# The Effect of Family Psychoeducation on Tuberculosis Treatment Adherence of Children in Indonesia

by Yuni Kusmiyati

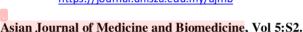
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# The Effect of Family Psychoeducation on Tuberculosis Treatment Adherence of Children in Indonesia

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# **Abstract**

Tuberculosis (TB) is an infectious disease leading cause of death in the world but treatment adherence the most underrated and understudied factor affecting the outcome of TB therapy. The aim of this study was to determine the effect of family psychoeducation on TB treatment adherence of children. The study used a randomized controlled trial (RCT). The sample was 40 pairs of primary caregivers and children who received TB treatment and experienced no side effects of anti-TB drugs in Wonosari Hospital Indonesia in 2019. The treatment group was given psychoeducation by trained health personnel psychoeducators, while the control group was given education by health workers. Psychoeducation was carried out individually, 3 meetings in the first week of the study. Adherence was measured at the sixth month which was the end of treatment period, using a questionnaire. Data were analyzed by using multiple logistic regression. The results showed that family psychoeducation had a significant effect on TB treatment adherence in children after controlling for mother's knowledge (P-value 0.05  $\leq$  0.05). Family psychoeducation is a preventive factor for non-adherence to TB treatment. It is important that psychoeducation is provided to all TB patients to reduce psychological problems that can lead to treatment non-adherence.

Keywords: Family Psychoeducation, Treatment Adherence, Tuberculosis

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### Introduction

Tuberculosis (TB) is caused by Mycobacterium tuberculosis, is the leading infectious cause of death worldwide. Millions of people fell ill with TB each year. Globally, the estimate is that 10.0 million people sick with TB disease in 2017, and two thirds were in eight countries: India (27%), China (9%), Indonesia (8%), Philippines (6%), Pakistan (5%), Nigeria (4%), Bangladesh (4%) and South Africa (3%) <sup>[1,2]</sup>. The World Health Organization (WHO) has designated Indonesia a high burden country for tuberculosis. In Indonesia, there are roughly 500,000 new cases of TB annually and 175,000 attributable deaths. Tuberculosis is the second major killer of adults after cardiovascular disease and the deadliest pathogen out of all communicable diseases <sup>[2]</sup>.

According to WHO, children represent about 10% of all TB cases. Estimated 1 million children became ill with TB and 233 000 children died of TB in 2017 [3]. The impact of TB on children is far reaching Children with TB are also more likely to be left severely disabled, as they are more vulnerable to complex forms of the disease such as TB meningitis. TB remains a leading infectious cause of global childhood morbidity and mortality [4]. Childhood TB is a serious public health problem and a consequence of poor control of TB in the adult population [5,6]. Treatment is recommended for children with TB infection to prevent them from developing TB disease. TB disease is treated by taking several anti-TB medicines for 6 to 9 months. If a child stop taking the drugs before completion, the child can become sick again and if drugs are not taken correctly, the bacteria that are still alive may become resistant. TB that is resistant to drugs is harder and more expensive to treat, and treatment lasts much longer (up to 18 to 24 months) [7]. The most likely cause of poor response to treatment, is nonadherence [8]. Previous studies in Indonesia reported that the prevalence of non-adherence TB patients was around 27.3%. This is higher than the WHO data of less than 10% [9].

Many factors cause nonadherence in TB treatment including poor knowledge about tuberculosis, side effects of drugs, forgetting to take medication, being far from health services, lack of transportation costs, lack of social support including family support, poor communication between patients and health care providers, and out of stock drugs [10,11]. Many efforts have been made to improve the adherence to TB treatment, such as the use of health digital technology, helping clients deal with social problems that might hinder their abilities during the treatment process, to increase effective cooperation and communication between the care workers and the supervision of the clients directly and indirectly through PMO, through the care workers and through the family who act as self-reminders for the clients [12,13].

The various programs that have been carried out to improve adherence to TB treatment have not been integrated with psychological problems, while TB itself has many psychosocial impacts, such as feeling bored, lack of motivation, to serious mental disorders such as major depression, feeling fear of incurable diseases, fear of being shunned by society because it can transmit the disease to other children, and parental anxiety due to the child's



condition. This becomes an obstacle the healing process for children with TB. Psychosocial problems and lack of motivation and support from family will affect patient adherence to medication. If this is allowed, the impact that will arise is resistance to drugs, treatment control is increasingly difficult, treatment response is poor and increased mortality [14,15]. Based on this background, the researchers are interested to determine the effect of family psychoeducation on TB treatment adherence of children.

### Methodology

This study used a randomized controlled trial (RCT). The population was pairs of primary caregivers and children receiving TB treatment at Wonosari Hospital in 2019, totaled 53. The samples were pairs of primary caregivers and children receiving TB treatment who were willing to be research subjects and children received TB treatment for a maximum of one month. Samples were excluded if the child had side effects from TB drugs. The sample size of 40, consisting of 20 treatment groups and 20 control groups, was calculated using the hypothesis test of a difference of 2 proportions, using  $\alpha=0.05$ , power = 80. Sampling was by simple random sampling using random numbers, on samples that met the criteria inclusion and exclusion, to determine the intervention group and the control group.

The treatment group was given psychoeducation by psychoeducators of health workers who had been trained by psychologists and experts of TB. Psychoeducation was carried out individually, with 3 meetings in the first week of the study, for 30-40 minutes per meeting using the psychoeducation module guide. The module has been validated by psychologists and experts of TB. All of subjects were interviewed at their home by trained interviewers. To prevent TB transmission, psychoeducators use personal protection such as masks according to health protocols and interviews were conducted at a distance of about 1 meter. The control group was also given education according to the standards usually carried out by health workers who are in charge of assisting TB patients in the area but did not receive psychoeducation training. To prevent bias, the researchers used the blinding approach, namely the collection of outcome data was carried out by enumerators who did not know whether it was a control or intervention group. The outcome data collection was carried out by enumerators who had the same educational qualifications, namely midwifery and had received

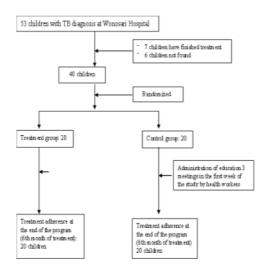
Treatment adherence was evaluated at the sixth month, which is the end of the TB treatment period, using a questionnaire consisting of 12 questions. Adherence is classified as adherence if all the answers show behavior in accordance with the TB treatment rules and non-adherence if there are one or more answers that are not in accordance with the TB treatment rules. Data were analyzed using multiple logistic regression. The p-value of the likelihood ratio to the chi-square was used as a guide to the model's goodness of fit. All p-values were two-tailed, and statistically significant level was set as less than 0.05. The SPSS for Windows (version 15) programs were used for the data analysis. Ethical approval was obtained from the Gadjah Mada University Ethics Committee No:

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KE.FK/0091/EC/2019. Subjects received explanations of the aims, risks, and procedures of the study and signed an informed consent as an agreement before the study was conducted.

There were 53 children with TB diagnosis at Wonosari Hospital in 2019. There were 7 children who had finished treatment and 6 children who could not be found. The number of subjects who met the inclusion and exclusion criteria was 40 children. The subjects of 40 children were then randomized to be grouped into the treatment group and the control group. During the study, no subjects were lost to follow-up. The description of recruitment flow chart is presented in Figure 1:

Figure 1 Diagram of Participants' Recruitment, Allocation, and Number of Participants



# Results

The sample was 40 pairs of primary caregivers and children receiving TB treatment at Wonosari Hospital Indonesia in 2019, who were grouped into 20 intervention groups and 20 control groups. Baseline data between the two groups, namely TB treatment adherence at the start of treatment were the same between the two groups. Subject characteristic data, namely the age of the child, the occupation and gender of children between the two groups are homogeneous. Characteristics and comparability of subjects based on parental demographic factors, child demographic factors, between the treatment group and the control group are presented in the Table 1.



 Table 1 Subject comparability (experimental and control groups)

Variable	Experimental group (n=20) n (%)	Control group (n=20) n (%)	P-Value
Mother with basic education *	11(55.0)	10(50.0)	0.014
Mother works	8(40.0)	6(30.0)	0.740
Low economic status	12(60.0)	3(15.0)	0.009
Gender male	7(35.0)	5(25.0)	0.730
Age (mean, SD)	77(194.8)	71(50.4)	0.904

### Notes:

n = the number of samples, SD=standard deviation

\*Basic Education (Elementary, Jr. School)

\*\*Child's age in months

Table 1 shows that there is no difference in sociodemographic factors, namely the age of the child, the gender of children and the mother's occupation (P-value>0,05), while the education and economic status of the mother have differences between the control and intervention groups. This study revealed that the overall treatment adherence level was 65% and non-adherence was 35%. The effect of family psychoeducation and external variables on tuberculosis treatment adherence are presented in Table 2.

**Table 2** The effect of family psychoeducation and external variables on tuberculosis treatment adherence

Variable	Non- adherence n (%)	Adherence n (%)	P-Value
Family psychoeducation	4(20.0)	16(80.0)	0.047
Mother with basic education *	10(47.6)	11(52.3)	0.237
Mother works	4(28.6)	10(71.4)	0.730
Low economic status	4(26.7)	11(73.3)	0.608
Gender male	5(41.7)	7(58.3)	0.565
Mother's	7(36.8)	12(63.2)	0.026
knowledge low			
Unsupportive attitude	8(33.3)	16(66.7)	1.000

Notes:

n = the number of samples

\*Basic Education (Elementary, Jr. School)

Table 2 shows that the variables that have an effect on treatment adherence are the family psychoeducation and mother's knowledge low, while other external variables, such as the gender of the child, the mother's education, the mother's occupation, the family economy, attitude, have no effect significant on treatment adherence. The fixed model of the effect of family psychoeducation and external variables on treatment adherence is presented in Table 3.

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**Table 3** The effect of family psychoeducation on tuberculosis treatment adherence after being controlled for variable mother's knowledge

Variable	β	SE	P- value	Exp B
Constant	- 0.832	0.662		
Family	-1.508	0.778	0.05	0.22
psychoeducation				
Mother's	1.663	0.774	0.03	5.27
knowledge low				

Notes:  $n = \beta = \text{coefficient}$ ; SE = standard error

Table 3. shows that family psychoeducation had a significant effect on TB treatment adherence in children after controlling for mother's knowledge (P-value  $0.05 \leq 0.05$ ). The regression equation is  $Y=\alpha+\beta 1X1$ . Y=-0.832+(-1.508 (family psychoeducation) + 1.669 (mother's knowledge). Y=-0.671. The probability to predict the magnitude of the effect of family psychoeducation on adherence to TB treatment in children is 1/1+e-(0.671)=1/1.05=67%. So, it can be concluded that child TB patients who do not receive family psychoeducation and have mothers with low education have a 67% chance of not adhering to treatment.

### Discussion

This study found evidence of the effect of family psychoeducation on TB treatment adherence. The strength of the design of this study is a logical direction of inquiry so that it better guarantees the principle of temporality, namely cause precedes effect. The causal variable (psychoeducation) was given at the start of treatment and the outcome (adherence) was assessed at the end of treatment. Selection bias in experimental studies can occur when different criteria are used to select the intervention group and the control group. In this study, selection bias was prevented by selecting both groups using the same criteria, namely all children who had been diagnosed with TB by a doctor and were domiciled in the same area.

The results of this study are consistent with research conducted by Nisa (2018), which states that psychoeducation is effective in providing a positive effect in improving the patient's psychological and emotional health during treatment [16]. The psychosocial impact experienced by the family is the presence of emotional problems related to illness such as feeling bored, lack of motivation, to serious mental disorders such as major depression. Lack of motivation and support from the family will affect treatment adherence. If this is allowed, the effect is drug resistance, treatment control becomes more difficult, and the mortality rate increases. Psychoeducation is a form of education or training to develop and increase patient acceptance of diseases and increase patient participation in therapy so as to accelerate the healing process [14,15]. Drug resistance and treatment failure may happen as a result of non-adherence to anti-TB treatment. Thus, the finding of this study plays a paramount role in achieving the TB treatment success rate by decreasing the occurrences of drug resistance [17].



Psychoeducation therapy is often given to patients with psychiatric disorders. However, psychoeducation can also be applied to individuals or groups to face certain challenges so that they can avoid problems. Psychoeducation has the potential to be applied to a wide area of various forms of disorders and life challenges <sup>[15]</sup>. Based on the results of this study, psychoeducation can be used for assisting TB patients. Policy makers at the regional or central level can formulate a policy on the need for families psychoeducators so that they can increase the success of the TB treatment program which takes a very long time.

This study revealed that the overall treatment adherence rate was 65%, which was higher than the study in northern Portugal (63.9%) but lower than the Ethiopian study (73.3%) and the systematic review and meta-analysis conducted by Zegeye et al. (2019) (78.71%) [17,18]. The differences in findings may be due to variations in the definition of anti-TB non-adherence. There is no gold standard definition of adherence to anti-TB treatment although the quantity and time missed by treatment or hospital appointments is recommended by WHO. In our study, patient non-adherence was when the drug consumption behavior was not in accordance with the rules and the patient did not take the drug within 1 day, while another measured non-adherence if the patient stopped medication for 6 days.

This study found that most of the mothers' education was low. A person's behavior is influenced by the level of knowledge, while the level of knowledge is influenced by the level of one's education. The higher a person's education level, the more information received and the better the ability to receive information. The results of this study found that there was no relationship between mothers' education with adherence to TB treatment. The results of this study are consistent with research conducted by Zanani (2009), which states that a higher level of education does not necessarily affect the emergence of attitudes or actions in accordance with the expected goals [19]. The results of this study are also in accordance with the results of research by Ruditya (2015), who found there was no relationship between education level and examination adherence during TB treatment [20].

The occupation of mothers in this study was divided into working and not working. The type of occupation affects a family's monthly income. This is related to the ability of a family's lifestyle. This study found that most mothers do not work. There is no relationship between mothers' occupation with adherence to TB treatment. The results of this study are consistent with research by Ruditya (2015), which states that there is no relationship between mothers' occupation with adherence during TB treatment <sup>[20]</sup>. This is possible because most of the work of mothers is self-employed whose activities are carried out at home, so that they have the same intensity of meetings with children as mothers who do not work so that it does not affect treatment adherence.

The results of this study indicate that the majority of respondents with a lower socioeconomic level are more adherent in treatment. Social support and economic conditions are things that support the achievement of

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patient adherence in achieving his treatment program. In this study, there was no relationship between family economic level and treatment adherence. The high level of adherence to pulmonary tuberculosis patients with low-income levels is because the TB eradication program does not need to pay or is free for both drugs and examinations during treatment. This program is an effort by the government to eradicate and reduce the incidence of TB in Indonesia.

Male gender is one of the risk factors for pulmonary TB. The prevalence of TB in male tends to be higher at all ages [17]. The results of this study found that most of the gender of children with TB were women. There is no relationship between gender and TB treatment adherence. The difference in the results of this study is probably because this study is a study of TB in children which is still heavily influenced by parenting styles and the environment in which they live.

Low knowledge can determine treatment irregularities due to lack of information about TB disease, how to treat it, the dangers of not taking medication regularly and its prevention. The results of this study prove that there is an effect of low mothers' knowledge on adherence to TB treatment in children. A person's knowledge can influence behavior in treatment. The results of this study are consistent with the research conducted by Yuni, (2016), that there is a relationship between the level of knowledge with adherence to treatment TB [21]. Patients with low knowledge had 1,164 times the risk of non-adherence compared to patients who were with high knowledge [21]. In this study, it was found a greater risk was that mothers with low knowledge had a 5 times risk of non-adheren. Attitude is a major predictor of daily behavior (action), although there are other factors. This means that attitudes can determine a person's actions, but sometimes attitudes don't turn into actions. The results showed that most families supported the treatment of TB in children. There is no relationship between attitude and treatment adherence. This result is consistent with the research of Sari et al, (2016) which found no relationship between attitudes and adherence with TB treatment in Jakarta [9]. This result is different from the research conducted by Octavienty et al, (2019) which shows that there is a significant relationship between knowledge and adherence to early-stage treatment

Psychoeducation therapy is often given to patients with psychiatric disorders. However, psychoeducation can also be applied to individuals or groups to face certain challenges so that they can avoid problems. Psychoeducation has the potential to be applied to a wide area of various forms of disorders and life challenges [14]. Based on the results of this study, psychoeducation can be used for assisting TB patients. Policy makers at the regional or central level can formulate a policy on the need for families psychoeducators so that they can increase the success of the TB treatment program which takes a very long time.

# Conclusion

Family psychoeducation had an effect on TB treatment adherence in children. The probability to predict the



magnitude of the effect of family psychoeducation on adherence to TB treatment in children is 67%.

### Recommendation

Family Psychoeducator are needed to support TB treatment programs in children. Psychoeducation training should be provided to all health workers to improve adherence to TB treatment in children.

### Abbreviations

RCT: Randomized Controlled Trial. TB:Tuberculosis. WHO:World Health Organization

## **Ethics Approval and Consent to Participate**

Ethical approval was given from the Gadjah Mada University Ethics Committee No: KE.FK/0091/EC/2019. Subjects were given an explanation of the aims, risks, and procedures of the study and signed an informed consent as an agreement before the study was conducted.

### Competing interests

We declare we have no competing interests.

### Availability of data and material

All data generated or analyzed during this study are included in this published article.

# Author's contributions

All authors collaborated in the study: Yuni Kusmiyati, Suherni, Yuliasti Eka Purnamaningrum, Sih Rini Handajani, Agung Jaya Endranto and Serap Ejder Apay conceptualized the study, outlined the design and supervised data analysis, as well as wrote the manuscript, collected the data and worked out details and led the field study. All authors have read and approved the final manuscript.

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