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The Correlation Between Knowledge and Family Support for Self-Care of Leprosy Patients

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Abstract

Leprosy is a contagious infectious disease that is still a health problem in Indonesia. Good knowledge about leprosy will greatly help families in dealing with leprosy problem. In besides to knowledge, family support is also needed for people with leprosy. The family will provide a sense of security and motivation. The purpose of this study is to knowing the relationship between knowledge and family support about self-care of people with leprosy. This research is descriptive observational with a cross sectional approach. The research was conducted at Kalumata Health Center of Ternate City in Jan-Feb 2024. The sample is 51 patients using total sampling technique. Then, analyzed using the Fisher's Exact Test. Data collection through interviews using a questionnaire. 51 samples, the majority were 46-55 years old (51,0%), male gender (74,5%), primary school (5,0%), self-employment (49,0%), knowledge (62,7), family support (52,9%), and self-care (54,0%). Based on the results of bivariate, a p-value of 0,000 ($p<0,05$) was obtained on knowledge and family support and most of the respondents know leprosy as an infectious disease and try to cover up the disease because they feel ashamed, insecure and afraid of being ostracized from the family and community (self-stigma).

INTRODUCTION

Leprosy is a chronic infectious disease caused by the obligate intracellular bacterium Mycobacterium Leprae. The bacteria invade the peripheral nerves of the skin and mucosa of the upper respiratory tract, then spread to other organs except the central nervous system. The exact route of spread of leprosy is unknown but some studies suggest that leprosy transmission can occur through prolonged and close direct contact between the skin of a patient and another person. Leprosy is also transmitted by inhalation through the droplets of lepers (Menaldi, Bramono and Indriatmi, 2018).

Data from the World Health Organization (WHO) states that the global prevalence of leprosy is 165,459 registered cases and 174,087 new cases, of which 67,657 (39%) are in women. Globally, 9,554 cases of grade 2 disability were detected, of which 278 (3%) were in children. Indonesia is still in the process of leprosy elimination by 2021.

The prevalence in Indonesia was reported at 12,230 cases with a discovery rate of 10,976 new cases. North Maluku recorded around 696 new cases, with 574 cases classified as multibacillary and around 122 cases as paucibacillary with a Case Detection Rate (CDR) of 56.46%. Ternate City itself noted that in 2019 there were 103 new cases and 13 of them were children, in 2020 there were 93 new cases and 22 of them were children then, in 2021 there were 92 new cases and 6 of them occurred in children.

Furthermore, in 2022 with 78 new cases and 8 of them occurred in children, and the latest data in 2023 for the January-October period there were 95 cases and 16 of them were children (Dinas Kesehatan Kota Ternate, 2023; Kemenkes RI, 2018; Kementrian Kesehatan RI, 2022).

Steps that can be taken to reduce the incidence of leprosy are to increase knowledge about leprosy and family support in self-care is very important to prevent the severity of leprosy. Leprosy sufferers must understand that leprosy treatment is not enough with Multi Drug Therapy (MDT), because MDT only kills the leprosy germs, but the defects of the eyes, hands, and feet that have occurred will remain for life (Dwihartanti et al., 2015; Menaldi et al., 2018). Self-care for people with leprosy includes regular check-ups, wearing footwear to prevent wounds, treating wounds, and other self-care (Nur Laili, 2017). Good knowledge about leprosy will help families in dealing with leprosy problems. Families with good knowledge are expected to make efforts to treat leprosy appropriately. Awareness will begin to arise in the family to make healing efforts if the family has good knowledge (Nur et al., 2019). Family support is fundamental for people with leprosy, as it provides a sense of security and motivation for the lives of people with leprosy (Sholehuddin et al., 2019; Nur et al., 2019).

Research conducted at Kalumata Health Center between 2018-2021 described the characteristics of leprosy patients in the area but did not explore the factors influencing self-care practices. The high number of cases in Ternate City, particularly within the Kalumata Health Center working area, underscores the urgency of this research. Understanding the specific knowledge gaps and family support dynamics in this community is essential for designing effective interventions to improve self-care and prevent disability. The novelty of this study lies in its focus on the correlation between both knowledge and family support with self-care in this specific, underserved population.

Based on the explanation above, researchers are interested in conducting research on the relationship between knowledge and family support regarding self-care of leprosy patients at the Kalumata Health Center in Ternate City. The selection of Kalumata Health Center as the research location was motivated by the distribution of the most leprosy cases in Ternate City which were in the Kalumata Health Center Working Area based on data from the Ternate City Health Office.

METHOD

This study was an observational analytic study using a cross-sectional approach. This study was conducted at the Kalumata Health Center working area in Ternate City and was conducted in January 2024. The target population in this study were all patients suffering from leprosy who sought treatment at the Kalumata Health Center working area in Ternate City. While the affordable population in this study were all patients suffering from leprosy who sought treatment at the Kalumata Health Center working area of Ternate City in 2019-2023 who met the inclusion and exclusion criteria. The method of data collection in this study was used secondary data taken from data on leprosy patients who have completed treatment at the Kalumata Health Center in Ternate City in 2019-2023, then collected primary data by using a questionnaire given to respondents based on the secondary data obtained. The collected data processed using SPSS. Data analysis used univariate and bivariate analysis.

Univariate analysis displayed in the form of a frequency distribution table of the variables studied. Meanwhile, bivariate analysis carried out using Fisher's Exact Test. The research conducted after obtaining research approval from the respondents based on the informed consent application, the interests and confidentiality of the respondents are prioritized and only write the initials of the respondents.

RESULTS AND DISCUSSION

Based on research of the relationship between knowledge and family support about self-care of leprosy patients that was conducted in January-February 2024, 51 respondents who met the inclusion and exclusion criteria were willing to be samples in the study.

Tabel 1 Characteristics of Leprosy Patients

Variable	Frequency	
	N	(%)
Age		
17-25 yo	2	3.9
26-35 yo	7	13.7
36-45 yo	2	3.9
46-55 yo	26	51.0
56-65 yo	8	15.7
>65 yo	6	11.8
Gender	38	74.5
Man	13	25.5
Woman		
Education	4	7.8
Uneducated	26	51.0
Elementary School	15	29.4
Junior High School	5	9.8
Senior High School	1	2.0
College Graduated		
Work	16	31.4
Not Working	0	0
PNS/TNI/Polri	25	49.0
Entrepreneur	0	0
Employees	10	19.6
Housewife		
Knowledge	4	7.8
Good	15	29.4
Enough	32	62.7
Poor	17	33.3
Family Support	7	13.7
Good	27	52.9
Enough		
Poor	6	11.8
Self-Care	17	33.3
Good	28	54.9
Enough		
Poor		
Total	**51**	**100**

Based on table 1, out of 51 samples of leprosy patients who had characteristics based on age 17-25 years, 2 samples (3.9%), age 26-35 years, 7 samples (13.7%), age 36-45 years, 2 samples (3.9%), age 46-55 years, 26 samples (51.0%), age 56-65 years, 8 samples (15.7%),

and age >65 years, 6 samples (11.8%). Furthermore, the characteristics of leprosy patients based on gender were found to be 38 samples (74.5%) male and 13 samples (25.5%) female. Then, the characteristics of leprosy patients based on their latest education were found to be 4 samples (7.8%) not in school, 26 samples (51.0%) in elementary school, 15 samples (29.4%) in junior high school, 5 samples (9.8%) in high school, and 1 sample (2.0%) in college. Characteristics of leprosy patients based on occupation: 16 samples (31.4%) were not working, 25 samples (49.0%) were self-employed, and 10 samples (19.6%) were housewives. For civil servants / soldiers / Polri and employees were not found in this study.

The distribution of knowledge variables in this study for the good category was 4 samples (7.8%), the sufficient category was 15 samples (29.4%), and the deficient category was 32 samples (62.7%). Furthermore, the distribution of family support variables in the good category was 17 samples (33.3%), the sufficient category was 7 samples (13.7%), and the deficient category was 27 samples (52.9%). Then, self-care variables with good categories were 6 samples (11.8%), sufficient categories were 17 samples (33.3%), and insufficient categories were 28 samples (54.9%).

Tabel 2 Relationship between Knowledge and self-care of Leprosy Patients

Knowledge	Self-Care			Total	p-value
	Good	Enough	Poor		
Good	1 (2.0%)	2 (3.9%)	1 (2.0%)	4 (7.8%)	
Enough	5 (9.8%)	8 (15.7%)	2 (3.9%)	15 (29.4%)	0,000
Poor	0 (0%)	7 (13.7%)	25 (49.0%)	32 (62.7%)	
Total	6 (11.8%)	17 (33.3%)	28 (54.9%)	51 (100%)	

Based on table 2 above, it was found that patients who had good knowledge about self-care in the good and less categories were 1 sample (2.0%) and patients who had good knowledge about self-care were 2 samples (3.9%). Patients with sufficient knowledge about self-care in the good category were 5 samples (9.8%), 8 samples (15.7%) in the fair category, and 2 samples (3.9%) in the poor category. Meanwhile, patients with less knowledge about self-care in the good category were not found in this study, 7 samples (13.7%) were found in the fair category, and 25 samples (49.0%) were in the poor category.

Based on bivariate analysis with Fisher's Exact Text, a p-value of 0.000 ($p<0.05$) was obtained, which means that H0 is rejected and H1 is accepted. This means that there is a significant relationship between knowledge and self-care of leprosy patients.

Tabel 3 Relationship between Family Support and Self-Care of Leprosy Patients

Family Support	Self-Care			Total	p-value
	Good	Enough	Poor		
Good	5 (9.8%)	10 (19.6%)	2 (3.9%)	17 (33.3%)	
Enough	1 (2.0%)	3 (5.9%)	3 (5.9%)	7 (13.7%)	0,000

Poor	0 (0%)	4 (7.8%)	23 (45.1%)	27 (52.9%)
Total	6 (11.8%)	17 (33.3%)	28 (54.9%)	51 (100%)

Based on table 3 above, it was found that patients who had good family support for self-care with good categories were 5 samples (9.8%), sufficient categories were 10 samples (19.6%), and deficient categories were 2 samples (3.9%). Furthermore, patients who had sufficient family support for self-care in the good category amounted to 1 sample (2.0%) while, patients who had family support for self-care in the sufficient and deficient categories amounted to 3 samples (5.9%) each. Then, patients who had less family support for self-care in the good category were not found in this study, 4 samples (7.8%) in the moderate category, and 23 samples (45.1%) in the deficient category.

Based on bivariate analysis with Fisher's Exact Text, the p-value of 0.000 ($p < 0.05$) was obtained, which means that H0 is rejected and H1 is accepted. This means that there is a significant relationship between family support and self-care of leprosy patients.

The results of this study are in line with the results of Koli et al. (2021), which found that the highest age group for leprosy was between 40–65 years old, with 43 samples (45.7%). This is also in line with research by Siswi & Rohayanih (2019), in which the highest sample of leprosy patients was found in the age group 46–60 years with a frequency of 23 samples (51.1%) (Dwihartanti et al., 2015).

Leprosy patients are more common in the adult age group compared to children. Although the disease can affect all age groups, from infants to the elderly, the prevalence is higher in patients who are young and in their productive years. This is because in the productive age phase, social interaction and daily activities tend to be higher compared to older age who are no longer productive (Menaldi et al., 2018).

Based on table 1, it can be seen that the incidence of leprosy occurred mostly in the male gender, as many as 38 samples (74.5%), this is in line with research conducted by Aisyah & Agusni (2018) which obtained 103 samples (14.4%) with the highest gender being male. In addition, another study conducted by Pranata et al. (2022) found a frequency of 97 samples (70.3%) with male gender, it can be concluded that men are more dominant in leprosy because they do more activities outside the home which makes them more vulnerable to infection (Nur Laili, 2017).

According to a report from the Indian Association of Leprologists (IAL), in various countries including Indonesia, there is a higher prevalence of leprosy in men than women with a ratio of 2:1. Environmental and social factors may play a role in the low incidence of leprosy in women (Kurniatillah et al., 2022). Men are more often involved in various activities and interactions in various places and do activities with other people almost every day because generally men are the backbone of the family (Wicaksono et al., 2015). The low incidence of leprosy in women may be due to environmental, biological and lifestyle factors. Differences in behavior and lifestyle also play a role, because women are more accustomed to taking care of themselves and maintaining their health, which is also why men tend to get infectious diseases more often than women (Sari & Darmada, 2018; Nur et al., 2019).

Based on the variable level of education in table 5.1, it shows that the incidence of leprosy is more prevalent at the elementary school education level with a frequency of 26

samples (51.0%). This is in line with research by Rokani et al. (2021) which found that the majority of all respondents had an elementary school educational background with 23 samples (85.2%). The results of this study are also in line with research conducted by Lutfi & Wahyudi (2019) which shows that most respondents have an elementary school education level as many as 15 samples (62.2%) (Sholehuddin et al., 2019).

Based on table 5.1 the employment variable found as many as 25 samples (49.0%) in the self-employed employment group. Research conducted by Refitlianti & Isfandiari (2018) showed that the highest percentage was found in the self-employed profession, reaching 17 samples (31.5%). This is also in line with research conducted by Fitri et al. (2023) which found the highest frequency based on occupation was self-employed with a frequency of 8 samples (29.6%) (Koli et al., 2021).

Work is an activity or activity of a person to earn income to fulfill daily needs. Length of employment reflects an individual's experience which will influence their development in their work. The majority of leprosy patients in the world are in developing countries including Indonesia, where the majority of the population earns income through farming. Therefore, the incidence of leprosy reactions is believed to be more common among manual laborers who perform manual labor and require a large expenditure of energy because this causes a decrease in stamina and can lead to physical stress in leprosy sufferers, which can then lead to changes in the immune response that can trigger the occurrence of ENL. Thus, occupation can be a tool to evaluate the possible risk of certain diseases (Curnelia, 2016; Siswi & Rohayanih, 2019).

Based on the results of table 2, the p-value is 0.000 ($p < 0.05$), meaning there is a significant relationship between knowledge and self-care of leprosy patients. This is in line with research conducted by Hidayah et al. (2019), where the p-value of 0.006 indicates that there is a relationship between the level of knowledge and self-care practices in individuals with leprosy in Semarang City (Rokani et al., 2021).

Based on table 2, the p-value of 0.000 ($p < 0.05$) means that h0 is rejected and h1 is accepted, which means that there is a significant relationship between family support and self-care of leprosy patients. This is in line with research conducted by Nur Laili (2017) which shows the analysis of the relationship between family support and self-care obtained a p-value of 0.690 (<0.05) with a confidence level of 95%. It shows there is a relationship between family support and self-care. The results of this study are also in line with Yulia (2017) showed the results of statistical tests regarding family support and self-care of leprosy patients in Gorontalo City, with a p-value of just 0.00, indicating a relationship between family support and self-care in leprosy patients in the city.

A study explains that although families have a high level of empathy towards the physical, psychological, and social issues faced by leprosy patients, it is rare for families to be involved in the care of these patients. Leprosy patients themselves tend to cope with their problems in their own way, without involving other family members, in order to avoid conflict, as they still believe that leprosy is a shameful condition for their family. Additionally, another study shows a supporting conclusion that all leprosy patients do not want the people in their community or their friends to know that they are undergoing treatment for leprosy or have ever received treatment for it. This is done to avoid being labelled or stigmatized by society, allowing the respondents to escape from stigma (Amaliah et al., 2023).

CONCLUSION

Based on the results of research and discussion about the relationship between family support and knowledge about self-care of leprosy sufferers, it can be concluded that the characteristics with the highest frequency based on age were 51.0% at the age of 46-55 and based on gender, 74.5% were male. Then the last education was 51.0% in the elementary school category and leprosy patients based on employment were 49.0% in the self-employed category. In addition, the characteristics of leprosy patients based on the level of knowledge for the good category were 7.8%, followed by the sufficient category of 29.4% and the poor category of 62.7%. Then, the family support variable with a good category of 33.3% and a sufficient category of 13.7% and then a deficient category of 52.9. Then, the self-care variable is in the good category 11.8% and sufficient 33.3% then the category is less by 54.9%. There is a significant relationship between knowledge and self-care of leprosy patients with a p-value of 0.000. There is a significant relationship between family support and self-care of leprosy patients with a p-value of 0.000. Based on the results of this study, researchers only had the opportunity to discuss the knowledge and relationship of family support to self-care of leprosy patients. There are still many other aspects that should be studied. Therefore, it is necessary to conduct research that focuses more on the causes or risk factors of leprosy, to assist in the development of more effective prevention strategies and propose ideas for research that focuses on developing and evaluating family education intervention programs aimed at increasing family knowledge and involvement in the self-care of leprosy patients.

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