The Relationship Of Family Support On The Quality Of Life Of Leper Patients

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Abstract. The discovery of leprosy cases in Blora Regency continues to experience a fluctuating increase over the last 5 years 2020-2024 with the number of new cases discovered as many as 234 people, and experienced a significant increase with the existence of a leprosy screening program with the largest number of findings at the Kunduran health center. One of the factors causing this disease is a lack of support from family members. Poor family support is a factor in decreased productivity, decreased personal and social relationships and even depression which has negative implications for the quality of life of leprosy sufferers. Determine the relationship between family support and the quality of life of leprosy sufferers at the Kunduran health center. The type of research used is quantitative correlation/case control research with correlation test analysis (Rank-Spearman). The sampling technique used was total sampling. The total sample was 35 patients at the Kunduran Community Health Center based on data from the Blora District Health Service for 2020-2024. That the quality of life of leprosy sufferers in the poor category is more often found in leprosy sufferers who do not receive family support (20.0%), while the quality of life of leprosy sufferers in the good category is more often found in leprosy sufferers who receive family support (68,6%). From this study, it was concluded that the results of bivariate rank-spearman analysis concluded that family support was significantly related to the quality of life of leprosy sufferers (p-value = 0.000), correlation coefficient 0,701

Keywords: Family support, quality of life, leprosy sufferers

INTRODUCTION

Leprosy, also known as moorbus hansen disease, is an infectious, chronic disease caused by the leprosy germ (Mycobacterium leprae) which is obligate intracellular. An infectious disease that mainly affects the skin, peripheral nerves, mucous membranes and eyes and can be cured using a combination of drugs called Multi Drug Teraphy (MDT) if left untreated can cause disability (Kemenkes, 2023). Leprosy disability is irreversible/permanent and is divided into 3 levels: 1st degree disability, 2nd degree disability and 3rd degree disability. Leprosy patients can transmit the disease to the surrounding community, which is determined by environmental factors and immunity (Kemenkes, 2020).

Currently, leprosy cases in the world are still relatively high. The number of new cases of leprosy in the world in 2023 is around 210,758 spread across 120 countries. Of these, most are in the Southeast Asian region (156,118) followed by the Americas (28,806) and Africa (20,004) and the rest are in other regions. Leprosy cases in Indonesia in 2023 were found to be 14,376 with the largest distribution of cases in 11 provinces and 124 districts/cities, while Central Java ranks 4th with 973 new cases, while Blora district recorded 38 new leprosy cases. New leprosy data in Blora district from 2020 to July 2024 recorded 234 cases. The highest number was found in Kunduran health centre with 43 new cases.

The discovery of leprosy cases through Posbindu and screening activities as well as RVS (Rapid Vilage Survey) of leprosy at Puskesmas Kunduran, has had a major impact on the discovery of new leprosy cases in Blora district. This shows that Blora district, especially Puskesmas Kunduran, is a leprosy endemic area or high risk of leprosy transmission with a leprosy prevalence of >1 per 10,000 in 2022 of 3.46 which exceeds the national target.

Most leprosy cases found at the Kunduran puskesmas have grade 1 and 2 leprosy disabilities, whereas if we find leprosy cases earlier, further disability can be prevented so that moral and material losses can be minimised so that the quality of life of leprosy patients with leprosy disabilities at all levels does not worsen. The notion of quality of life means a person's social relationships to enjoy the possibilities in his or her life. This enjoyment has two components, namely experience and satisfaction and possession or achieving some characteristics and these possibilities are the result of each person's opportunities and limitations in life (Chang and Weissman, 2018). A further implication of this disability is that most sufferers become unproductive because they cannot live independently to fulfil their own needs, becoming physically and financially dependent, thus leprosy sufferers who cannot live independently contribute to being a burden to their families and also to society.

Family support is a form of interpersonal relationship that protects a person from the adverse effects of stress (Mahanani, 2023). Family support also includes several aspects that can help patients in the process of healing their illness. Family support also includes several aspects that can help patients in the process of healing their illness. The family has several forms of support such as paying attention to the patient's complaints, providing clear information to recover from their illness so as to provide solutions to their illness. Leprosy patients are often also neglected for family support, this can be seen from the accidental sampling conducted during the preliminary study at the Kunduran puskesmas from 8 respondents, only 2 people who take routine medication are taken by leprosy patients themselves, 4 are taken by their families and the other 2 people, the medicine is delivered by the Kunduran puskesmas leprosy officer to the patient's home. The most important family support is to maintain control mechanisms, thus affecting the quality of life of leprosy patients.

METHODS

The type of research used is quantitative correlation research. In this study, the independent variable is family support and the dependent variable is the quality of life of leprosy patients. This study was conducted at the Kunduran health centre and the research sampling was carried out on 5 October 2024 - 5 November 2024 using total sampling with a sample size of 35 respondents. The instrument used was a questionnaire consisting of 10 family support questions and the quality of life of leprosy patients using the World Health Organization Quality Of Life (WHOQOL)-100 which consists of 26 questions. Hypothesis testing between two variables using Rank Spearman.

RESULTS AND DISCUSSION

1. Result

Table 1. Respondent characteristics

Respondent Characteristics	Frequency	(%)
Age		
Young	11	31,4
Middle-aged	14	40,0
Old	10	28,6
Total	**35**	**100,0**
Gender		
Male	23	65,7
Female	12	34,3
Total	**35**	**100,0**
Education		
Primary School	18	51,5
Junior high school	5	14,3
High school	12	34,3
Total	**35**	**100,0**
Occupation		
Labourer	4	11,4
Farmer	16	45,7
Trader	4	11,4
Self Employed	7	20,1
Employee	4	11,4

Total	**35**	**100,0**
Married Status		
Unmarried	2	5,7
Widower	4	11,4
Widowed	2	5,7
Married	27	77,1
Total	**35**	**100,0**
Duration of Treatment		
< 6 month	6	17,1
6-12 month	2	5,7
> 12 month	27	77,2
Total	**35**	**100,0**
Comorbidities		
Comorbidities present	10	28,6
No comorbidities	25	71,4
Total	**35**	**100,0**

Table 2. Family Support

No	**Family support**	**Frequency**	**(%)**
1	Good	26	74,3
2	Less	9	25,7
	Total	35	100

Table 3. Quality of Life

No	**Quality of Life**	**Frequency**	**(%)**
1	Good	26	74,3
2	Poor	9	25,7
	Total	35	100

Table 4. The Relationship between Family Support and Quality of Life of Leprosy Patients

Family Support	Quality of Life				Total		*p-value*$^{*)}$	*Correlation coefficient*
	Good		Poor					
	f	%	f	%	f	%		
Good	24	68,8	2	5,7	26	74,3	0.000	0,701
Less	2	5,7	7	20,0	9	25,7		
Jumlah	9	25,7	26	74,3	35	100,0		

2. DISCUSSION

1. Family Support

Family support is defined as the attitude, action and acceptance of the family towards their family members. This support can be in the form of verbal, non-verbal support, advice or advice, real help, presence, and things that can provide emotional benefits so that it will have an impact on the quality of life of sick family members. Family support is the family's way of protecting the safety and health of all family members, ensuring the fulfilment of physical, mental, and spiritual development needs both (Achjar, 2019)

The results of research at the Kunduran health centre the majority of respondents received family support of 26 people (74.3%). The most family support in this study in the total respondents was in the form of emotional support (82.9%,) in this case the family gave the same love as before (leprosy). This study is also in line with research (Wiranto, 2019) which states that ‘families of leprosy sufferers as the closest and trusted people by sufferers are expected to always provide and increase family (emotional) support such as attention to sufferers, do not isolate sufferers’.

The results of the study from the total respondents found that 54.3% if their families accept them (lepers) with all their limitations of course this condition will result in the spirit of life of lepers will be better. Family instrumental support is a full support or assistance from the family in the form of providing assistance with labour, funds, or taking the time to help or serve and listen to clients in conveying their feelings. This form of assistance aims to make it easier for someone to carry out their activities related to the problems they face or to help directly with the difficulties they face (Friedman, 2020).

From the results of the study, it was also found that the total positive statements of respondents about family support in the form of family willing to take leprosy patients to health services (health centres/doctors/hospitals) amounted to (25.7%) and family willing to touch the sick body parts of leprosy patients (25.7%). In this study it was also found that intensive family support was given to leprosy respondents, they stated that the family was happy because the respondent had carried out leprosy treatment (94.3%), the family reduced the respondent's anxiety / concern about leprosy (62.9%), the family gave encouragement to the respondent to maintain health (71.4%), the family gave affection to the respondent just like before suffering from leprosy (82.9%), the family served and helped when the respondent needed something (62.9%). The reason why the family is the central focus of care is because all family members will affect other family members in any dysfunction, the presence of health problems in one family member can lead to the discovery of risk factors in other members, the level of understanding and functioning of a person cannot be separated from the family's contribution, and the family is a vital support for individual needs (Andarmayo, 2018).

From this study it can also be seen that the question contains family support from the total respondents who stated that the family listened when the respondent confided in them about personal problems by 80% of course this is in line with the emotional support provided by the family as a safe and peaceful place for rest and recovery and helps control emotions. Aspects of emotional support include support manifested in the form of affection from others, trust, attention, listening and being listened to and appreciation. Lepers not only need physical support but emotional relationships between family members will greatly support lepers in maintaining their independence. Friedman, 2020 states that family support for leprosy patients is given in the form of emotional support, instrumental support, and informational support. Emotional support given to patients is in the form of affection, providing an atmosphere of calmness in the family, and motivating patients not to worry too much about the disease they are suffering from.

The need for special attention for 9 respondents (25.7%) with insufficient family support is important because family members are closely related or play an important role in a person's life phase, which is influential throughout their life. Family support that needs to be given to people with leprosy must be comprehensive, including emotional support, information support, instrumental support and valuation support. In previous research (Ameliasari, 2018) family support was not entirely successful in overcoming leprosy, but there were other factors that influenced it including: knowledge, compliance with treatment, nutritional status, personal hygiene, type of leprosy and age. Meanwhile, in research (Hanan, 2020) stated that the role of health workers is very dominant in people with leprosy (64.0%). Thus, the Kunduran health centre should adopt this research to overcome the problem of people with leprosy without family support.

Lack of family support will make leprosy sufferers more depressed, stay away from social life and discontinue leprosy treatment, the total respondents in this study found the results (74.3%) the family did not want to take the respondent to the health service, of course this will result in LFU (Lost Follow Up) in leprosy patients, so that it will increase the level of disability of leprosy sufferers because they do not receive appropriate handling and treatment. These results are in line with previous research on the relationship between family support and the quality of life of leprosy patients with level 2 disability at the UPTD Liponsos Kusta Babat Jerawat Surabaya (Refitliani, 2023) which found that the lack of family support for leprosy patients in the form of emotional support is very low so that leprosy patients increasingly withdraw from social relationships which results in decreased productivity.

2. Quality of Life

Quality of life is the level of well-being in psychological, physical, social and environmental aspects in leprosy patients (Sitanggang et al., 2023). The quality of life of leprosy patients can be influenced by several demographic factors including age, marital status, medical factors (length of suffering), complications experienced, and psychological factors consisting of depression and anxiety

The quality of life of leprosy patients at Puskesmas Kunduran is influenced by several factors including the following: physical health, mental health and psychology, living environment, resources and social relationships. It can be seen from the results obtained that the majority of respondents have a good quality of life (74.3%). In previous research (Fatih, 2021) stated that some of the factors that affect quality of life are also influenced by these four factors. Other results in this study show that the total number of respondents in the middle/productive age range (40.0%) with this mature age leprosy sufferers can accept the disease they experience, while the male gender (65.7%) shows that leprosy is more common in people with high social relationships which indicates that social interaction is also high, respondents have a clear income working as farmers (45.7%) because the Blora district area is rice fields (25.37%) with geographical conditions like this farmers still have granaries for food security. Most respondents had primary school education (51.5%) and with primary school education leprosy patients can still read and write, so information about leprosy is still commonly accessed. With the linkage of demographic conditions like this, it is closely related to the good quality of life of leprosy sufferers. The results of this study are also similar to those found that the quality of life of leprosy sufferers is influenced by spiritual and demographic factors (age, gender, education and occupation).

Respondents also underwent leprosy treatment (leprosy package drugs, leprosy relapse and leprosy symptomatic drugs) until completion, namely more than 12 months (77.2%) and obtained the results of pure respondents with leprosy (71.4%), which means that health conditions are very concerned so that complications do not occur. This study is in line with research (Daryanto, 2018) which shows the results of research that the level of knowledge and obedience to taking medication is related to the level of leprosy disability, the importance of seriousness in the leprosy treatment process, with high obedience to taking medication at least able to prevent the severity of leprosy disability suffered so that it will improve the quality of life of leprosy sufferers.

In the measurement of quality of life in respondents about satisfaction with health 28.6%, satisfaction with activities 48.6%, Ability to work 42.9%, Satisfaction with self 45.7%, While the need for sleep rest, 48.6%, Sexual life 45.7%, Living conditions 45.7%, access to health services 54.3% and availability of transportation 40.0% are felt mediocre by respondents. The physical health domain, the things related to it include: daily activities, dependence on medical materials or medical help, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work capacity (WHOQOL, 2024). These quality of life points should be maintained by the Kunduran community health centre in providing services to leprosy patients.

This study also found that 9 respondents had a poor quality of life (25.7%) due to several things experienced and had a negative impact on leprosy patients. Most of the quality of life as an individual's perception of his position in life, in relation to the local culture and value system and in relation to his ideals, appreciation, and views, which is a multidimensional measurement, not limited only to the physical and psychological effects of treatment (Anindita et al, 2023). This research is also in line with research (Afifah, 2022) in factors that affect quality of life, stating that ‘the quality of life of sufferers will remain poor due to the daily physical, psychological, social impact’.

In this study, 54.3% of respondents said that their social skills were ‘poor’ which of course requires intensive assistance. The social domain includes personal relationships, social relationships and social support and sexual activity. Social support is the presence, willingness, and concern of people who are reliable, respectful, and loving. The social support that a person receives in his environment, whether in the form of encouragement, attention, appreciation, assistance or affection, will make him have a positive view of himself and his environment (WHOQOL, 2024). Personal social relationships 45.7% and support from friends were felt to be unsatisfactory by respondents While in the respondent's data about pain to prevent their activities 51.4%, the need for medical therapy to function in the respondent's life of 34.3% was felt in moderate amounts by respondents. Physical health includes all anatomical parts of the body such as upper and lower extremities and their parts, including problems with body function or body structure that result in a decrease or loss of body function (Syafrawati, 2022). This is a reference for puskesmas Kunduran and its staff to provide alternative activities related to these problems.

3. The Relationship between Family Support and Quality of Life of Leprosy Patients

In this study, it can be seen that there is good quality of life family support (68.6%), there is poor quality of life family support (5.7%), less good quality of life family support (5.7%), less poor quality of life family support (20.0%). The results of rank-spearman bivariate analysis obtained the results (p-value = 0.000) <0.05 with a Correlation Coefficient of 0.701 Thus, Ha is accepted and H0 is rejected, which means that family support is significantly related to the quality of life of leprosy patients at Kunduran health centre, which indicates a strong correlation relationship.

The results of this study found that 54.3% if their families accept them (lepers) with all their limitations so that it affects the quality of life of lepers with the results of 51.4% they stated their lives were mediocre, conditions like this should be a consideration for families and puskesmas Kunduran to improve persuasive approaches in providing services to lepers and providing family nursing care. Quality of life is the degree to which a person can enjoy all important events in his life or the extent to which a person feels that he can master or remain in control of his life in all conditions that occur (Safitri, 2023).

From this study it can also be seen that the question containing family support which states that the family listens when respondents confide in them about personal problems by 80%, is in line with respondents' negative statements about the condition of leprosy sufferers, with 51.4% of answers experiencing physical pain that can prevent them from doing activities according to their needs, which should need assistance, motivation and empathy from the family. In addition, this study is also in line with the results found that 42.9% of leprosy patients expressed negative feelings such as “feeling blue” (loneliness), hopelessness, anxiety and depression. This is in line with research (Hutagalung, 2023) that family support in the form of social and psychosocial support is highly related to improving the quality of life of leprosy patients.

This study also shows that respondents with good quality of life who get family support are 68.6%, which means that the majority of respondents who get family support compared to respondents who lack family support. This is in line with research (Meiningtyas, 2018) which states that good social support received by lepers has a good impact on the quality of life of lepers.

Family members play an important role in this phase of a person's life, influencing them throughout their life. Likewise in this case, where the support provided by the family to leprosy sufferers is related to the good quality of life of leprosy sufferers (Umberson et al., 2020). A Concept and Case Study, ‘states that good family relationships can provide a good meaning of life to a person and improve a person's well-being’ Social Integration book (Hartwell, 2017)

Emotional support provided by families to sufferers is related to a good quality of life, especially in the psychological domain. As is known, the psychological domain is related to six things, namely positive and negative feelings, cognitive function, self-esteem, body image, physical appearance, and personal beliefs (Gavric, 2017). Family is the most important part for patients to foster a good and positive perception of their illness.

Although in this study there were still 2 respondents (5.7%) or leprosy patients who received family support, but had a poor quality of life, this was due to the psychological impact attached to the sufferers themselves. Patients feel that the disease will result in their role and function in the family regressing and becoming a burden on the family. It is undeniable that leprosy has had an impact on sufferers, both physically and psychologically. This is in line with Sekarningsih's research in 2018 which states ‘that although leprosy sufferers get good support from their families, leprosy itself has a definite psychological impact on leprosy sufferers’. The fear of ostracisation received by sufferers makes it difficult for sufferers to adapt in the family.

Less family support, but the impact on quality of life remains good in 2 respondents or (5.7%) can be due to the rapid advancement of technology. The needs of leprosy patients can be obtained from the internet which can be accessed freely via mobile phones. Health information, online shopping as well as mobile finance and entertainment, all provide convenience so that they can replace some of the roles of the family. In addition, the role of the Kunduran puskesmas leprosy officers is increasingly active in health services, using the latest breakthroughs, innovations with a direct approach to leprosy patients and ‘ball pick-up’. Officers come directly to the patient's home to deliver medicine to LFU (Lost Follow Up) patients for health checks and health consultations. In addition, the recipient of support can be influenced by a sense of discomfort when asking for help and not knowing why to ask for help, so some patients do not believe that they are in need of help from others because they are used to being independent so they do not want to disturb others.

CONCLUSION

The poor quality of life of leprosy patients was mostly found in leprosy patients with less family support (20.0%), while the good quality of life of leprosy patients was mostly found in leprosy patients who received family support (68.6%). Family support is significantly associated with the quality of life of leprosy patients.

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