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Original Research

The Effect of Social Support on Self-Care Behavior of People with Leprosy in Madura Indonesia

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ABSTRACT
Background: *Leprosy has a long-standing history and continues to cause not only health-related complications but also major social difficulties. Individuals affected by this disease require interpersonal support to perform proper self-care and to minimize the risk of further transmission. This research sought to examine the effect of social group support on self-care practices among people with leprosy in Sumenep Regency, Madura, Indonesia.*

Methods: *A cross-sectional study was carried out between August and November 2021 in Sumenep Regency. The target population comprised 232 leprosy patients registered at 28 health centers, from which 145 participants were chosen using proportional random sampling. The research instrument was questionnaire covers two main domains: Social Group Support and Self-Care Behavior. Data were analyzed using Structural Equation Modeling (SEM) with SmartPLS.*

Results: *The findings revealed that social group support had a significant impact on self-care behaviors, with a T-value of 6.368 (>1.96). In addition, personal factors also influenced self-care, as indicated by a T-value of 4.110 (>1.96).*

Conclusion: *Both social and personal support significantly enhance self-care behavior in leprosy patients. Strengthening group-based and individual support is therefore essential to improve self-care practices and decrease the likelihood of disease transmission.*

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INTRODUCTION

Leprosy remains a global health problem, persisting in endemic areas across several countries, including Indonesia. This chronic infectious disease, caused by *Mycobacterium leprae*, affects the skin, peripheral nerves, mucosa of the upper respiratory tract, and eyes (Putri et al., 2022). Indonesia ranks third in the world for leprosy cases, contributing nearly 8% of the global burden. Within Indonesia, East Java

Province is among the regions with the highest incidence, with Sumenep Regency ranking second after Sampang (Wahyuni et al., 2024).

Beyond its physical effects, leprosy also poses significant social challenges. Patients often experience social withdrawal, embarrassment, and reluctance to seek treatment. They frequently face discrimination, unemployment, and limited opportunities, which reduce their quality of life. For individuals with leprosy, interpersonal support plays an essential role in practicing self-care to prevent further transmission. According to the Health Promotion Model (HPM), health-promoting behaviors are shaped by both personal and interpersonal factors. Interpersonal influences—particularly from family, peers, and healthcare providers—can directly or indirectly affect health behavior through encouragement, motivation, or social pressure (Bhadra, 2022).

Individuals with leprosy require interpersonal support in self-care to prevent complications and transmission of the disease to others. Self-care is an effort to meet the needs of maintaining health and well-being, both for sick and healthy individuals (Udo, 2022). The initial HPM model included two variables that influence health promotion behavior, namely modifying factors and cognitive or perceptual factors. One of the modifying factors is interpersonal influence (Abdelazem et al., 2024).

Interpersonal influence can affect health behavior, primarily originating from family, social groups, and health workers. There are three interpersonal components that influence health behavior, namely social norms, social support, and role models. The HPM states that interpersonal variables can directly or indirectly influence health behavior through social pressure or encouragement to perform a certain action (Bermeo et al., 2023).

Previous studies have shown that people with leprosy often delay seeking healthcare due to fear of stigma and social isolation. Therefore, social support is critical to empower patients to perform consistent self-care practices that help reduce disease spread. This study investigates how social group support influences the self-care behaviors of individuals living with leprosy in Sumenep Regency, Madura, Indonesia (Hannan, Notobroto, & Hidayat, 2022).

In addition, most existing interventions are individual or clinical in nature, while community-based self-care has not been widely implemented, especially in endemic areas. In fact, a group approach has the potential to create a supportive social environment, build a sense of solidarity, and improve self-care skills in a sustainable manner. This gap highlights the need to evaluate how social group support can directly influence the self-care behavior of leprosy patients in endemic communities (Eze et al., 2021).

A preliminary study on 16 lepers in Sumenep Regency found that social support for lepers in self-care was still lacking. The surrounding community does not participate in the patient's self-care process because most sufferers feel ashamed and cover up their illness. Pereira (2019) revealed that the high incidence of leprosy in endemic areas relates to adults, children, gender, social contact, and care (Juwariyah & Nuridayanti, 2022)

People affected by leprosy in the early phase of the disease are generally suspicious of the diagnosis. Still, they fear social isolation, which causes hesitation to seek advice and health care services (Hannan, Notobroto, Hargono, et al., 2022). Social support is essential to help improve patients' self-care by preventing leprosy transmission in self-care-based contacts. This study aimed to determine the effect of social group support on the self-care behavior of leprosy patients in Sumenep Regency, Madura Indonesia.

Based on the above description, this study aims to examine the effect of social group support on self-care behavior among leprosy patients in Sumenep Regency, Madura. The novelty of this study lies in its social group-based approach as a non-clinical empowerment strategy, which emphasizes collective social intervention to improve self-care, differing from previous studies that focused more on individual or clinical aspects. The findings are expected to provide new empirical evidence for the development of more effective leprosy prevention strategies in endemic communities.

MATERIALS AND METHOD

Research Design

This study used a cross-sectional design because the main objective was to identify and analyze the relationship between various factors (demographics, knowledge, family support, perception of health services, and patient attitudes) and the level of treatment adherence in leprosy patients simultaneously at a single point in time. This design was chosen because it allows for efficient data collection from a large population and provides an overview of the relationships between variables without requiring long-term observation.

Population and Sample Research

The study population consisted of 232 leprosy patients registered at 28 community health centers in Sumenep District during the period August–November 2021. The sample size was determined using the Slovin formula with a 5% error rate, resulting in 145 participants selected through proportional random sampling, so that each community health center had a balanced proportion of participants with the number of registered patients.

This proportional random sampling aimed to ensure representativeness and reduce selection bias. Inclusion criteria included patients who were actively registered, able to understand and answer the questionnaire, and willing to provide written consent. Exclusion criteria included patients with serious complications that prevented participation or inability to answer the research instrument.

Data Collection

Data collection was conducted during the period of August–November 2021 after obtaining ethical approval from the Health Research Ethics Committee. Data were collected using a structured questionnaire that had been tested for validity and reliability. Data collection was conducted face-to-face at 28 community health centers in Sumenep Regency by trained researchers and enumerators.

Before filling out the questionnaire, participants were given an explanation of the research objectives, procedures, and their rights as respondents. Respondents who were willing to participate were asked to sign a written consent form (informed consent). The questionnaire filling process took place in a safe and private room to ensure comfort and maintain the confidentiality of participants' personal data.

Data was collected using structured interviews to minimize misunderstandings of questions and ensure consistency of answers. Each questionnaire was rechecked during collection to ensure completeness and minimize missing data. After the collection process was complete, all data was coded and entered into statistical software for further analysis.

Instruments

The research instruments were developed based on a review of relevant literature and adapted to the local context, then tested for validity and reliability before use. The questionnaire covers two main domains: (1) Social Group Support, which is measured through four indicators, namely emotional support, informational support, instrumental support, and positive appraisal or appreciation from the social environment; and (2) Self-Care Behavior, which is measured through four indicators, namely personal hygiene, environmental sanitation, behavioral medicine, and the ability to interact with others without social barriers. The validity and reliability of the questionnaire were found to be very good (>0.75). The internal consistency reliability of this study was obtained with a Cronbach's coefficient of 0.938.

Data Analysis

The independent variables studied included demographic factors, knowledge about leprosy, family support, and patients' perceptions of health services. The dependent variable was the level of patient compliance in undergoing leprosy treatment and care. Data analysis was performed using Structural Equation Modeling (SEM) through SmartPLS software to test the direct and indirect effects between variables. SEM was chosen for its ability to handle research models with latent variables and multi-item measurements, as well as its ability to provide estimates of complex causal relationships.

Ethical Clearance

Ethical considerations were an important part of this study. The study obtained ethical approval from the Health Research Ethics Committee, Faculty of Health Sciences, Wiraraja University, with approval number 215.1/KEPK/VIII/2021. All participants were given complete information about the purpose of the study, procedures, rights to refuse or withdraw, and were guaranteed the confidentiality of their personal data.

RESULTS

Table 1. Distribution of Personal Factors of Leprosy in Sumenep Regency, Madura, Indonesia in 2021 (n = 145)

Variable	Category	n	%
Age (years)	0 – 14	12	8.3
	15 – 59	106	73.1
	≥ 60	27	18.6
	Total	**145**	**100**
Gender	Male	81	55.9
	Female	64	44.1
	Total	**145**	**100**
Education	No formal education	57	39.3
	Elementary school	47	32.4

Variable	Category	n	%
	Junior high school	22	15.2
	Senior high school	16	11.0
	University	3	2.1
	Total	**145**	**100**
Occupation	Unemployed	39	26.9
	Employed	106	73.1
	Total	**145**	**100**
Income	< Minimum Wage	133	91.7
	≥ Minimum Wage	12	8.3
	Total	**145**	**100**

Note: n = number of observations; % = Percentage

The majority of respondents were between 15 and 59 years of age (73.1%), with males accounting for 55.9%. Nearly 40% had not completed primary education. Most participants (73.1%) were employed, yet the vast majority (91.7%) reported incomes below the regional minimum wage. Regarding disease duration, most individuals (62.1%) had experienced leprosy for one to two years.

Table 2. Distribution of Pain Period of Leprosy in Sumenep Regency, Madura Indonesia in 2021 (n = 145)

Variable	Category	n	%
Pain Period	< 1 Years	33	22.8
	1 – 2 Years	90	62.1
	> 2 Years	22	15.2
	Total	**145**	**100**

Note: n = number of observations; % = Percentage

Based on the research data, the majority of respondents (62.1%) experienced pain for 1–2 years. A total of 22.8% of respondents experienced pain for less than 1 year, while 15.2% experienced pain for more than 2 years. These results indicate that most patients experience pain in the medium term, which can affect their compliance and quality of life.

Table 3. Social Group Support and Self-Care Behavior of Leprosy Patients in Sumenep Regency, Madura, Indonesia, 2021 (n = 145)

Domain/Indicator	High/Good n (%)	Moderate/Fair n (%)	Low n (%)	Total n (%)
Social Group Support				
Emotional	14 (9.7)	87 (60.0)	44 (30.3)	145 (100)
Informational	15 (10.3)	26 (17.9)	104 (71.7)	145 (100)
Instrumental	13 (9.0)	29 (20.0)	103 (71.0)	145 (100)
Appraisal/Appreciation	13 (9.0)	22 (15.2)	110 (75.9)	145 (100)
Self-Care Behavior				

Domain/Indicator	High/Good n (%)	Moderate/Fair n (%)	Low n (%)	Total n (%)
Personal Hygiene	40 (27.6)	87 (60.0)	18 (12.4)	145 (100)
Environmental Sanitation	28 (19.3)	95 (65.5)	22 (15.2)	145 (100)
Behavioral Medicine	90 (62.0)	34 (23.4)	21 (14.6)	145 (100)
Interaction with Others	19 (13.1)	35 (24.1)	91 (62.8)	145 (100)

Note: n = number of observations; % = percentage of total respondents (n = 145)

Table 3 indicates that emotional support was predominantly at a moderate level (60.0%), while informational (71.7%), instrumental (71.0%), and appraisal or appreciation support (75.9%) were largely reported at low levels. Findings show that personal hygiene (60%) and environmental sanitation (65.5%) were predominantly at a fair level, while treatment behavior was generally good (62%). In contrast, social interaction was mostly poor (62.8%).

To assess the influence of social support on self-care, Structural Equation Modeling (SEM) was applied. During validity testing, three variables—age, education, and occupation—were excluded due to loading values below 0.5 (Figure 1). The Average Variance Extracted (AVE) for all remaining constructions exceeded 0.5, confirming adequate explanatory power. Reliability analysis further indicated strong internal consistency, with composite reliability values above 0.6 (Table 4).

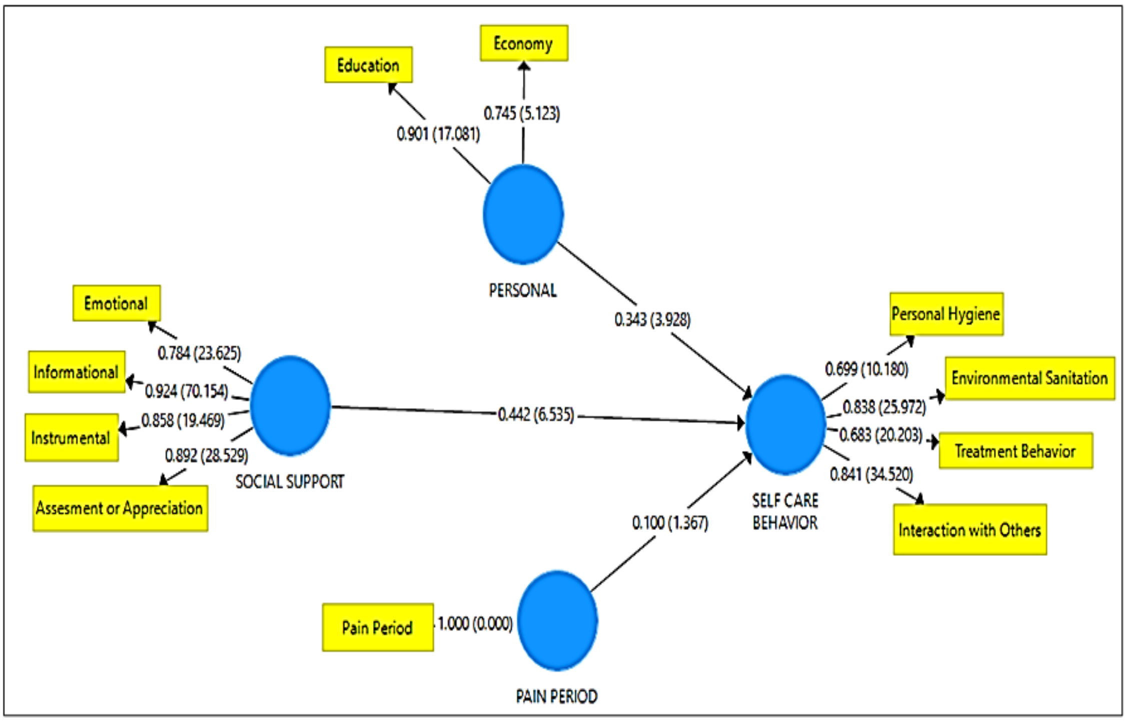

Figure 1. Analysis of Factor Loading Model Fit

Table 4. Composite Reliability (CR) and Average Variance Extracted (AVE) of Constructs

Construct	Composite Reliability (CR)	Average Variance Extracted (AVE)
Social Support	0.923	0.750

Construct	Composite Reliability (CR)	Average Variance Extracted (AVE)
Pain Period	1.000	1.000
Self-Care Behaviour	0.851	0.591
Personal	0.810	0.683

This table shows the Composite Reliability (CR) and Average Variance Extracted (AVE) values for each construct. All constructs, namely Social Support (CR = 0.923; AVE = 0.750), Pain Period (CR = 1.000; AVE = 1.000), Self-Care Behavior (CR = 0.851; AVE = 0.591), and Personal (CR = 0.810; AVE = 0.683), meet the criteria for reliability and convergent validity, indicating that the research instrument is reliable and valid.

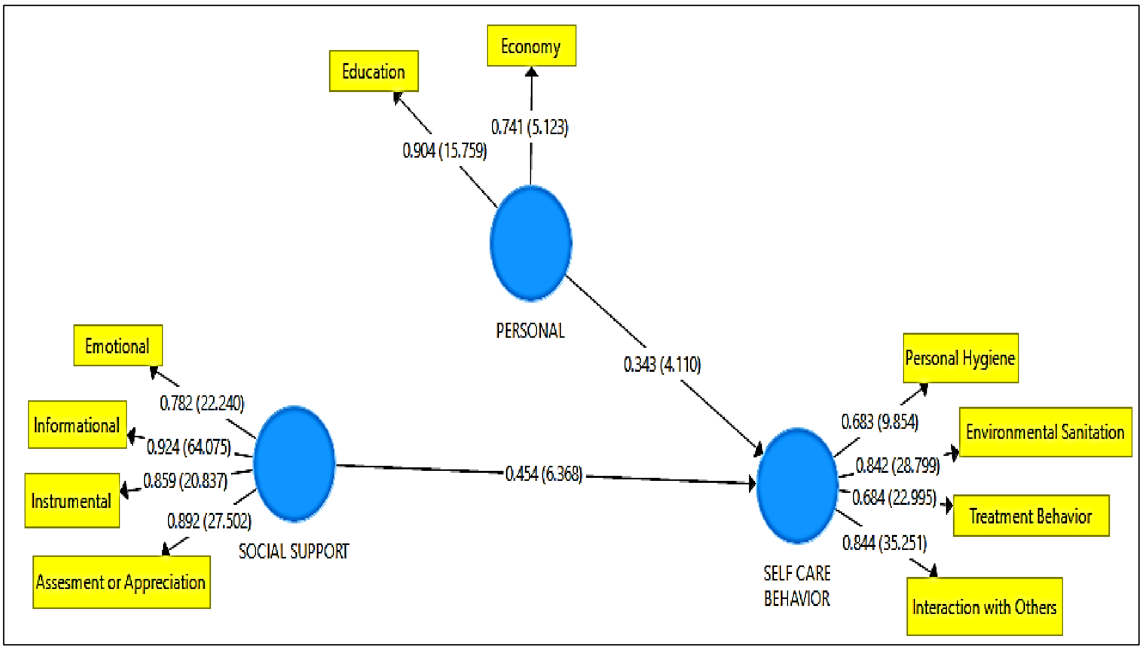

Figure 2. Analysis T Value Model Fit

Figure 2 demonstrates that social support had a significant effect on self-care behavior, with a T-value of 6.368 (>1.96). Personal factors also showed a significant influence, indicated by a T-value of 4.110 (>1.96). However, the relationship between disease duration and self-care behavior was not significant (T-value <1.96) and was therefore excluded from the model.

DISCUSSION

Social support has a pivotal influence on the self-care behaviors of individuals with leprosy. Patients who receive consistent encouragement and assistance from their surroundings are generally more motivated to practice effective self-care, while those who lack such support often encounter obstacles arising from fear of stigma or negative judgment (Xu et al., 2023). According to the WHO, self-care refers to the actions undertaken by individuals, families, and communities to maintain health, prevent illness, reduce the impact of disease, and restore well-being.

In line with the HPM, social support can affect health-related behavior directly or indirectly by fostering motivation, applying social pressure, or encouraging individuals to adopt healthier practices. Interpersonal factors, such as assistance from family, community networks, and healthcare professionals, further contribute to shaping health behavior. In addition, consistent social support can strengthen individuals' belief in their own abilities, thereby encouraging more adaptive and sustainable health behaviors (Hannan, Notobroto, & Hidayat, 2022)

Behavior itself can be understood as an individual's response to internal or external stimuli, which may manifest in observable actions or internalized processes, and is broadly classified as either overt or covert (Surya & Sundaram, 2025). Emphasize that working with leprosy patients requires an interpersonal approach, as this facilitates motivation and provides essential support for maintaining proper self-care, thereby preventing further transmission. Social support is multidimensional, encompassing both functional and structural elements. categorizes it into emotional, informational, and tangible forms, with emotional support typically emerging from networks of family, peers, neighbors, and community organizations (Pepito et al., 2023).

Interpersonal support has been shown to play an important role in leprosy self-care interventions, helping to prevent transmission and manage disabilities. Van't Noordende et al. (2021) also highlight the critical role of family and social networks in facilitating effective self-care. Consistent with the findings of Choudhury et al. (2021), the integration of community-based rehabilitation programs is recommended to strengthen self-care practices among leprosy patients.

Social contact and caregiving are also recognized as strong determinants of leprosy outcomes (Pereira et al., 2019; Xiong et al., 2019). While most individuals with leprosy engage in self-care and experience its benefits, many do not receive sufficient group support in their communities, leading to social withdrawal and limited participation in collective activities. Regular self-care practices are vital not only for preventing transmission but also for minimizing complications of the disease (Nadri et al., 2021). Thus, social support is indispensable in enhancing patients' capacity for self-care, ultimately helping to curb disease spread and promote better health outcomes.

In addition to social factors, personal attributes significantly shape self-care behavior. Education, for example, is essential in equipping individuals with knowledge and strategies to manage leprosy effectively, while the absence of educational support can hinder disease control (Riegel et al., 2021). Socioeconomic conditions also play a role; families with limited income may lack access to adequate nutrition, increasing their susceptibility to infectious diseases that poverty and insufficient awareness of the value of education in rural communities contribute to the persistence of leprosy (Humphries et al., 2021).

According to the HBM, demographic, structural, and psychosocial variables can indirectly influence health beliefs and behaviors. Factors such as education can alter perceptions of susceptibility, severity, benefits, and barriers, thereby shaping self-care practices. The results of this study confirm that social support plays an important role in improving self-care behavior among leprosy patients. Support from family, friends, the community, and nurses can motivate patients to consistently implement preventive measures, thereby reducing the risk of transmission and improving quality of life (Muchow, 2021).

Based on the findings of the study, it is recommended that leprosy health programs strengthen community-based social support interventions by optimizing the role of peer groups, families, and health cadres in providing emotional, informational, and instrumental support to patients. Health care facilities also need to provide educational materials tailored to the educational level of the Madurese community, especially for patients with low literacy, so that information is easier to understand and apply. In addition, the integration of routine counseling activities, home visits, and community empowerment can increase patient motivation, improve treatment adherence, and reduce the strong social stigma associated with leprosy. Strengthening collaboration between health workers, community leaders, and local organizations is important to ensure the sustainability and effectiveness of these interventions in improving the quality of life of leprosy patients in Madura.

However, this study has limitations, including its cross-sectional design, which cannot show a causal relationship, the use of self-reported data that is prone to bias, and its focus on one region in Madura, which limits the generalizability of the findings (Xu et al., 2023). Psychological factors, such as anxiety or depression, have also not been analyzed in depth, even though they can influence self-care behavior. In addition, social and cultural environmental variables that may influence self-care behavior have not been comprehensively explored in this study. Further research should use longitudinal or mixed methods designs to examine causal relationships and include psychosocial factors. In addition, efforts to reduce stigma and increase public awareness about leprosy are needed to create an environment that supports patients in optimizing self-care.

CONCLUSION

Both social support and individual characteristics substantially influence the self-care practices of people living with leprosy. Strengthening the involvement of families and communities is essential to enhance preventive measures and overall patient care. Future research should prioritize community-based interventions to assess the effectiveness of support programs that engage healthcare providers, peer networks, and rehabilitation initiatives. In clinical practice, nurses are encouraged to integrate emotional, informational, instrumental, and motivational assistance into patient care, while also fostering peer support systems to empower individuals in managing their condition.

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