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CASE-CONTROL STUDY: STIGMA'S OF TUBERCULOSIS PATIENT IN BENGKULU CITY, INDONESIA

JIHAN SAMIRA THABIT, KARLINA MAHARDIENI, NOVIANI PRASETYANINGSIH, SURIYANI TAN, JEFRI SUYANTO

MICROBIOLOGY DEPARTMENT, FACULTY OF MEDICINE, UNIVERSITAS TRISAKTI, JAKARTA, INDONESIA
ANESTHESIOLOGY DEPARTMENT, FACULTY OF MEDICINE, UNIVERSITAS TRISAKTI, JAKARTA, INDONESIA
OPHTHALMOLOGY DEPARTMENT, FACULTY OF MEDICINE, UNIVERSITAS TRISAKTI, JAKARTA, INDONESIA
PARASITOLOGY DEPARTMENT, FACULTY OF MEDICINE, UNIVERSITAS TRISAKTI, JAKARTA, INDONESIA
PUBLIC HEALTH DEPARTEMENT, FACULTY OF HEALTH SCIENCE, UNIVERSITAS DEHASEN, BENGKULU, INDONESIA
Email: jefrisuyanto@gmail.com

ABSTRACT

Background: Negative stigma has the possibility of provoking adverse behaviour. This indicates that people with pulmonary tuberculosis have a diminished likelihood of recovery. Objective: To assess the probability of stigmatisation associated with pulmonary tuberculosis in Bengkulu City. Methods: This research utilises a case-control study design, with simple random sampling as the sampling approach. The ratio of respondents to groups is 1:1. This research was conducted in Bengkulu City, employing a questionnaire as the research instrument. This study utilised two tests: a univariate test and a bivariate test, employing the Stata tool for data analysis. Results: The test outcomes indicated that the majority of respondents in the case group exhibited negative societal stigma towards tuberculosis, inadequate family support, deficient health literacy, low quality of life, and insufficient information. Conversely, most respondents in the control group demonstrated a favourable social stigma towards tuberculosis, possessed robust family support, exhibited great health literacy, maintained a superior quality of life, and displayed substantial knowledge. Conclusion: Mitigating stigma is essential for enhancing early detection and treatment of pulmonary tuberculosis, hence facilitating more successful disease management.

Keywords: Tb Patient Stigma, Social Stigma, Family Support, Health Literacy, Quality of Life

INTRODUCTION

The Mycobacterium TB bacteria infect over one-fourth of the global population, with adults accounting for 89% of tuberculosis cases and children for 11%. As of now, TB remains the major cause of mortality following HIV/AIDS. Indonesia ranks third globally in the prevalence of tuberculosis patients, following India and China. Approximately 9.9 million individuals worldwide are afflicted with pulmonary tuberculosis (WHO, 2022). The incidence of pulmonary tuberculosis in Indonesia has risen over the past three years, from 393,323 cases in 2020 to 443,235 cases in 2021, reflecting a 17% increase, and further escalating by 65% to 694,808 cases in 2022 (Kemenkes RI, 2023). From a gender viewpoint, men constituted the majority of cases countrywide, representing 57.5% of male cases and 42.5% of female cases. In 2021, the 45-54 age demographic accounted for 17.5% of pulmonary tuberculosis cases, followed by the 25-34 age demographic at 17.1% and the 15-24 age demographic at 16.9% (Kemenkes RI, 2022).

According to data from the Bengkulu Provincial Health Office, the number of pulmonary tuberculosis patients was 11,035 in 2020, decreased to 7,188 in 2021, and then rose to 12,339 in 2022. Bengkulu City has the highest number of cases in Bengkulu Province, totalling 685 individuals, while South Bengkulu Regency has the lowest, with 33 individuals (Bengkulu Provincial Health Office, 2022). The Bengkulu City Health Office reported 352 cases of pulmonary tuberculosis in 2021, 606 in 2022, and 686 in 2023.

Pulmonary tuberculosis (TB) is among the most transmissible and lethal infectious illnesses globally, resulting from the bacterium Mycobacterium tuberculosis (Van Brakel et al., 2019). Notwithstanding the existence of efficacious therapies, pulmonary tuberculosis continues to pose a considerable public health challenge, particularly in developing nations like Indonesia (Fuady et al., 2024). The stigma patients associate with the disease significantly influences effective therapy and disease management. Comprehending patient perceptions of pulmonary tuberculosis can facilitate the development of more effective therapies. Understanding of the disease frequently affects patients' impressions of pulmonary tuberculosis. A significant number of patients possess insufficient comprehension of the disease's propagation, symptoms, and the necessity of appropriate therapy. This deficiency in comprehension may result in their underestimation of the hazards linked to pulmonary tuberculosis and the dismissal of symptoms (Kane et al., 2019).

Social stigma is a crucial element influencing patient stigma regarding pulmonary tuberculosis. Numerous persons afflicted with tuberculosis experience feelings of isolation and discrimination from the surrounding population. This stigma frequently arises from the perception that pulmonary tuberculosis is a transmissible and lethal illness, instilling dread throughout the population (Bresenham et al., 2020). Consequently, patients may hesitate to pursue therapy or reveal their condition to others, perhaps exacerbating their health status. The psychological ramifications of a pulmonary tuberculosis diagnosis cannot be overlooked. Patients frequently encounter anxiety, despair, and a sense of helplessness following their diagnosis (Foster et al., 2024).

This may affect their motivation to pursue therapy and engage in health programmes. Emotional and psychological support from family, friends, and healthcare professionals is crucial for assisting patients in overcoming these obstacles (Nuttall et al., 2022). Compliance with treatment is essential for the management of pulmonary tuberculosis. Patients' views of treatment efficacy and possible adverse effects can affect their decision to persist with therapy. Patients' uncertainties or apprehensions regarding treatment may hinder their adherence to the suggested regimen. Consequently, it is essential for healthcare

professionals to deliver explicit information and assist patients throughout the therapy process (Fekih-Romdhane et al., 2023).

Despite numerous hurdles, there is optimism for managing and decreasing the prevalence of pulmonary tuberculosis in Indonesia (Fuady et al., 2024). By enhancing awareness, diminishing stigma, and improving healthcare access, we can assist pulmonary TB patients in obtaining necessary therapy and elevating their quality of life. Ongoing research and collaborative efforts from all stakeholders will be essential in tackling this challenge and achieving a tuberculosis-free society (Chen Du et al., 2021).

METHOD

Study Design

This study employs a case-control approach to investigate societal stigma, familial support, health literacy, quality of life, knowledge, and stigma among pulmonary tuberculosis patients.

Setting

This study was conducted in Bengkulu City, encompassing the operational regions of Telaga Dewa Public Health Centre, Jembatan Kecil Public Health Centre, Pasar Ikan Public Health Centre, and Kuala Lempuing Public Health Centre. The research was conducted from June to July 2024.

Participants

This study utilised a simple random sampling method, guaranteeing that the number of respondents equalled the total number of participants. This study included inclusion and exclusion criteria for respondent selection. The inclusion criteria encompass individuals with tuberculosis who have resided at the research site for a minimum of two years and are amenable to participating as respondents. The exclusion criteria include the existence of illness complications and tuberculosis kinds other than pulmonary tuberculosis. We divided the respondents into two groups: the case group, which did not receive treatment, and the control group, which received tuberculosis treatment.

Instrument

This study utilised a questionnaire that encompassed enquiries regarding societal stigma, familial support, health literacy, quality of life, knowledge, and the stigma related to pulmonary tuberculosis. All questions employed a Likert scale of five points: five for highly agree, four for agree, three for neutral, two for disagree, and one for severely disagree.

The data analysis

Before data processing, we performed normality and homogeneity tests to determine the appropriate biostatistical model for the bivariate testing phase. The normality test findings indicate a p-value over 0.05, signifying that the data follows a normal distribution. The homogeneity test indicates a p-value greater than 0.05, signifying data homogeneity and permitting the application of the logistic regression test in the bivariate analysis phase. This study employed two tests: a univariate test and a bivariate test. The univariate test seeks to ascertain the frequency distribution of all variable components seen by the group. The bivariate test utilises logistic regression to determine the relationship between independent and dependent variables.

Ethical consideration

Ethics committee approval was obtained from Bengkulu Province, with number 0038/D-KEPK/FD/V/2023. Informed consent by signing the consent form has been obtained.

RESULT

Univariate Test

Table 1. Frequency Distribution of Respondent Characteristics

Characteristics	Case group		Control group	
	Frequency (n)	Percentage (%)	Frequency (n)	Percentage (%)
Social Stigma				
Positive	13	26	41	18
Negative	37	74	9	82
Family support				
Good	15	30	32	64
Not good	35	70	18	36
Health literacy				
Good	9	18	25	50
Enough	11	22	15	30
Not good	30	60	10	20
Quality of life				
High	17	34	29	58
Low	33	66	21	42
Knowledge				
Good	10	20	22	44
Enough	9	18	9	18
Not good	31	62	19	38
TB Patient Stigma				
Positive	18	36	29	58
Negative	32	64	21	42
Total	50	100	50	100

Table 1 indicates that the majority of respondents in the case group exhibited negative societal stigma towards tuberculosis, inadequate family support, deficient health literacy, low quality of life, and insufficient information. Conversely, the majority of participants in the control group demonstrated a favourable societal stigma towards tuberculosis, possessed robust family support, exhibited great health literacy, maintained a superior quality of life, and displayed substantial knowledge.

Bivariate Test

Table 2. Relationship between independent variables and stigma of pulmonary TB patients

Variable	Case					Control				
	Positive Stigma		Negative Stigma			Positive Stigma		Negative Stigma		
	n	%	n	%	OR (95% CI)	n	%	n	%	OR (95% CI)
Social Stigma					**0.014**					**0.000**
Positive	5	27.8	13	72.2	5.2 (2.1 – 13.5)	2	75.2	7	24.1	2.1 (1.1 – 4.9)
Negative	8	25	24	75		9	90.9	3	9.5	
Family support					**0.033**					**0.004**
Good	6	33.3	12	66.7	3.1 (1.1 – 9.8)	2	68.9	9	31.6	1.3 (1.3 – 7.9)
Not good	9	28.1	23	71.9		0	57.1	9	42.9	
Health literacy					**0.001**					**0.012**
Good	6	66.7	3	33.3	4.3 (1.3 – 9.3)	2	80.1	5	20.7	3.7 (1.3 – 6.9)
Enough	10	63.2	6	36.8		0	66.7	4	33.3	
Not good	0	6	20	66.7		0	36	6	64	
Quality of life					**0.002**					**0.002**
High	1	55.9	8	44.1	2.9 (1.1 - 7.4)	2	79.3	6	20.7	4.4 (1.1 – 9.3)
Low	7	21.2	25	78.8		1	52.1	10	47.6	
Knowledge					**0.013**					**0.001**
Good	7	70	3	30	4.9 (1.3 – 8.3)	1	54.2	10	45.4	5.7 (2.1 – 9.23)
Enough	5	55.6	4	44.4		7	77.8	2	22.2	
Not good	9	29	22	71		0	52.6	9	47.4	

Table 2 illustrates a substantial and definitive correlation among all variable components and the stigma associated with pulmonary TB patients. Within the case group, it is evident that social stigma is the primary element contributing to negative stigma for lung tuberculosis patients, succeeded by knowledge, health literacy, familial support, and quality of life. In the control group, knowledge is the variable most likely to incur negative stigma among new TB patients, followed by family support, quality of life, health literacy, and social stigma.

DISCUSSION

The stigma associated with people suffering from pulmonary tuberculosis (pulmonary TB) constitutes a significant barrier to the prevention and treatment of this disease within the community. Multiple factors, including insufficient comprehension of the disease, its transmission, and its health consequences, might contribute to this stigma. Numerous individuals continue to regard pulmonary tuberculosis as a stigmatising and infectious illness, resulting in sufferers frequently facing discrimination and social ostracism (Moonsarn et al., 2023).

The presumption that individuals with pulmonary tuberculosis neglect their health or engage in hazardous behaviours is a prevalent kind of stigma. This leads patients to experience depression and hesitance in pursuing treatment due to apprehension of negative judgement from others (Mbuthia et al., 2020). The stigma is both external and internal, leading patients to experience feelings of humiliation and inferiority due to their diagnosis. Consequently, numerous patients opt to conceal their disease, thereby exacerbating their health and heightening the risk of transmission to others (Foster et al., 2022). Stigma adversely affects patients' access to healthcare services. Numerous individuals exhibiting signs of pulmonary tuberculosis are reluctant to get testing due to the potential stigma they may encounter. This results in delays in diagnosis and treatment, potentially leading to severe consequences and heightened mortality from tuberculosis (Datiko et al., 2020).

In this context, stigma becomes a substantial impediment to the realisation of patients' entitlement to adequate care. Assistance from family and community is crucial in surmounting the stigma faced by pulmonary tuberculosis patients. Families that comprehend the sickness and offer emotional support can enhance patients' sense of acceptance and motivation to pursue therapy (Hayward et al., 2024). Furthermore, the community must engage in educational programmes to improve understanding of pulmonary tuberculosis, therefore diminishing stigma. Effective education can transform community perceptions and foster a more supportive atmosphere for patients. The function of health workers is essential in combating stigma (Fuady et al., 2024). They must be capable of delivering precise information and assisting patients throughout the therapy procedure. Effective communication between healthcare professionals and patients might mitigate the guilt and fear encountered by patients (Sekandi et al., 2024). Moreover, Hayward et al. (2024) underscore the necessity for healthcare professionals to be trained in identifying and mitigating potential patient stigma.

Studies indicate that stigma can influence patient compliance with pulmonary tuberculosis treatment. Patients experiencing stigma often exhibit reduced adherence rates, leading to poor treatment and the development of resistant bacterial strains. Consequently, it is essential to design solutions that address both physical treatment and the psychosocial factors affecting the patient experience (DeSanto et al., 2023).

Initiatives to mitigate stigma should engage several stakeholders, including governmental bodies, non-governmental organisations, and the community. Public awareness initiatives that highlight the facts regarding pulmonary tuberculosis and the significance of treatment can alter individuals' perceptions (Chen et al., 2021). We aim to diminish stigma and enhance patient support for seeking treatment by fostering a deeper awareness of the disease (Wouters et al., 2020).

The stigma associated with pulmonary tuberculosis patients is a multifaceted issue necessitating a comprehensive treatment. Mitigating stigma can enhance patients' quality of life and bolster overall tuberculosis control initiatives (Liboon Aranas et al., 2023). Establishing a more inclusive and supportive atmosphere can facilitate access to necessary care for pulmonary TB patients and

mitigate the disease's societal burden (Chiang et al., 2023).

CONCLUSION

The stigma associated with pulmonary tuberculosis (TB) patients in Bengkulu City remains significantly elevated, with 74% of patients seeing adverse reactions from the community regarding the illness. This stigma substantially affects low patient adherence to medication regimens. The interplay of community stigma, familial support, health literacy, quality of life, and awareness of the stigma associated with pulmonary tuberculosis patients indicates that these elements contribute to patients' diminished motivation to pursue treatment. Consequently, mitigating stigma is essential for enhancing the early identification and management of pulmonary tuberculosis, thereby facilitating more effective disease control.

SUGGESTION

The recommendations put out by the researcher are as follows:

1. Community Education: Enhanced community education initiatives are essential to alter negative perceptions of tuberculosis. This education must encompass details on transmission mechanisms, symptoms, and the significance of treating pulmonary tuberculosis.
2. Community Empowerment: To elevate knowledge regarding the importance of tuberculosis prevention and treatment, it is imperative to augment community empowerment initiatives. Empowerment enables communities to actively help tuberculosis patients and mitigate stigma.
3. Multi-Stakeholder Collaboration: Collaboration between the government, health institutions, and non-governmental organisations is necessary to reduce stigma and increase case-finding coverage of BTA-positive TB. This may encompass public awareness initiatives, training for healthcare professionals, and psychosocial assistance for patients.

We anticipate that the implementation of these recommendations will diminish the stigma surrounding pulmonary TB patients, encourage patients to pursue treatment, and enhance community awareness of the significance of TB prevention and treatment. This would enhance tuberculosis control in Bengkulu City and its surroundings.

REFERENCES

Bresenham, D., Kipp, A. M., & Medina-Marino, A. (2020). Quantification and correlates of tuberculosis stigma along the tuberculosis testing and treatment cascades in South Africa: a cross-sectional study. Infectious Diseases of Poverty, 9(1). https://doi.org/10.1186/s40249-020-00762-8

Chen, X., Du, L., Wu, R., Xu, J., Ji, H., Zhang, Y., Zhu, X., & Zhou, L. (2021). Tuberculosis-related stigma and its determinants in Dalian, Northeast China: a cross-sectional study. BMC Public Health, 21(1). https://doi.org/10.1186/s12889-020-10055-2

Chen, X., Xu, J., Chen, Y., Wu, R., Ji, H., Pan, Y., Duan, Y., Sun, M., Du, L., Gao, M., Wang, J., & Zhou, L. (2021). The relationship among social support, experienced stigma, psychological distress, and quality of life among tuberculosis patients in China. Scientific Reports, 11(1). https://doi.org/10.1038/s41598-021-03811-w

Chiang, S. S., Zeng, C., Roman-Sinche, B., Altamirano, E., Beckhorn, C. B., Leon-Ostos, K., Espinoza-Meza, R., Lecca, L., Franke, M. F., & Chiang, S. S. (2023). Adaptation and validation of a TB stigma scale for adolescents in Lima, Peru. International Journal of Tuberculosis and Lung Disease, 27(10), 754–760. https://doi.org/10.5588/ijtld.23.0104

Datiko, D. G., Jerene, D., & Suarez, P.

(2020). Stigma matters in ending tuberculosis: Nationwide survey of stigma in Ethiopia. In BMC Public Health (Vol. 20, Issue 1). BioMed Central Ltd. https://doi.org/10.1186/s12889-019-7915-6

DeSanto, D., Velen, K., Lessells, R., Makgopa, S., Gumede, D., Fielding, K., Grant, A. D., Charalambous, S., & Chetty-Makkan, C. M. (2023). A qualitative exploration into the presence of TB stigmatization across three districts in South Africa. BMC Public Health, 23(1). https://doi.org/10.1186/s12889-023-15407-2

Fekih-Romdhane, F., Obeid, S., Chidiac, G., Dabbous, M., Malaeb, D., Hallit, R., & Hallit, S. (2023). Measuring public attitudes towards people living with chronic diseases in Arabic-speaking populations: adaptation and development of the Social Stigma Scale of Chronic Diseases (SSS-CD). BMC Public Health, 23(1). https://doi.org/10.1186/s12889-023-16315-1

Foster, I., Biewer, A., Vanqa, N., Makanda, G., Tisile, P., Hayward, S. E., Wademan, D. T., Anthony, M. G., Mbuyamba, R., Galloway, M., Human, W., van der Westhuizen, H.-M., Friedland, J. S., Medina-Marino, A., Schoeman, I., Hoddinott, G., & Nathavitharana, R. R. (2024). “This is an illness. No one is supposed to be treated badly”: community-based stigma assessments in South Africa to inform tuberculosis stigma intervention design. BMC Global and Public Health, 2(1). https://doi.org/10.1186/s44263-024-00070-5

Foster, I., Galloway, M., Human, W., Anthony, M., Myburgh, H., Vanqa, N., Wademan, D. T., Makanda, G., Tisile, P., Schoeman, I., Hoddinott, G., & Nathavitharana, R. R. (2022). Analysing interventions designed to reduce tuberculosis-related stigma: A scoping review. PLOS Global Public Health, 2(10 October). https://doi.org/10.1371/journal.pgph.0000989

Fuady, A., Arifin, B., Yunita, F., Rauf, S., Fitriangga, A., Sugiharto, A., Yani, F. F., Nasution, H. S., Putra, I. W. G. A. E., Mansyur, M., & Wingfield, T. (2024). Stigma, depression, quality of life, and the need for psychosocial support among people with tuberculosis in Indonesia: A multi-site cross-sectional study. PLOS Global Public Health, 4(1). https://doi.org/10.1371/journal.pgph.0002489

Hayward, S. E., Vanqa, N., Makanda, G., Tisile, P., Ngwatyu, L., Foster, I., Mcinziba, A. A., Biewer, A., Mbuyamba, R., Galloway, M., Bunyula, S., van der Westhuizen, H.-M., Friedland, J. S., Medina-Marino, A., Viljoen, L., Schoeman, I., Hoddinott, G., & Nathavitharana, R. R. (2024). “As a patient I do not belong to the clinic, I belong to the community”: co-developing multi-level, person-centred tuberculosis stigma interventions in Cape Town, South Africa. BMC Global and Public Health, 2(1), 55. https://doi.org/10.1186/s44263-024-00084-z

Hayward, S. E., Vanqa, N., Makanda, G., Tisile, P., Ngwatyu, L., Foster, I., Mcinziba, A., Biewer, A., Mbuyamba, R., Galloway, M., Bunyula, S., Westhuizen, H.-M., Friedland, J. S., Marino-Medina, A., Viljoen, L., Schoeman, I., Hoddinott, G., & Nathavitharana, R. R. (2024). “As a patient I do not belong to the clinic, I belong to the community.” Co-developing a multi-level, person-centred tuberculosis stigma intervention in Cape Town, South Africa. Research Square. https://doi.org/10.21203/rs.3.rs-3921970/v1

Kane, J. C., Elafros, M. A., Murray, S. M., Mitchell, E. M. H., Augustinavicius, J. L., Causevic, S., & Baral, S. D. (2019). A scoping review of health-related stigma

outcomes for high-burden diseases in low- and middle-income countries. In BMC Medicine (Vol. 17, Issue 1). BioMed Central Ltd. https://doi.org/10.1186/s12916-019-1250-8

Kemenkes RI. (2023). Profil Kesahatan Indonesia 2022. Kementerian Kesehatan Republik Indonesia. Jakarta

Liboon Aranas, L., Alam, K., Gyawali, P., & Alam, R. M. (2023). Drug-Resistant Tuberculosis Stigma Among HealthCare Workers Toward the Development of a Stigma-Reduction Strategy: A Scoping Review. In Inquiry (United States) (Vol. 60). SAGE Publications Inc. https://doi.org/10.1177/00469580231180754

Mbuthia, G. W., Nyamogoba, H. D. N., Chiang, S. S., & McGarvey, S. T. (2020). Burden of stigma among tuberculosis patients in a pastoralist community in Kenya: A mixed methods study. PLoS ONE, 15(10 October). https://doi.org/10.1371/journal.pone.0240457

Moonsarn, S., Kasetjaroen, Y., Bettex-Baars, A. M., & Phanumartwiwath, A. (2023). A Communication-Based Intervention Study for Reducing Stigma and Discrimination against Tuberculosis among Thai High-School Students. International Journal of Environmental Research and Public Health, 20(5). https://doi.org/10.3390/ijerph20054136

Nuttall, C., Fuady, A., Nuttall, H., Dixit, K., Mansyur, M., & Wingfield, T. (2022). Interventions pathways to reduce tuberculosis-related stigma: a literature review and conceptual framework. In Infectious Diseases of Poverty (Vol. 11, Issue 1). BioMed Central Ltd. https://doi.org/10.1186/s40249-022-01021-8

Sekandi, J. N., Quach, T., Olum, R., Nakkonde, D., Farist, L., Obiekwe, R., Zalwango, S., & Buregyeya, E. (2024). Stigma and Associated Sex Disparities Among Patients with Tuberculosis in Uganda: A Cross-Sectional Study. https://doi.org/10.21203/rs.3.rs-3794900/v1

Van Brakel, W. H., Cataldo, J., Grover, S., Kohrt, B. A., Nyblade, L., Stockton, M., Wouters, E., & Yang, L. H. (2019). Out of the silos: Identifying cross-cutting features of health-related stigma to advance measurement and intervention. BMC Medicine, 17(1). https://doi.org/10.1186/s12916-018-1245-x

WHO. (2022). Global Tuberculosis Report 2022. World Health Organization 2022.

Wouters, E., Sommerland, N., Masquillier, C., Rau, A., Engelbrecht, M., Van Rensburg, A. J., Kigozi, G., Ponnet, K., & Van Damme, W. (2020). Unpacking the dynamics of double stigma: how the HIV-TB co-epidemic alters TB stigma and its management among healthcare workers. BMC Infectious Diseases, 20(1). https://doi.org/10.1186/s12879-020-4816-3