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Family Empowerment with SEDAP Method (Sharing, Education and Practice) in Improving the Quality of Life in Lung Tuberculosis Patients

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ABSTRACT

Introduction: Family empowerment might be considered as an effort to strengthen the role and knowledge of family with TB patients. **Objective:** Proving the effectiveness of family empowerment with SEDAP (Sharing, Education, and Practice) method to improve the quality of life in pulmonary tuberculosis patients. **Methods:** Mixed methods research, qualitative research was done using FGD approach, while pre-post control group design was used for the quantitative research. Thirty-eight trials of TB patients were divided into 2 groups: intervention group where family empowerment was introduced using the SEDAP method and control group. Qualitative data were collected using a recording device which would be transcribed, followed by keyword observation and analysis. Quantitative data were obtained using SGRQ questionnaires, both on knowledge and quality of life variables. Qualitative data were analyzed by interactive models, whereas quantitative data by independent samples t-tests and paired samples t-test. **Results:** Three main domains (knowledge, attitude, and behavior) were obtained from the FGD results, along with the keywords analyzed from each domain. Knowledge domain was associated with TB causes and routes of transmission, attitude was related to the negative stigma on TB patients, and lastly, behaviour was linked with patients' forgetfulness in taking medication and the side effects occurred due to the medication. P-value <0.05 was obtained on the variables of knowledge and quality of life (symptoms, activities, and impacts). **Conclusion:** Intervention of SEDAP method (Sharing, Educating, and Practice) on family empowerment was effective in improving the overall quality of life of TB patients.

Keywords: SEDAP (sharing, education, and practice) method; tuberculosis; family empowerment

INTRODUCTION

Tuberculosis (TB) is an infectious disease caused by the *Mycobacterium tuberculosis*. It is a very strong bacilli bacteria hence the need of long treatment time⁽¹⁾. Pulmonary tuberculosis has continued to be a global health problem especially in developing countries⁽²⁾.

Results of the Basic Health Research in 2018 showed that nationally, the prevalence of pulmonary TB did not change from 2013 to 2018, which was 0.4, with an incidence of 321 / 100,000 population. This suggested that the efforts to reduce the prevalence of pulmonary TB were not successful⁽³⁾. In Indonesia, the government through the Ministry of Health set a target in which the incidence of pulmonary TB would be 245 / 100,000 population in 2019. Based on 2018 Basic Health Research, North Sumatra ranks 20th nationally in the number of pulmonary TB cases. Furthermore, the prevalence of pulmonary TB in 2018 has increased from 0.2 to 0.3 compared to 2013⁽⁴⁾.

A fluctuation in the number of pulmonary TB cases has been observed in Medan. Medan City has the largest number of pulmonary TB patients when compared to the population from each district or other cities. In 2013, there were a total of 6056 pulmonary TB cases detected in Medan, with 3096 people developed a positive Acid-Fast Bacilli (AFB+) when tested. The number of cases, however, has decreased to 5863 and 5843 in 2014 and 2015, respectively⁽⁵⁾.

A study done by Hidayah, et al (2014) showed that, based on the AFB+ conversion rate in sputum examination of pulmonary TB patients at Sukamerindu Public Health Center in Bengkulu city, the majority (75.7%) of drug-taking supervisor has low motivation in assisting patients with the medication⁽⁶⁾. Drug-taking supervisors did not get enough evaluation and information from public health center regarding their duties and obligations. Treatment failure and lack of discipline of pulmonary TB patients were strongly influenced by several factors and one of them is the role of the drug-taking supervisor. Thus, the collaboration between health workers with appointed families to

assist patients when taking medication was another factor that needed to be evaluated to determine the level of success of effective medication⁽⁷⁾.

Abrori & Ahmad (2018) found that families have failed to carry out their duties as stated by Friedman, which were, recognizing family health problems, deciding appropriate actions, caring for members, families with health problems, modifying the environment that supports health, and the ability to use health facilities⁽²⁾. According to Marwansyah & Solikhah (2015), families often did not know the actions that should be taken to help with the prevention and healing process of pulmonary TB. Despite the family involvement in TB treatment at home, this has not been accompanied by adequate knowledge regarding the actions that must be taken by the family from the healthcare workers. This emphasized that family empowerment must be done to accomplish the successful treatment and care of TB patients so as to reduce the TB prevalence⁽⁸⁾.

Family empowerment in previous studies was based on health education accompanied by demonstrations⁽⁶⁾,⁽⁹⁾,⁽¹⁰⁾. In this study, family empowerment was modified by first analyzing the problems arising in the family when treating TB patients at home with the Sharing method. The next step was to provide the family with knowledge through health education based on the problems that had been analyzed previously. This study also observed and assessed family actions in treating TB patients (Practice). This program will then be known as family empowerment using the SEDAP method. Furthermore, this study measured the quality of life of TB patients, as there has not been much research related to the effect of family empowerment on the quality of life of patients found in the literature. This is important because the quality of life will affect all aspects of life. Thus, research on the effect of family empowerment with SEDAP modification needed to be conducted on the quality of life of TB patients in Medan⁽¹¹⁾.

This study was done to prove the effectiveness of family empowerment with SEDAP method to improve the quality of life in pulmonary TB patients in Pancur Batu Health Center, Deli Serdang Regency.

METHODS

This research used a mixed method. Focus Group Discussion (FGD) was used in the qualitative research while pre-post test with control group design was applied in the quantitative research. The entire pulmonary TB patients (86 people) in Pancur Batu Health Center, Deli Serdang Regency served as the population in this study. Based on the total population of pulmonary TB patients in Pancur Batu Health Center and the prevalence of pulmonary TB population of 0.2 from Basic Health Center (2018), a sample size of 16 patients were obtained. The calculation was done with Sample Size Determination in Health Studies Software version 2.0, Lwanga & Lemeshow, which give the final sample of 38 patients. Descriptive analysis was used to analyze the frequency of each of the measurement results. In this study the measurement results of quality of life were displayed in the form of categories and then frequency. Bivariate analysis was done to prove the hypothesis that has been formulated. The statistical analysis in this study was performed using SPSS software version 19. Wilcoxon test was used to determine if there is an effect due to certain treatment in a group with pre and post test. The Mann-Whitney test was used to determine the differences in quality of life between the control and intervention groups. The difference was significant if $p < 0.05$. For qualitative analysis, the results were obtained from interview, which would later be transcribed. Furthermore, the results would be coded according to the topic of the problem. Data analysis for the qualitative study in this study was done using the interactive analysis model.

RESULTS

Quantitative

This study was conducted in July - September 2019. Following are the respondent attributes that were collected in this study. Based on table 1, the majority of respondents in this study were over 50 years (34.2%) and the younger patients (<20 years old) contributed to 13.2% of the total sample. Based on table 2, the majority of respondents were male (52.6%). Based on table 3, the majority of respondents in this study were not working (34.2%). Based on table 4, the majority of respondents in this study has been suffering from TB for 4-6 months (31.6%).

Table 1. Distribution of age

No.	Age	Frequency	Percentage
1	<20	5	13.2
2	20-30	7	18.4
3	31-40	5	13.2
4	41-50	8	21.1
5	>50	13	34.2

Table 2. Distribution of sex

No.	Sex	Frequency	Percentage
1	Male	20	52.6
2	Female	18	47.4

Table 3. Distribution of occupation

No.	Occupation	Frequency	Percentage
1	Driver	1	2.6
2	Does not work	13	34.2
3	Village official	2	5.3
4	Entrepreneur	9	23.7
5	Education sector	1	2.6
6	Staff	1	2.6
7	Waitress	1	2.6
8	Student	3	7.9
9	Farmer	2	5.3
10	Housewife	5	13.2

Table 4. Distribution of duration of disease

No.	Suffering time	Frequency	Percentage
1	< 1 month	1	2.6
2	1-3 months	10	26.3
3	4-6 months	12	31.6
4	7-9 months	3	7.9
5	10-12 months	6	15.8
6	>12 months	6	15.8

Table 5. Average score of knowledge

No.	Group	Knowledge score (mean±SD)	p-value
1	Treatment	81,2±9,5	0,000
2	Control	69,33±5,8	

Based on table 5, the p-value was <0.05 was obtained, which means that there was a significant difference in the knowledge score between the treatment and control group.

Table 6. Average score of quality of life

No.	Group	Score quality of life (mean±SD)	p-value
1	Treatment	18,25±1,4	0,000
2	Control	24,9±3,0	

Based on table 6, the p-value was <0.05, thus there was a significant difference in the quality of life of respondents between the treatment and control group.

Table 7. Average score of quality of life components

No.	Component	Treatment	Control	p-value
1	Symptom	40,1±14,7	44,7±17,9	0,396
2	Activity	12,1±0,3	12,9±0,4	0,018
3	Impact	16,9±1,9	22,9±2,4	0,000

Based on table 7, the p-values of the activity and impact components were <0.05, which means that there were significant differences in the activity and impact component between the treatment and control groups. On the other hand, the symptom component had a p-value >0.05, which means that there was no significant difference in symptom between the treatment and control groups.

Qualitative

Table 8. In-depth interview matrix

No.	Domain	keywords	Interview passage
1	Knowledge	Germes	"TB is caused by germs
		bacteria	"TB is caused by ... bacteria"
		viruses	"TB is caused by virus
		cough	"TB is a disease that could be transmitted through cough"
2	Attitude	Embarrassing	"I think this disease is shameful ..."
		Priority (TB being less important)	"Coming from low-income family, it is more important that we earn money rather than seek treatment ..."
		Forgetful	".... I take the medicine only if I remember" "How would it be possible for us to remember to take medicine every day, we are both old, forgetful ..."
3	Behavior	Side effects from medication	"..... side effects of drugs a lot "I sometimes feel nauseous, diarrhea and dizzy due to the side effects of the drugs"
			"..... how would it be possible for me to work and move around if the side effects of drugs made me feel dizzy"

Qualitative research was conducted with the *sharing* method. Based on in-depth interviews, three domains, which were knowledge, attitude, and behavior of respondents related to TB were obtained.

DISCUSSION

In this study, treatment was done through family empowerment with SEDAP method. The first step is *sharing*, where patients and families shared their views on TB. It used a qualitative approach through in-depth interviews. From the results, 3 domains were obtained, namely knowledge, attitudes, and behavior. In the knowledge domain, majority of respondents in the treatment group knew that tuberculosis was caused by bacteria and could be transmitted through cough. However, respondents' knowledge were still very limited as there were no other keywords found which could indicate the depth of respondents' knowledge. Research conducted by Mbuthia et al (2018) showed similar results, with many TB patients were still having a number of misinformation in regards to TB⁽¹²⁾. Hasan et al (2017) added that TB-related information was still minimal, evidenced by the majority of respondents not knowing the detailed symptoms and causes of TB⁽¹³⁾. Suhariadi et al (2016) stated that the lack of information resulted in patients being late in seeking treatment⁽¹⁴⁾. Mbuthia et al (2018) emphasized that proper education is critical for patients to be able to increase the knowledge on TB, thus avoiding misleading information⁽¹²⁾.

In the attitude domain, the keyword 'embarrassing' was found, which means that TB is still considered as a stigma within the community. A study by Craig et al (2017) proved that stigma still correlate strongly with TB patients⁽¹⁵⁾. Gyimah & Gyeke (2019) stated that adequate knowledge was not even able to form a good perception related to TB, let alone the insufficient knowledge⁽¹⁶⁾. Hasan et al (2017) stated that poor attitudes related to TB were the result of poor knowledge about TB. Thus, the role of stigma is very critical in forming perceptions towards TB⁽¹³⁾. Humphreys et al (2017) stated that the stigma built against TB patients will eventually hinder their social relations (discrimination)⁽¹⁷⁾. Thus, many TB patients were reluctant to share their conditions with others, let alone to healthcare workers. Craig et al emphasized that this would be a large task for stakeholders to tone down the stigma towards TB in the community⁽¹⁵⁾.

In the behavioral domain, the keywords 'forgetfulness' and 'side effects' indicated that TB patients did not regularly take medication⁽¹⁸⁾⁽¹⁹⁾⁽²⁰⁾. This has led to many cases of drop-out during TB treatment. Hapsari & Prasetya (2018) stated the patient's negligence in remembering medication schedule, and the laziness experienced due to the side effects of the drug, were the reasons for treatment drop-out⁽¹⁸⁾. Thus, providing adequate knowledge is important for behaviour-shaping. Hasan et al (2017) stated that adequate knowledge could be shown patients' willingness to seek treatment, and vice versa⁽¹³⁾.

In the second stage, education, was done by providing proper health education to families and patients. The results showed that the average knowledge score in the intervention group (family of TB patients who were given health education) was significantly higher than the control group. This emphasized that proper health education affected the knowledge of respondents positively. Kigozi et al (2017) stated that the amount of information given to TB patients were in line with the increased knowledge about TB and had an overall impact on a more controlled spread of the infections⁽²¹⁾.

In the third stage, practice, the family used the knowledge provided from previous steps to take care of the patients. Families and patients were observed for one month with reinforcement each week. The quality of life of patients was measured after all three stages were carried out. From the results, there was an overall significant difference in the quality of life between treatment and control group. In the treatment group, the average score obtained was 18.25%, which means that the disruption in quality of life occurred was equivalent to 18.25%. The control group had a higher average score of 24.9% and this difference was statistically significant. Thus, family empowerment through SEDAP method has been proven to reduce disruption in quality of life of TB patients.

Three components, which were, symptoms, activities, and impacts were used to measure the quality of life through SGRQ questionnaire. As seen on the results, the interruption in activities and impacts components were lower in the treatment group, and this was statistically significant. Although the treatment group had a lower score in symptoms components than the control group, this difference did not prove to be significant ($p > 0.05$).

Salehitali et al (2019) stated that TB patients had a lower quality of life especially in the social and mental aspects during long-term treatment. Achadiono et al (2016) made it clear that quality of life correlate strongly with the severity of TB. Sartika et al (2016) added that TB had an overall negative impact on the quality of life of patients, with the physical aspect being the most affected.^{(22),(23),(24)}

Family empowerment is a process or effort to promote knowledge, awareness, and family willingness in maintaining and improving health status of patients⁽²⁵⁾. Family empowerment might increase family resilience, the potential and capacity of the family, family resources (strength, potential and ability to achieve goals), and the ability to manage problems and hardship in the family. Patients who lived in the family-supporting environment, will feel appreciated and cared for which affect the patient's motivation to recover. Family intensity in taking care of the patients will also influence the obedience in taking medication. Thus, giving overall positive impacts on the quality of life of patients.

CONCLUSION

The conclusions of this study are: 1) In the knowledge domain, respondents understood the causes and route of transmission of TB, in a simple manner. However, more information such as symptoms, transmission prevention, care, treatment, and proper environmental conditions for TB patients should be given

to provide more adequate knowledge in the community. In the attitude domain, TB was regarded as an embarrassing condition. In the behavioral domain, respondents tend to forget to take medication regularly and were discouraged by the side effects of the drug which affected their daily activities; 2) There was significant difference in the quality of life of respondents between the treatment and control group, in which intervention of SEDAP method was effective in increasing the quality of life

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