

THE DYNAMICS OF FAMILY SUPPORT AND SOCIAL CHALLENGES IN THE MANAGEMENT OF PULMONARY TUBERCULOSIS PATIENTS: A CASE STUDY IN BANDUNG CITY

Dinamika Dukungan Keluarga dan Tantangan Sosial dalam Penanganan Pasien Tuberkulosis Paru: Studi Kasus di Kota Bandung

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ABSTRAK

Tuberkulosis (TB) adalah infeksi paru yang membutuhkan pengobatan jangka panjang, dan ketidakpatuhan terhadap pengobatan dapat menyebabkan komplikasi dan kematian. Saat ini, banyak keluarga yang tidak memiliki pengetahuan dan keterampilan yang memadai untuk merawat pasien tuberkulosis di rumah, sehingga tidak memadai dukungan, penghentian pengobatan, komplikasi, kematian, dan penularan ke anggota keluarga. Penelitian ini bertujuan untuk mengkaji dinamika dukungan keluarga dan tantangan sosial yang dihadapi keluarga dalam merawat pasien TBC untuk meningkatkan kepatuhan pengobatan pasien. Studi ini menggunakan pendekatan penelitian lapangan untuk mengamati fenomena secara luas dan mendalam, seperti yang terjadi dalam pengaturan sosial. Responden untuk penelitian ini terdiri dari 37 kasus (33%). Wawancara yang digunakan dalam penelitian ini adalah wawancara mendalam. Narasumber adalah 30 keluarga pasien tuberkulosis paru di wilayah Desa Dunguscariang dan observasi terstruktur berdasarkan pedoman wawancara yang telah disusun, sebagaimana terjadi dan berkembang dalam konteks sosial. Hasil penelitian menunjukkan peningkatan kepatuhan pasien terhadap pengobatan tuberkulosis, menunjukkan bahwa dukungan keluarga efektif dalam meningkatkan kepatuhan pengobatan. Beberapa tantangan yang dihadapi oleh keluarga dan tenaga kesehatan dalam memberikan dukungan keluarga bagi pasien tuberkulosis berhasil diatasi.

Kata Kunci: dinamika keluarga, dukungan, pasien, tantangan sosial, tuberkulosis paru

ABSTRACT

Tuberculosis (TB) is a pulmonary infection that requires long-term treatment, and non-adherence to medication can lead to complications and death. Currently, many families lack sufficient knowledge and skills to care for tuberculosis patients at home, resulting in inadequate support, discontinuation of treatment, complications, death, and transmission to family members. This study aimed to examine the dynamics of family support and the social challenges faced by families in caring for tuberculosis patients to improve patient treatment adherence. The study used a field research approach to observe the phenomenon broadly and deeply, as it occurs in social settings. The respondents for this research comprised 37 cases (33%). The interview used in this research was an in-depth interview. The interviewees were 30 families of pulmonary tuberculosis patients in the Dunguscariang Village area and structured observations based on the interview guidelines that had been prepared, as they occur and develop within social contexts. The results showed an increase in patient adherence to tuberculosis treatment, indicating that family support is effective in improving treatment adherence. Several challenges faced by families and health workers in providing family support for tuberculosis patients were successfully addressed.

Keywords: *family dynamics, patients, pulmonary tuberculosis, social challenges, support*

INTRODUCTION

Education serves as the foundation of human life. Its primary goal is to act as a medium for developing human potential and fostering intelligence to prepare individuals for future life challenges [1]. Adult education can be lifelong self-directed and independent according to their learning orientation[2]. Improving the educational system is a manifestation of human resource development, which will eventually bear the responsibility of a nation [3]. Improving the quality of education through more effective and efficient delivery mechanisms is essential (Courtenay et al., 1994). Empowering families as devout and independent individuals, and nurturing them to become democratic and responsible citizens is crucial in managing pulmonary tuberculosis[4]. Through family support, tuberculosis care becomes an effort or process aimed at raising awareness, willingness, and ability to maintain and enhance health, with indicators such as patient compliance with tuberculosis treatment, continuity of medication, recovery without complications, and the avoidance of death[5].

Effective tuberculosis management requires the independence of tuberculosis patients. This independence is achieved through family empowerment, where the family acts as the Directly Observed Treatment, Short-course (DOTS) supporter, responsible for ensuring that the patient takes their medication regularly until completion, motivating them to adhere to the treatment, reminding them to undergo repeat sputum examinations, and educating them about the signs, symptoms, and prevention of pulmonary tuberculosis [6]. Pierre Bourdieu describes the cultural framework for families and neighborhoods that influence norms, values, ideas, frameworks, or environments described as habitus[7]. Independence refers to a condition experienced by society, marked by the ability to think, decide, and act appropriately in solving problems using one's capabilities[8]. Independence implies the autonomous ability to make decisions, act based on those decisions, and choose a course of action without interference from others. Chronic diseases, such as tuberculosis, which may persist for six months or longer, can undermine this independence [9]. Tuberculosis, a contagious lung disease, remains one of the deadliest infectious diseases globally due to its high mortality rate [10]. Improper treatment of tuberculosis can lead to drug resistance, complicating the healing process [11]. One cause of this is failure to adhere to the prescribed treatment regimen [12]. Multi-drug resistant tuberculosis (MDR-TB) is often the result of negligence or non-adherence to the treatment guidelines [13]. The number of drug-resistant tuberculosis cases continues to rise each year [14], leading to complications such as hemoptysis, pneumothorax, pleural effusion, emphysema, lung collapse, and spread to other organs such as meningitis, lymphadenitis (lymph nodes), and spondylitis (spinal inflammation) [15],[16]. Pulmonary tuberculosis is categorized as a contagious disease that has become a global health issue [17].

The World Health Organization (WHO) reported an estimated 10.6 million tuberculosis cases globally in 2021, an increase of approximately 600,000 cases from 2020, which saw 10 million cases. Of these 10.6 million cases, 6.4 million (60.3%) were reported and treated, while 4.2 million (39.7%) were undiagnosed or unreported [16]. Research shows that only 59% of DOTS supporters fulfill their role, while the remaining 41% do not[18]. These findings offer valuable feedback for healthcare workers to plan and implement health promotion or education programs for tuberculosis patients and their families [18]. Indonesia ranks second in the world for tuberculosis prevalence, following India. In 2020, Indonesia ranked third in terms of the highest tuberculosis burden, and the situation in 2021 was no better. It is estimated that Indonesia had 969,000 tuberculosis cases in 2020, with one person infected every 33 seconds [19]. Indonesia ranks second in the world for tuberculosis prevalence, following India. In 2020,

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cases in 2020, with one person infected every 33 seconds [20]. The Ministry of Health detected 717,941 tuberculosis cases in Indonesia in 2022, a 61.98% increase from 443,235 cases in 2021. The total number of cases was 969,000, with 93,000 deaths per year, equivalent to 11 deaths per hour. The success rate of drug-sensitive tuberculosis treatment in Indonesia in 2022 was 85%, while the treatment success rate for drug-resistant tuberculosis was 55% [21].

The achievement of family independence in lung health can be realized through a learning process. Families that engage in a well-organized learning process will gradually gain strength or abilities that are beneficial for independent decision - making. Empowerment, both at the individual and family levels, is marked by the attainment of independence, which can be achieved through empowerment processes [22].

Family empowerment activities in tuberculosis management focus on three aspects: enabling, which involves creating an environment that allows family potential to flourish; empowering, which strengthens family potential through concrete steps such as providing various inputs and opening up opportunities that enable the family to become more empowered; and protecting, which involves safeguarding and advocating for the family's interests to achieve independence in tuberculosis management [23].

The success rate of pulmonary tuberculosis treatment in West Java was 83.4%[24], meaning that 16.6% of cases were not successfully treated for various reasons. This small percentage could lead to increased transmission to others. Family and patient support for tuberculosis management has thus far relied on the DOTS strategy, where a trusted individual is appointed to monitor the patient's medication adherence, conduct follow-up sputum examinations, prevent treatment discontinuation, and quickly identify any side effects of anti-tuberculosis drugs [25]. Appropriate and suitable methods for families and patients need to be considered [26]. The family is a primary target for empowerment strategies, as they must have the knowledge, willingness, and ability to maintain and improve the health of their members [27]. Family members of tuberculosis patients are appointed as DOTS supporters and provided with education about the causes of tuberculosis, its treatment, side effects, and the importance of medication adherence [28]. This study aimed to examine the dynamics of family support and social challenges faced by families in caring for TB patients to improve patient treatment compliance

METHODS

This research utilized a qualitative method[29], adopting a field research approach, which examines phenomena more broadly and deeply. The research process was conducted with attention to on-the-ground conditions, specifically focusing on pulmonary tuberculosis patients in the Dunguscariang Subdistrict, which falls under the care of the Garuda Health Center in Bandung. Bandung City was chosen as the case study location for managing pulmonary TB due to its socioeconomic complexity for accuracy, high population density, and an epidemiological profile that indicates a significant prevalence of TB. At this stage the researcher begins to collect data and information from participants using the data collection guidelines that have been prepared. The interview used in this research is an in-depth interview, meaning that the researcher has prepared a list of interview questions in advance. In conducting interviews, researchers have prepared a recorder or other interview aids. The interviewees were 30 families of pulmonary tuberculosis patients in the Dunguscariang Village area and structured observations based on the interview guidelines that had been prepared, as they occur and develop within social contexts. The research process was conducted with attention to on-the-ground conditions, specifically focusing on pulmonary tuberculosis patients in

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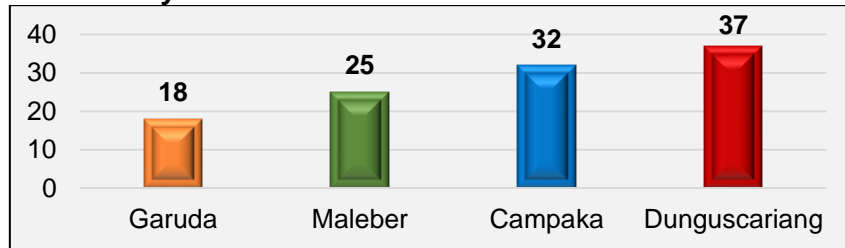
This study analyzed the family support process in managing tuberculosis patients. The respondents for this research comprised 37 cases (33%). The data collection involved 112 families of pulmonary tuberculosis patients through questionnaires. Additionally, a preliminary study was conducted in mid-October 2023 through questionnaires distributed to 30 families of tuberculosis patients residing in the Dunguscariang Subdistrict, under the supervision of the Garuda Health Center. This research has obtained ethical approval issued by the Research Ethics Committee of the Bandung Ministry of Health Polytechnic with No: 09/KEPK/EC/X/2023.

RESULTS

An Overview of the Empirical Conditions of Family Support in the Management of Pulmonary Tuberculosis Patients.

Identification was conducted over three weeks, from October 30 to November 18, 2023, through a review of tuberculosis case data in the area served by the Garuda Health Center, as well as interviews with the responsible personnel for the tuberculosis program regarding the family support process for tuberculosis patients, as follows:

Number of Pulmonary Tuberculosis Cases



Source: Garuda Health Center

Figure 1. Number of Pulmonary Tuberculosis Cases in the Garuda Health Center Area (as of August 2023)

Figure 1 shows that the number of pulmonary tuberculosis patients in the Dunguscariang Subdistrict is the highest within the area served by the Garuda Health Center, with a total of 37 cases (33.04%). The data collection involved 112 families of pulmonary tuberculosis patients through questionnaires, as follow:

Variable	Dunguscariang		Campaka		Maleber		Garuda		Total
	n	%	n	%	n	%	n	%	
Age									
Adolescent	6	16,2	5	15,6	3	12,0	3	16,7	17
Adult	20	54,1	15	46,9	12	48,0	8	44,4	55
Pre-Elderly	6	16,2	7	21,9	6	24,0	5	27,8	24
Elderly	5	13,5	5	15,6	4	16,0	2	11,1	16
Total	37	100	32	100	25	100	18	100	112
Gender									
Male	19	51,6	20	62,5	15	60	11	61	65
Female	18	48,4	12	37,5	10	40	7	39	47
Total	37	100	32	100	25	100	18	100	112
Education									
Elementary	0	0	1	3,1	0	0	1	5,6	2
Junior Highschool	7	18,9	7	21,9	6	24	4	22,2	24
Senior Highschool	24	64,9	20	62,5	15	60	8	44,4	67
University	6	16,2	4	12,5	4	16	5	27,8	19
Total	37	100	32	100	25	100	18	100	112

Table 1 shows that the respondents, namely the families of pulmonary tuberculosis patients in the area served by the Garuda Health Center, are predominantly adults, with a total of 55 individuals (49.1%) based on the age of respondents obtained in the field. Thus, the researcher has a clear picture of the patients who require support in the field. The families of pulmonary tuberculosis patients in the area served by the Garuda Health Center, are predominantly male, with a total of 65 individuals (58%), and the highest education level being high school graduates, totaling 67 individuals (59.8%).

Overview of the Initial Conditions of Family Support Implementation for Pulmonary Tuberculosis.

The initial conditions of family support implementation for pulmonary tuberculosis patients in the area served by the Garuda Health Center, Bandung City, are presented in Table 4 below.

Table 2. Overview of the Initial Conditions of Family Support Implementation for Pulmonary Tuberculosis Patients in the Garuda Health Center Area

No	Question	Answer			
		Yes		No	
		n	%	n	%
1	Family support services for pulmonary tuberculosis patients are known to families and patients.	21	18.75	91	81.25
2	Benefits of Family Support Services for Pulmonary Tuberculosis Patients	61	54.46	51	45.54
3	Family Readiness to Provide Support to Pulmonary Tuberculosis Patients	30	26.79	82	73.21
4	Pulmonary Tuberculosis Patients Receive Support from Their Families	49	43.75	63	56.25
5	Families Consider It Necessary to Have Family Support from Healthcare Workers	82	73.21	30	26.79

Source: Primary data from the researcher

Table 2 shows that in the area served by the Garuda Health Center, only a small percentage of families are aware of the family support services available for pulmonary tuberculosis patients (18.75%). However, a majority (54.46%) of the families of tuberculosis patients understand the benefits of family support in managing tuberculosis, and 71.43% feel that family support from health workers is necessary in the management of tuberculosis. Additionally, 56.25% of pulmonary tuberculosis patients have not received adequate family support.

The data above is consistent with the results from interviews with personnel responsible for the tuberculosis service program (PP1/Ners F):

"... during 2023, the number of pulmonary tuberculosis patients, both those who came directly to the health center and to the hospital, totaled 112, with the highest number being 37 patients (33%) from Dunguscariang Subdistrict. Patients who came for treatment were provided with education related to managing tuberculosis at home.

The families of the patients were given assistance that resulted in family independence in caring for tuberculosis patients, reduced morbidity and mortality rates due to tuberculosis disease, and improved health status of the community in Dunguscariang Village.

"... in general, families of tuberculosis patients are unaware of the support services available. Initially, families view pulmonary tuberculosis like any other disease that does not require special or prolonged treatment. Even though education is provided at health service facilities after patients are diagnosed with pulmonary tuberculosis, they still do not understand the support services, leaving families unprepared to receive assistance, with very limited time available.

“... due to the families' lack of readiness for support, they have not received adequate assistance. It seems that families also fear that if a health worker visits their home, other families will find out.”

Research by Sitepu indicates that 44.4% of patients do not adhere to their anti-tuberculosis medication (OAT) [30]. Additional information from PP2/Ners D, who is also a service provider for tuberculosis patients at the health center and oversees the area, states:

“... during 2023, the number of pulmonary tuberculosis patients in this area was 32 cases (28.56%), including patients diagnosed with tuberculosis at the hospital. All patients were provided with explanations or education regarding how families should care for and manage tuberculosis at home. “... families of pulmonary tuberculosis patients are unaware that managing pulmonary tuberculosis is a lengthy process, making support services necessary. Even with brief educational sessions, when patients are diagnosed with pulmonary tuberculosis, families generally do not feel prepared to provide support to the patients. “... families have not received adequate support; however, many families feel that assistance from health workers or others is essential.”

Assistance provided to the family as well as patients with pulmonary tuberculosis is measured by the patient's compliance in treatment, discipline in conducting re-examinations until they are declared cured. Family interaction is necessary because it will have a positive impact and result on health behavior.

In developing a conducive family climate in family interaction, it is seen from the arrangement of the physical environment including the arrangement of the room where the family lives must be maintained, clean, and the family members look neat and healthy, the arrangement of the family social environment where all family members have rules and discipline that must be obeyed together and the arrangement of family personnel where each family member is responsible for maintaining conduciveness.

DISCUSSION

The results showed that in the area served by the Garuda Health Center, only a small number of families were aware of the family support services available for pulmonary tuberculosis patients. In addition, pulmonary tuberculosis patients have not received adequate family support. However, the majority of families of TB patients already understand the benefits of family support in TB treatment, and feel that family support from health workers is needed in TB treatment.

In the management of pulmonary tuberculosis (TB), families play a crucial role. Families not only provide emotional support but also help ensure patient adherence to treatment, maintain a healthy diet, and provide financial and social support. However, the importance of family support is often overlooked, especially among communities that lack understanding of TB care dynamics or face economic difficulties. Research by Anaam, et al. showed that patients who did not receive support were 4.1 times more likely to be non-compliant in TB treatment[31]. Support as a basis for community education emphasizes that participants can engage in independent learning through a supportive process where they control the process and identify their own learning needs [32]. This is supported by some that show that patients who have family members who often supervise their treatment, family members who provide spiritual encouragement, good relationships with doctors, and patients who have good knowledge about TB have good medication adherence[33],[34].

The study of Woimo, et al. showed a relatively high level of non-compliance among new patients with pulmonary tuberculosis. Barriers to anti-TB treatment adherence were knowledge, distance, non-decentralization of DOT services, health information at each

visit and the cost of treatment[30]. 49.5% of patients who had to pay for treatment other than anti-TB were likely to not comply with aOR treatment 4.7; 95% CI 1.7-13.4), absence of exposure to TB-related information per visit to a healthcare facility was significantly at higher risk to make patients non-compliant with treatment, TB patients with low knowledge were 4.6 times more likely to be non-compliant. In addition, patients who have to travel >10 km to a healthcare facility are 5.7 times more likely to be non-compliant in TB treatment[35].

During treatment, patients must be disciplined in taking their medication and routinely follow up with healthcare services until they are considered completely cured; otherwise, the TB treatment process becomes incomplete, and the TB bacteria may become resistant [36]. Many families do not have adequate knowledge about TB, its transmission, and the importance of treatment adherence. In many cases, TB patients are unable to work during treatment due to their weakened physical condition or fear of transmitting the disease, which adds to the family's economic burden and may lead to treatment discontinuation. Some patients feel isolated and lack the critical support needed during treatment, and both tuberculosis patients and their families often face discrimination [37]. Continuous support for TB patients, which requires ongoing attention, can become a psychological burden for families. Family support in managing pulmonary TB is vital to ensuring patient adherence to treatment, providing emotional support, and mitigating the negative impact of social stigma. Patients may experience boredom and face side effects from the medication, which can lead them to decide to stop taking their medication[38]. However, many gaps still need to be addressed, such as a lack of family education about TB, economic limitations, and persistent stigma. Therefore, it is crucial for the government, healthcare workers, and community organizations to enhance educational programs and support for families of TB patients to ensure a more effective and holistic care process. By strengthening the role of families in support, it is hoped that the success rate of TB treatment can improve, and the social challenges faced by patients and their families can be addressed more comprehensively.

Family support is a process or effort to cultivate awareness and willingness within families to maintain and improve their health status. This support helps to empower individuals, families, and communities towards independence [39]. Increasing knowledge, awareness, and skills regarding health maintenance and enhancement is the first step towards health empowerment, which subsequently fosters the desire to take health-promoting actions, enabling families to engage in healthy behaviors. The capabilities mentioned include cognitive, conative, psychomotor, and affective skills, as well as other resources within the family [40]. The family is a social environment formed by a group of people living together, interacting in shaping mindsets and culture, and mediating children's relationships with their surroundings. Furthermore, it is stated that a complete and functional family can enhance the mental health and emotional stability of its members [41].

Support represents a form of lifelong education service for the community, which encompasses groups, families, and individuals [42]. Support involves activities carried out by individuals or groups that provide teaching, guidance, or training, enabling those receiving support to gain control over themselves and their problems. Both families and patients must shift their paradigm towards a healthy perspective, focusing health efforts not only on recovery (curative) but also emphasizing prevention (preventive) and promotion (promotive).

This paradigm shift will change behaviors in achieving health, moving from dependency on government health services to individuals taking responsibility for their own health while not neglecting the role of health workers. Most families recognize the benefits of family support services for pulmonary tuberculosis patients, given that the recovery process from tuberculosis takes a long time. The presence of health workers is

crucial in preparing families to effectively support tuberculosis patients, ensuring that families possess the knowledge and skills to manage tuberculosis at home.

The advantages of the implementation of the Enempro family assistance model in 37 families of pulmonary tuberculosis patients run smoothly, this is due to good support and motivation from families and pulmonary tuberculosis patients as well as from the Puskesmas, Kelurahan and all cadres. All families were identified as having the potential and ability to provide assistance so that pulmonary tuberculosis patients adhere and recover, all families were involved in understanding their needs, namely the ability to provide assistance to pulmonary tuberculosis patients and also the patient's need to adhere to the treatment of pulmonary tuberculosis and recover in the interaction, families and assistants communicate effectively and therapeutically so that no family refuses the implementation of assistance activities.

Weaknesses in this study When families and patients begin to lose motivation to recover because the treatment takes a long time and if missed in administering drugs, it determines the failure of pulmonary tuberculosis therapy, namely patient adherence to treatment. Non-adherence to treatment can lead to relapse and/or failure. The impact can lead to germ resistance and continuous transmission of the disease from person to person. The consequences of long-term treatment non-adherence on a regular basis (every day) can worsen health conditions and increase treatment costs. The limitations of this study on treatment non-adherence in pulmonary tuberculosis patients where the target is still limited, it is hoped that the results of the study can be further expanded and can be implemented in other areas.

CONCLUSION

In general, families of pulmonary tuberculosis patients are aware of the family support services available in the area served by the Garuda Health Center; however, only a small percentage of these families know about the services. Most families of tuberculosis patients believe in the benefits of such support and feel the need for assistance from healthcare workers.

On the other hand, families play a crucial role in supporting the health of TB patients, providing emotional, physical, and financial support. However, gaps in knowledge, resources, and understanding of TB often hinder their ability to provide optimal support. Therefore, it is essential for TB management programs to focus not only on the patients but also to involve families in educational and intervention efforts so that they can become effective partners in the healing process for TB patients.

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