

THE HEALTHCARE NEEDS OF FAMILIES CARING FOR PATIENTS WITH PULMONARY TUBERCULOSIS

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Abstract

Tuberculosis (TB) is a global public health problem. Families need to meet healthcare needs during the treatment of TB sufferers. This study aims to identify healthcare needs of families caring for patients with the disease. The cross-sectional study involved 83 families caring for TB patients. The research was conducted at a Primary Healthcare Center in an urban area in West Java. The results revealed that 60.2% of caregivers were 18–40 years old, 60.2% were female, 51.8% were senior high school educated, 43.4% were housewives, 86.7% had an income under the regional minimum wage, and 55.4% had cared for the TB patients for 3–6 months. The families had healthcare needs for emotional support (mean 33.72, SD 4.16); information support (mean 33.28, SD 4.09); instrumental support (mean 32.4, SD 3.73); and appraisal support (mean 28.01, SD 5.93). The greatest support need was how to encourage clients to take treatment completely (Score: 140); TB treatment information (Score: 138); financial support for chest x-ray costs (Score: 114); and how to assess patient behavior in maintaining health (score: 133). Based on the study result, the families need to improve their ability to give appraisal support during the patient's treatment. The identification of families' healthcare needs in caring for patients with pulmonary TB can provide primary data for developing innovative programs integrated with DOTS programs in healthcare services to improve family support.

Keywords: family nursing, pulmonary Tuberculosis, support system

Abstrak

Kebutuhan Perawatan Kesehatan Keluarga yang Merawat Pasien Tuberkulosis. Tuberkulosis (TB) merupakan masalah kesehatan masyarakat global. Keluarga harus memenuhi kebutuhan perawatan kesehatan selama pengobatan pada pasien TB. Penelitian ini bertujuan untuk mengidentifikasi kebutuhan perawatan kesehatan pada keluarga yang merawat pasien TB. Penelitian cross-sectional ini melibatkan responden sebanyak 83 keluarga yang merawat pasien TB. Penelitian ini dilaksanakan di sebuah Puskesmas di Kota Depok, Jawa Barat. Penelitian ini melaporkan sebanyak 60,2% berusia 18–40 tahun, 60,2% perempuan, 51,8% lulus sekolah menengah atas, 43,4% ibu rumah tangga, 86,7% pendapatan di bawah upah minimum regional, 55,4% merawat pasien TB selama 3–6 bulan. Keluarga memiliki kebutuhan perawatan kesehatan untuk dukungan emosional (rerata 33,72, SD 4,16), dukungan informasi (rerata 33,28, SD 4,09), dukungan instrumental (rerata 32,4, SD 3,73), dukungan penghargaan (rerata 28,01, SD 5,93). Kebutuhan tertinggi yaitu bagaimana mendorong pasien melakukan pengobatan secara tuntas (140), informasi pengobatan TB (138), dukungan keuangan untuk biaya pemeriksaan rontgen (114), dan bagaimana mengkaji perilaku pasien dalam mempertahankan kesehatan (133). Keluarga membutuhkan peningkatan kapasitas dalam memberikan dukungan penghargaan selama pengobatan pasien. Kebutuhan akan perawatan kesehatan pada keluarga yang merawat pasien TB dapat dijadikan data dasar dalam mengembangkan program inovatif terintegrasi dengan program DOTS di fasilitas layanan kesehatan dalam meningkatkan dukungan pada pasien TB.

Kata kunci: keperawatan keluarga, sistem dukungan, Tuberkulosis paru

Introduction

Tuberculosis (TB) remains a community health problem around the world, especially in develop-

ing countries. TB diseases regulated in the 2015–2030 Sustainable Development Goals (SDGs) focus on controlling TB. Indonesia is one of the countries with the highest prevalence of pulmo-

nary TB in ASEAN and ranked second after India. Sixty percent of new TB cases reported in India, Indonesia, China, Nigeria, Pakistan, and South Africa. The disease is the tenth highest cause of death globally and can cause dangerous complications if not treated thoroughly. More than 95% of total cases (1.4 million cases), pulmonary TB deaths occur in developing countries (WHO, 2016). The prevalence of pulmonary TB in Indonesia was 330,910 cases in 2016. West Java is the province with the highest number of new cases, with 23,774 in 2016 (Ministry of Health Republic of Indonesia, 2017). Depok City had 2,823 cases of TB in 2016 (Depok Health Office, 2018). This number increased compared to 2015 when the figure stood at 2,563. Cimanggis District is the area with the highest number of pulmonary TB cases in Depok City, 32 cases in 2017. Various efforts can control and prevent the increasing number of TB cases in Indonesia.

The provision of the BCG vaccine is one of the efforts to prevent the transmission of TB. However, the results show it has not reduced morbidity and mortality (Ministry of Health Republic of Indonesia, 2017). Therefore, various kind of programs have been implemented, such as the capacity building of human resources. However, the number of incomplete treatment cases is still high. The limited knowledge of clients and families regarding TB and the demand for care during treatment cause poor treatment (Putera et al., 2015). Efforts to prevent TB transmission need to be made, not only by patients but also by families, as the closest party in healthcare and decision making. The lack of public attention to these efforts also increases the number of TB cases. Therefore, family, community, and health service participation can control transmit TB in the community.

Previous studies explain that family functions in the care of TB patients play two central roles: as a source of support or information and in assistance in overcoming the disease until treatment is complete. The goal is to reduce morbidity and mortality (Rezal et al., 2019). Factors

that influence the efforts to prevent TB transmission include the role of each family member and knowledge about the needs in providing care to TB patients. Families play an essential role in emotional, instrumental, and appraisal supports (Biswas, 2010). Besides, family awareness and knowledge need to be improved to minimize the risk of TB transmission.

In a preliminary study of six Drug Swallowing Supervisors (DSS) in Cimanggis Primary Healthcare Center, more than two stated that they faced constraints in meeting emotional, information, and instrumental needs. In contrast, they all faced conditions in meeting the needs for rewards while caring for pulmonary TB patients. Families need to seek information so they can treat TB clients and make treatment successful. TB patients need: 1) information support, which includes information on knowledge related to TB, and the advice that needs to be conveyed to TB clients when they are experiencing stress due to the side effects of drugs or other issues; 2) appraisal support, including involving TB clients in decision making, accepting feedback and giving positive rewards; 3) emotional support, including a sense of empathy, attention, and a caring attitude towards TB clients; 4) instrumental support, in the form of direct help, either financially for medical or transportation costs, or help in providing healthy nutrition (Biswas, 2010).

Emotional needs had the highest percentage (96.49% of families) (Rachmawati et al., 2015). The treatment of pulmonary TB takes 6–12 months and makes TB clients unwilling to take medicine or continue the treatment because of long-term treatment duration. Therefore, the risk of preventing the treatment non-adherence relatively high and becomes one of the problems faced by the family in motivating clients. The actual problem happens if it will lead to family despair in caring for TB clients. This study is in line with a study conducted by Hannan and Hidayat (2013), who state that a good family takes the lead in making treatment successful and has a high awareness of the care for TB clients.

Rezal et al. (2019) state that families who understand emotional support will fulfill patients' needs, so there is the potential for successful treatment of TB clients and recovery. Furthermore, Hayati et al. (2012) argue that with complete information about the treatment of pulmonary TB, families can undertake the healthcare functions for pulmonary TB clients who are undergoing treatment. Pulmonary TB clients need medical therapy and positive attention and feedback from the family (Sukumani et al., 2012).

The support and motivation from the family have influenced the success of TB treatment. The family always reminds the patient to take their medicine regularly and, in general, take care of them. Support needs are provided to patients when they comply with the treatment and have confidence in their recovery (Kartikasari & Handayati, 2012). This study describes the healthcare needs of families in caring for patients with pulmonary Tuberculosis.

Methods

The study is a cross-sectional study with convenience sampling. The samples were 83 families or DSS who collected medicine from the primary healthcare center in Depok City. The researcher's assistant conducted the data collection following the anti-TB drug collection schedule in each primary healthcare center. The respondents were given research information and asked for informed consent before completing a questionnaire. The inclusion criteria included families who care for TB patients who have positive sputum smear results and have clinical symptoms; as a drug swallowing supervisor undergoing six-month treatment; DSS aged 18–59; was conscious and *compos mentis*; and were cooperative.

On the other hand, the exclusion criteria were families with cognitive or mental disorders or illiterate. The research modified the family support for pulmonary TB questionnaire developed by Solikhah and Fitriyani (2018). The questionnaire consisted of family characteristics and fa-

mily needs, had an acceptable validity value of 0.364–0.738, with a reliability value of 0.826. The instruments have tested on 30 families that had the same criteria in other areas. Data analysis was the 95% significance level ($\alpha = 0.05$), and the data analyzed with univariate analysis using computer software (SPSS version 25).

Results

Table 1 shows the characteristics of the families caring for pulmonary TB patients, including age, gender, educational background, type of work, monthly income, and length of care for the patients. The table shows that most of the DSS were 18–40 years old (adults) (60.2%); female (60.2%); had completed education equal to high school (51.8%); housewives (43.4%); as many as 86.7% had income below the regional minimum wage (IDR3,297,489 equal to USD 226.95), and just over half had treated the patients for 3–6 months (advanced stage) (55.4%). Table 2 describes the needs of the family as caregivers of TB patients. Based on research result in Table 2, it explains that the families who are caring TB patients had healthcare needs for emotional support (mean 33.72, SD 4.16); information support (mean 33.28, SD 4.09); instrumental support (mean 32.4, SD 3.73) and appraisal support (mean 28.01, SD 5.93).

As seen in Table 3 about healthcare needs of families based on emotional, informational, instrumental, and appraisal support, caregivers in the highest aspect of emotional support are how to complete TB treatment with a score of 140, with the lowest figure relating to how to relieve stress, with 125. In the information support aspect, the highest need for care is how to treat TB patients, with a score of 138, and the lowest is how to fulfill health needs, with a score of 122. About instrumental support, the highest care need is financial assistance for transportation, with a score of 112, and the lowest is help in providing food, with a score of 89. The requirements in assessment support are to assess client behavior (score of 133), and the lowest is how to give authority, with a score of 118.

Discussion

Most of the DSS were adults. The findings regarding age characteristics in this study are similar to those of Firdaus and Widodo (2012), whose participants were 15–50 years old. Early adult age is a productive age group with a higher level of mobility and social interaction. Families who become DSS must have high mobility because they have to accompany TB clients every week or month to take TB drugs or undergo supporting investigations. The DSS must also interact with health workers, the community, and other DSSs while accompanying TB

clients in the treatment process. Early adults are responsible for completing their family tasks and caring for TB clients (Herawati et al., 2015). The families who participated in this study were primarily female. This study is similar to the study of Lailatul et al. (2015) about family efforts to prevent TB transmission among family members, in which most participants were female. This study also describes that women pay more attention to health and are willing to use healthcare facilities. Therefore, they will be more concerned about the health problems experienced by TB clients and convince them to visit healthcare centers (Panjaitan, 2012).

Table 1. Family characteristics (n = 83)

Variable	Category	n	%
Age	18–40 years old (early adult)	50	60.2
	41–60 years old (middle adult)	33	39.8
Gender	Male	33	39.8
	Female	50	60.2
Education	Not graduated from elementary school	2	2.4
	Elementary school	11	13.3
	Junior high school	21	25.3
	Senior high school	43	51.8
	University	6	7.2
Occupation	Private employee	13	15.7
	Housewife	36	43.4
	Laborer	13	15.7
	Student	2	2.4
	Entrepreneur	6	7.2
	Other	13	4.8
Income	< IDR3,297,489	72	86.7
	≥ IDR3,297,489 (Minimum Wages Regional Depok City)	11	13.3
Time caring for pulmonary TB patients	0–2 months	37	44.6
	3–6 months	46	55.4

Table 2. Healthcare needs of families caring for pulmonary TB patients (n = 83)

Variable	Mean	SD	Min–Max
Emotional support	33.72	4.16	19–40
Informational support	33.28	4.09	16–40
Instrumental support	32.40	3.73	24–40
Appraisal support	28.01	5.93	10–40

Table 3. Healthcare Needs of Families Based on Emotional, Informational, Instrumental, and Appraisal Support

Type of Healthcare Need	Subvariables	Score	n	%
Emotional support	How to encourage taking treatment until complete	140	44	44.6
	How to encourage patients feeling bored with their treatment	134	39	47.0
	How to give motivation	136	45	54.2
	How to reduce anxiety	130	48	57.8
	How to relieve stress	125	47	56.6
	How to communicate well	134	47	56.6
	How to care with affection	138	44	53.0
	How to give a sense of security	136	45	54.2
	How to give a sense of comfort	134	48	57.8
	How to give attention	133	46	55.4
Informational support	How to prevent TB transmission	123	51	61.4
	How to treat TB	138	45	54.2
	Video related to taking medicine	133	46	55.4
	Information about treatment benefits	131	44	53
	Information about side-effects of treatment	123	51	61.4
	How to monitor treatment	129	44	53
	How to meet health needs	122	53	63.9
	Information about healthy diets	134	41	49.4
	Information about the need for adequate rest	131	39	47
	How to prevent bad habits	133	42	50.6
Instrumental support	Financial assistance for transportation	112	51	61.4
	Financial assistance to pay for drugs	111	50	60.2
	Financial assistance for daily living costs	104	53	63.9
	Financial assistance for sputum checking	110	57	68.7
	Financial assistance for x-ray examinations	114	49	59
	Financial assistance for other needs	104	41	49.4
	Help in taking medicine	96	49	59
	Help in providing food	89	42	50.6
	Help in supervising the taking of medicine	93	50	60.2
	Help caring for patients	91	50	60.2
Appraisal support	How to reduce negative self-assessment of patients	126	49	59
	How to reduce negative public stigma	124	44	53
	How to set time for discussion	126	44	53
	How to arrange a time to travel	125	42	50.6
	How to involve patients in making decisions	126	43	51
	How to assess patient behavior	133	47	56
	How to give a reward when a patient is compliant with taking medicine	125	40	48
	How to give praise when the patient maintains their health	131	34	41
	How to involve patients in family events	120	34	41
	How to give authority	118	36	43.4

Most of DSS had graduated from senior high school. Data from Statistics Indonesia (2016) show that most of the population of Depok City had at least a high school education or equivalent. The level of education affects the suc-

cess of treatment for TB clients. Families who understand TB will be more concerned about the patients' health problems, so they will be willing to act as DSS (Panjaitan, 2012). Half of the DSS were housewives; the 2013 Basic Health

Research report shows that homemakers dominated families who cared for TB clients. In this study, DSS felt more flexible as housewives, had more time to care for the pulmonary TB clients (Ministry of Health Republic of Indonesia, 2013).

Moreover, they can adjust their daily activities according to their needs, which is different from workers who have to follow a predetermined working time. The income of almost all the families (86.7%) was below Depok City's regional minimum wage (IDR 3,297,489). Arikunto and Jabar (2009) state that economic factors influence the causes of infectious diseases. Pulmonary TB is a contagious infectious disease related to poverty factors. Based on WHO (2016) report data, nearly 90% of pulmonary TB sufferers globally have low socio-economic conditions. Poverty affects people's purchasing power for basic needs, so they unmeet the nutritional intake necessary (Panjaitan, 2012).

Most families had been treating the patients at the advanced stage for 3–6 months. The study results show that some families who were given treatment at the initial stage (0–2 months) refused to participate as they were busy and embarrassed. Those who had been treating patients for 3–6 months said they were compliant with treatment and would soon be completed. However, they felt that they needed to obtain further information to prevent relapse. Half of the families in the research had little interest in meeting the emotional needs of the patients.

Contrary to a study by Rachmawati et al. (2015) related to the psychosocial needs of families with pulmonary TB sufferers, emotional needs had the highest percentage, 96.49%. Emotional support is given in the form of love, empathy, respect, listening, attention, caring, and positive feelings. This support can increase self-confidence and reduce the stress levels of patients during the treatment period. Adaptive coping will be formed with emotional support, thus helping the patients deal with their health problems (Kaakinen et al., 2010). Based on the stu-

dy results, families need interventions to fulfill the emotional needs of the patients, such as by giving the motivation to complete the treatment, feeling empathy, being good listeners, giving positive feelings, improving coping, and motivating abilities.

The families needed to fulfill information needs. In line with Hayati et al.'s (2012) research, the provision of complete information about the treatment of pulmonary TB can affect the healthcare function and optimize the treatment of family members suffering from pulmonary TB. Hendesa et al. (2018) state that family knowledge about pulmonary TB becomes a fundamental skill to give informational support for TB patients. Informational support could be advice, suggestions, direction, and constructive instructions to improve the health status of the patients (Biswas, 2010). Moreover, this support suppresses 'patients' stressors because the information provided can generate positive suggestions. Based on the results of this study, families have sufficient knowledge about pulmonary TB because health professionals provide health education at the time of anti-TB drug retrieval schedules and examination of TB patients. Nevertheless, families still need information about treating pulmonary TB, especially how to manage drugs' side effects.

Instrumental support is provided in financial help, food and drink provision, energy, time, and the provision of a comfortable environment (Biswas, 2010). Although almost all the families have incomes below the Depok City minimum regional wage (IDR 3,297,489), they had everyday needs for increasing instrumental support. The TB patients need these aspects during treatment because most of them stop working during this period, so they do not receive a fixed income every month. Based on the study results, families have standard financial terms because of the costs of TB treatment borne by national health insurance. Families only need to pay for transportation to healthcare facilities. Other prices include those of chest x-rays, which must pay independently. The families do not need

instrumental support because their residence is quite close to the healthcare facilities. The family residence area is also close to the village midwife's house and health cadres, making access easier.

Half of the families had a high need to fulfill the requirements for giving the award to TB patients to improve treatment adherence. Appraisal support gives positive feedback and rewards (Biswas, 2010) and this support motivates TB patients during treatment. Therefore, TB patients can fulfill their self-actualization needs in the community. The high family needs related to increasing appraisal support are due to the inability of families to provide feedback and appreciation for sufferers by demonstrating an attitude of encouragement or approval of ideas and giving praise when a patient takes their medication regularly. Pulmonary TB patients need medical therapy to recover and require positive attention and feedback from their families (Sukumani et al., 2012). Based on the study results, families need interventions to improve their ability to assess daily patient behavior in maintaining health.

Conclusion

Some families have a high interest in increasing appraisal support. The order of family needs to offer support is emotional, informational, appraisal, and instrumental support. The family needs to fulfill emotional support to motivate patients to follow their treatment; information support needs refer to treatment methods. Besides, instrumental support relates to providing financial help for chest x-ray examinations and appraisal support regarding assessing healthy behavior. Suggestions for further research include increasing research sites so that the research scope is broader than the recent study, identifying factors that influence family support provision for TB patients, and developing interventions that improve families ability to provide patient support.

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