (29-31). Because of the social stigma that occurs in tuberculosis patients will cause their motivation for life to be low (22,30). The negative stigma against tuberculosis causes prolonged physical and psychological pain (13,32). Tuberculosis is a disease with social implications due to the stigma attached to psychology in society (7,13). Negative stigma against tuberculosis will further strengthen the condition of patients who feel isolated from people's lives, and this will cause the life quality of tuberculosis patients to get worse (29,33).

Physical and psychological conditions affected by tuberculosis patients significantly affect the quality of life because they are both domains of quality of life, so it is not uncommon for patients with tuberculosis to have a low quality of life due to depression experienced (10,34). Depression and social stigma will affect how tuberculosis patients undergo disease processes and decrease their quality of life (12,35). Decreased quality of life in tuberculosis patients can cause delays in treatment and negatively impact treatment continuity. This leads to severe or incomplete treatment (22,36).

The decreased quality of life in tuberculosis patients is due to several factors affecting socio-demographics, including gender, age, education level, occupation, income, marital status, and drug adherence (37,38). Because tuberculosis patients obediently take the drug will improve their quality of life, decreasing morbidity and death of tuberculosis patients (17,39). Efforts to overcome social stigma in tuberculosis patients are to change the social stigma that exists in

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society by improving knowledge and good self-perception in tuberculosis patients, which are predicted to trigger an improvement in the quality of life of patients (40,41). Improving the quality of life means increasing the expectation of tuberculosis patients to get a total recovery both physically and psychologically (15,42). Based on this, the researchers felt the study was important, so the researchers were interested in further examining how social stigma relates to the quality of life of tuberculosis patients (43,44). Looking at some of the problems experienced by pulmonary tuberculosis patients concerning physical and psychological conditions. This study aims to examine the relationship of social stigma with the quality of life of tuberculosis patients in East Java.

### METHODS

This study used descriptive with a cross-sectional approach design. The research sample was tuberculosis patients treated at the Perak Timur Health Center in Surabaya. Data collection through questionnaires sent via google form to respondents in the WhatsApp group. The stigma questionnaire includes community acceptance, family acceptance and social environment conditions, and quality of life, consisting of 26 questions covering physical health, psychological health, social relationship, and environmental health. The researcher created the stigma and quality of the live questionnaire and tested its validity and reliability with an alpha Cronbach of 0.518 and a validity level of 0.0001. The variables in this study are social stigma and quality of life. This study measured social stigma based on the community's view of tuberculosis patients in this study. Some indicators, namely social stigma, can sympathize with the community, categorized as a good stigma. On the other hand, social stigma also can give rise to discriminatory behaviors from the society that is classified as bad.

The population in this study is all tuberculosis patients and families who are still active in community health centers at Surabaya in 2 groups, namely 65 families and 65 people who are tuberculosis patients. Sample research with inclusion criteria is tuberculosis patients

who are routinely in the health center and have been suffering from the disease for more than two years. Exclusion criteria are pulmonary tuberculosis patients who have the comorbid disease. Therefore, this study was 55 respondents' families with tuberculosis patients and 55 respondents with tuberculosis patients, with a total sampling technique.

Data collection in this study uses primary data which researchers provide social stigma questionnaires and quality of life. Respondents are given a seat to allow them, respondent to answer calmly and comfortably. Respondents were given questionnaires and briefed before filling out questionnaires. Then the respondent fills in the respondent's identity. While filling out the questionnaire, the respondent was under the supervision and guidance of the researcher.

The data was analyzed to determine the relationship between stigma variables and quality of life variables using tabulation. To find the relationship between social stigma and quality of life, the collected data were processed and analyzed using the Chi-Square test using SPSS with a level of meaning  $\alpha = 0.05$ . All participants in this study have been given an explanation by the researcher and their consent to be involved in this research.

### RESULTS

Based on Table 1 concerning respondents distribution characteristics in the tuberculosis patient, 55 respondents consisted of 34 male respondents with a percentage number 61.8 % and 21 female respondents with a percentage number 38.2 % and in families of tuberculosis patients consisted of 23 male respondents with a total percentage 41.8 % and 32 female respondents with total percentage 58.2 %. The 14 respondents were equal percentages of 25.5 % between the aged 17-25 years (late teens) and 36-45 years (late adults). But the highest-equal in family's number are aged 36 – 45 and 45 – 55 with total percentage 27.3 %. While in tuberculosis patients out of 55 respondents, most of the respondents are 70.9 % worked privately and family respondents, and with tuberculosis out of 55 respondents 54.5 % worked privately.

Table 1

Frequency Distribution characteristics of respondents

Characteristics of Respondents	Tuberculosis patients		Families with tuberculosis	
	n	%	n	%
Gender				
Male	34	61.8	23	41.8
Female	21	38.2	32	58.2
Age (years)				
17 - 25	14	25.5	13	23.6
26 - 35	7	12.7	12	21.8
36 - 45	14	25.5	15	27.3
46 - 55	8	14.5	15	27.3
56 - 65	9	16.4	0	0
>65	3	5.5	0	0
Occupations				
Private sector	39	70.9	30	54.5
Civil servants	2	3.6	3	5.5
Housewives	9	16.4	22	40.0
Fishing	0	0	0	0
Not Working	5	9.1	0	0
Education				
No School	4	7.3	0	0
Elementary School	17	30.9	15	27.3
Secondary School	32	58.2	38	69.1
College	2	3.6	2	3.6
Total	55	100	55	100

Source: Primary data, February 2020

Table 2 concerning social stigma and quality of life showed that 60 % of families with tuberculosis had a bad stigma against TB disease. 55 respondents, with 22 respondents' patients having good social stigma (40 %), 33 respondents' patients have a bad social stigma (60 %), the families having good social stigma with a total number of 15 respondents (20 %), and families having bad social stigma with a total number of 40 respondents (80 %). total percentage of 58.2 % of tuberculosis patients with poor quality of life. 33 respondents, with 72.7 % of families had a bad social stigma and poor quality of life, while about 22 respondents, most of the 63.6 % had a good social stigma and good quality of life. Chi-Square statistical test result with meaning value  $\alpha = 0.05$ , obtained value  $X^2 = 0.007$ , which means there is a relationship between social stigma and the quality of life of tuberculosis patients.

Table 2

Frequency Distribution of Respondents Based on Social Stigma and Quality of life

	Patients		Family	
	N	%	n	%
Social Stigma				
Good	22	40	15	20
Bad	33	60	40	80
Quality of life				
Good	23	41.8	20	38
Bad	32	58.2	35	62
Chi-Square test	$X^2 = 0.007$			

**DISCUSSION**

The social stigma in families with tuberculosis tends to be bad for family members affected by tuberculosis and is considered a source of family support (36,45). Social Stigma is a negative trait that attaches to a person's personality due to its environmental influence. This stigma may encourage a person to have prejudiced thoughts, behaviors, or actions by the government, society, employers, health care providers, co-workers, friends, and family (23,46). In addition, stigma restricted education, employment, housing, and health care (47,48).

Stigma can be experienced as shame or guilt or can be widely expressed as discrimination. This can lead to decreased confidence, loss of motivation, withdrawal from social life, avoidance of work, interaction in health, and loss of time planning (28,40). Stigma also means a phenomenon that occurs when a person is labeled, stereotyped, separated, and experiences family discrimination with tuberculosis. More assumes that the person affected by tuberculosis will transmit his disease to all members of his family, which makes the family more distanced from the patients (35,42).

The highest domain in measuring tuberculosis stigma for patients from tuberculosis is the fear of transmission of the disease, so a correct understanding of tuberculosis should be a concern (43). Therefore, for people with tuberculosis, the most important thing is to survive the stigma to give others a true understanding

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of tuberculosis. This study found about 34 respondents were mostly 61.8 % male. Based on lifestyle patterns, men are more at risk of tuberculosis with smoking habits, nighttime, and susceptibility to tuberculosis if exposed to tuberculosis (28,48). This age is an age of responsibility and burden on the family for a father who has a responsibility to his family and works as the backbone (46,49). Factors affecting the quality of life are gender, age, education level, occupation, income, and marital status (33,50).

The quality of life is a person's perception in the context of culture and norms that correspond to the person's place of life and are related to the purpose and expectation of the standard of care during their life (40,51). The quality of life of individuals with each other is different, and it depends on the definition or interpretation of each individual about good quality of life (37,52). Based on the understanding of the quality of life above can be concluded that the quality of life is the perception of the individual towards their position in life. This is related to physical health problems, psychological status, level of freedom, and social and environmental relationships (22,26). Individuals can be said to have a good quality of life if known aspects of life that the individual is not easily sick accelerate the healing process and become an important consideration in the effort to prevent the appearance of the disease (20,37). Several factors affect it, such as gender, age, education level, employment, income, marital status, drug compliance, and the social stigma in families and residential environments (42,53).

This study found a correlation between social stigma and the quality of life of tuberculosis patients. This can prove a relation between social stigma and the quality of life for tuberculosis patients. This can be seen from cross-tabulation analysis that 33 respondents, mostly 72.7 % of families have bad social stigma and poor quality of life, while of the 22 respondents, with an overall percentage of 63.6 % have good social stigma and good quality of life.

Based on the data, the higher is stigma, the lower is quality of life. Tuberculosis patients' low quality of life of tuberculosis patients occurs due to decreased physical health and high stigma (18,42). This means that when

tuberculosis patients have a good stigma, the quality of life will be high and speed up the healing process of tuberculosis patients because aspects of their quality of life are fulfilled (28,54). Regarding the relation between social stigma with quality of life, respondents have low social stigma toward the disease, 51 respondents or in percentage is (53.1 %). And about 31 respondents had a good quality of life, while in patients with high stigma, 45 (46.9 %) at most 17 hospitals have a moderate quality of life. Amount of 31 respondents had a good quality of life, while in patients with high stigma, 45 respondents (46.9 %) at most 17 hospitals have a moderate quality of life.

## CONCLUSION

There is a relationship between social stigma with quality of life. For example, a family does not have a bad perception of tuberculosis patients and supports routine treatment so that the tuberculosis patients will increase and accelerate recovery. Health workers should develop strategies that can eliminate community stigma in people with pulmonary tuberculosis through an individual approach or community leaders.

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