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Original Article

Leprosy Self-Care Health Management: A Quasi-Experimental Study for Assessing the Quality of Life and Stigma in People Affected by Leprosy in Rural Areas, Indonesia

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Abstract

Introduction: Leprosy is a neglected tropical disease that poses serious health challenges in Indonesia, necessitating comprehensive interventions to improve outcomes and quality of life (QoL). Accordingly, this research aimed to evaluate the effectiveness of leprosy self-care health management on the QoL and stigma of people affected by leprosy in the rural areas of Indonesia.

Methods: A quasi-experimental study with a control-group design was conducted, involving people affected by leprosy selected to receive the intervention (n = 46) and a control group (n = 45). Participants in the intervention group received two sessions of health education activities on leprosy self-care and health management over one month. The outcome measures included the QoL, social stigma and social distance, the dermatology life quality index, exercise of self-care agency, and knowledge, attitudes, and practices related to leprosy.

Results: The independent T-test revealed the significant effect of leprosy self-care health management on the QoL ($P = 0.001$). There was a significant difference in mean self-care scores among individuals affected by leprosy between the intervention and control groups ($P = 0.030$). The intervention group also demonstrated considerable effects on community stigma ($P = 0.026$), social distancing ($P = 0.001$), and knowledge, attitude, and practices related to leprosy among individuals influenced by leprosy ($P = 0.001$) before and after the intervention.

Conclusion: Our findings confirmed the benefits of self-care health management for persons affected by leprosy, emphasizing their role in improving QoL and self-care abilities.

Keywords: Leprosy, Self care, Stigma, Quality of life, Health management

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Introduction

Leprosy is a chronic infectious and neglected tropical disease still found in over 184 countries, posing a serious health challenge worldwide, including Indonesia.[1] It is associated with severe economic, social, and health consequences and influences the quality of life (QoL) of those affected.[2] Despite global progress in combating leprosy over the decade, over 180,000 new cases were reported worldwide, with 9,729 individuals demonstrating grade 2 disability at diagnosis in 2023.[3] In the same year, Indonesia recorded 14,376 new cases, representing a sharp increase of 3,200 cases compared with 2020, which was severely affected by the coronavirus disease 2019 pandemic.[3] In East Java province, particularly in Jember Regency, the number of newly diagnosed leprosy patients was 149 people in 2023, with 143 cases classified as multibacillary leprosy and a grade 2 disability proportion of 21.5%. Furthermore, the incidence rate rose from 5.4 cases per 10,000 in 2022 to 6 cases per 10,000 in 2024.[4] These statistics underscore the persistent prevalence of leprosy in the community, necessitating concerted health efforts to avert (mental) health, social, and economic effects.

Individuals affected by leprosy experience a worse QoL due to deformities and functional limitations that profoundly impact their QoL.[5–7] Additionally, 93.6% of individuals with leprosy reported experiencing stigma and prejudice, which was closely related to mental health problems.[8] Stigma is a serious barrier to leprosy therapy adherence and health education for families, while communities can help diminish stigma.[8, 9] Different, factors, such as motivation, side effects, and resistance to continuing treatment, are closely related to compliance in leprosy treatment.[9–11] This condition is exacerbated by a

shortage of accurate information, erroneous assumptions and beliefs, and fear of leprosy,[12] especially in rural areas. Therefore, to enhance the QoL for individuals affected by leprosy, a comprehensive intervention is needed to improve mental health conditions and socio-economic aspects while overcoming the stigma in society. However, there remains limited evidence on the effectiveness of structured self-care interventions, particularly when evaluated using a control group design in the rural Indonesian context.

Interventions implemented in rural areas to improve leprosy treatment include active monitoring using medical cards at the public health center (PHC). Health workers in the PHC track persons affected by leprosy who are not undergoing treatment.[4] Moreover, critical strategies to overcome stigma and reduce the transmission in a community involve community participation and people affected by leprosy, as well as allowing those affected to make decisions about their health and well-being. Self-management is an intervention that empowers individuals to promote and improve their health through education and training, specifically for people with leprosy.[13] According to previous research, participation in self-care groups is associated with increased self-confidence and satisfaction with the usefulness of self-care in preventing disability while enhancing social participation.[14,15] Despite these positive findings, it remains necessary to examine the effectiveness of implementing self-care interventions in leprosy management, particularly in the rural areas of Indonesia.

The World Health Organization (WHO) has developed a global strategy, 'Towards zero leprosy', for 2021-2030 that focuses on preventing transmission and working toward zero new autochthonous cases. It encourages innovative approaches and comprehensive services, including physical care, QoL improvements, and the eradication of stigma and discrimination.[16] Evaluating the effectiveness of leprosy self-care health management to enhance QoL aligns with pillars 3 and 4 of the global strategy, which concern managing the disease and its complications and combating stigma.[16] Furthermore, examining leprosy self-care health management can significantly contribute to achieving Sustainable Development Goal 3 (Good Health and Well-Being). Therefore, this study aims to investigate the influence of leprosy self-care health management on the QoL and stigma experienced by individuals affected by leprosy in the rural areas of Indonesia.

Materials and Methods

Study Design and Population

A quasi-experimental study with a control group was performed at the PHC in Jember Regency, East Java, Indonesia, from June 2024 to August 2024. Jember Regency has 50 PHCs, with approximately 129 people affected by leprosy. However, about 38 people from 26 PHCs were unwilling to participate in this study.

The population included persons affected by leprosy from 24 PHCs in Jember Regency, totalling 91 people. They were selected based on their willingness to partake in the study. Figure 1 displays the distribution of study participants between the control and intervention groups, as well as their distribution across PHCs in Jember Regency. For this study, a total sampling method was used with specific inclusion and exclusion criteria. The inclusion criteria were people affected by leprosy: (1) who were currently undergoing active treatment, (2) who resided and were registered at the PHC in the Jember Regency area, and (3) who were willing to participate in the study. On the other hand, the exclusion criterion was individuals affected by leprosy to whom health workers could not reach at the PHC.

The researcher collaborated closely with health workers who were responsible for the leprosy program in the PHC to verify data on the number of persons affected by leprosy

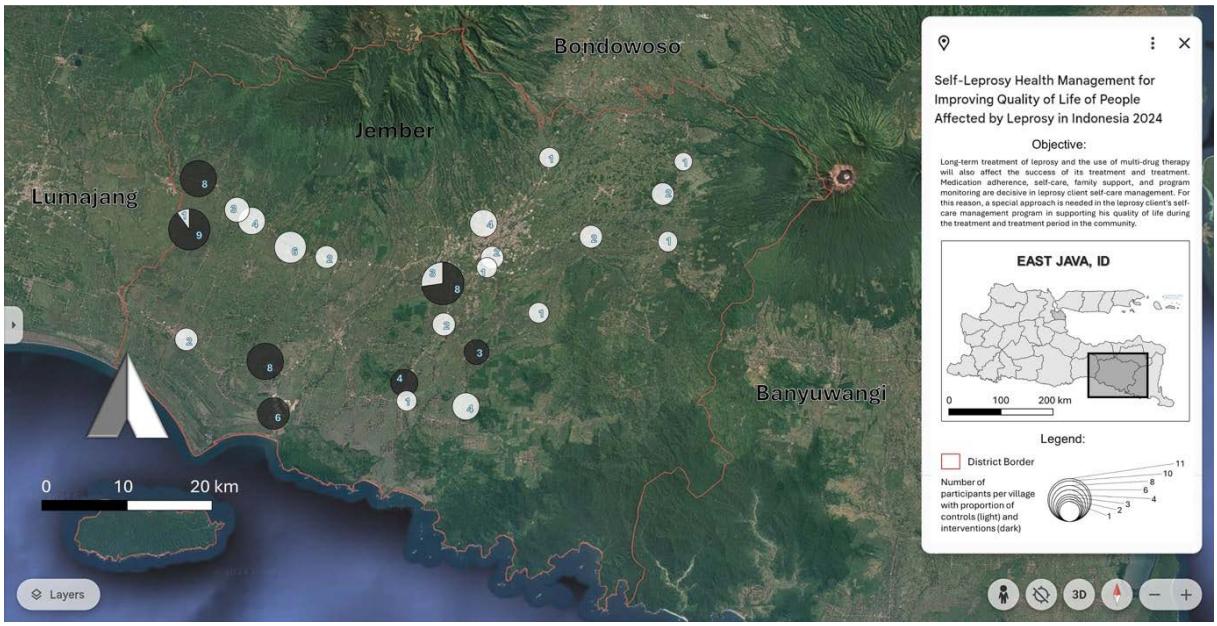

Figure 1. The Distribution of the Individuals Affected by Leprosy in the PHCs in Jember Regency. *Note*. PHC: Public health center

and their willingness to participate in the research. Overall, 38 respondents from 26 PHCs in Jember Regency were excluded for failing to meet the inclusion criteria. In the study, 91 eligible participants were initially randomized into the intervention (n = 46) and control (n = 45) groups. However, during the second measurement, 2 participants from the control group were lost to follow up. As a result, the intervention group comprised 46 participants, and the control group 43 persons with leprosy. The process of enrolling, allocating, and following up with the study participants is detailed in Figure 2. Before commencing the study, participants were required to provide informed consent after receiving verbal and written information about the study procedures.

Procedures

This study lasted four weeks (1 month) and involved using the Leprosy Self-Care Health Management Intervention for persons affected by leprosy. The leprosy self-care health management consisted of two sessions, each comprising three series of health educational activities. In addition, each session lasted between 45 minutes and 60 minutes. The health education programs included (1) physical care for persons affected by leprosy (60 minutes) and (2) environmental care, including room design and planning, the arrangement and use of household equipment, temperature and humidity regulation, as well as cleanliness and lighting (45 minutes). The programs also encompassed (3) psychological care for people affected by leprosy (60 minutes), (4) spiritual care for individuals influenced by leprosy (45 minutes), (5) independence in activities of daily living (60 minutes), and (6) social relations for people impacted by leprosy (60 minutes).

The intervention was delivered by the research team, led by the principal investigator (Tantut Susanto) and supported by trained research assistants. Additionally, the content of the health education was based on a guidebook module developed by the researchers, entitled "Family and Community Empowerment in Self-Care Management for People with Leprosy". This module synthesized information from the WHO guidelines and previous studies. The key topics for each session were delivered as follows:

1. Physical care, practical guidance on self-care for eyes (preventing dryness and infection), hands (wound care, exercises to prevent stiffness), and feet (proper soaking, ulcer prevention, and appropriate footwear)
2. Environmental care, education on modifying the home environment to improve safety and hygiene, including proper room layout, use of safe household equipment (e.g., blunt-edged furniture), temperature

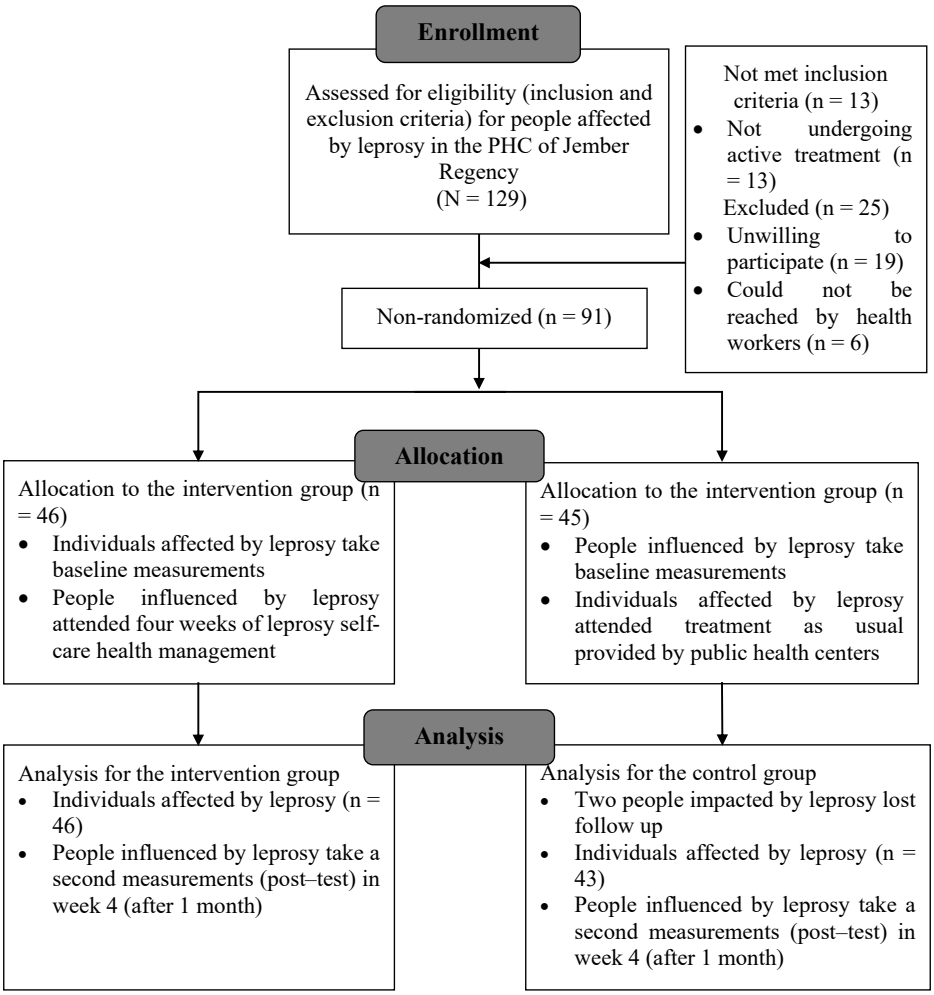

Figure 2. The Diagram of Enrolling, Allocating, and Following up on the Study of Persons Affected by Leprosy

and humidity control, and adequate lighting
3. Psychological care, sessions on managing the psychological impact of leprosy, which included introductions to psychological counselling, building family support, and developing effective coping strategies (e.g., mindfulness, relaxation techniques, and positive thinking).
4. Spiritual care, discussions on the role of spiritual support in providing strength and hope, covering various forms of spiritual activities (e.g., prayer and meditation/zikir) and their benefits for mental well-being
5. Independence in daily living, training to enhance self-reliance, focusing on understanding their condition, mastering self-care skills (e.g., routine skin self-examination), and properly managing medications to ensure treatment adherence
6. Social relations, guidance on strengthening social support by empowering patients to engage with their community, strategies for families in providing daily assistance, formation of peer support groups, and ways to increase social participation to combat stigma.

Participants in the intervention group also received a guideline module for one month while undertaking leprosy self-care health management. This module provided information on various aspects, including knowledge of leprosy, physical care for affected individuals, environmental care, psychosocial support, spiritual guidance, and social support. It further focused on promoting the independence of individuals affected by leprosy during the implementation of the leprosy self-care health management program. Conversely, the control group received routine treatment from the healthcare workers at the PHC in Jember. All study participants in both the control and intervention groups underwent assessments at baseline (pre-test) and at 1 month (post-test). Figure 3 provides a detailed overview of the study procedure.

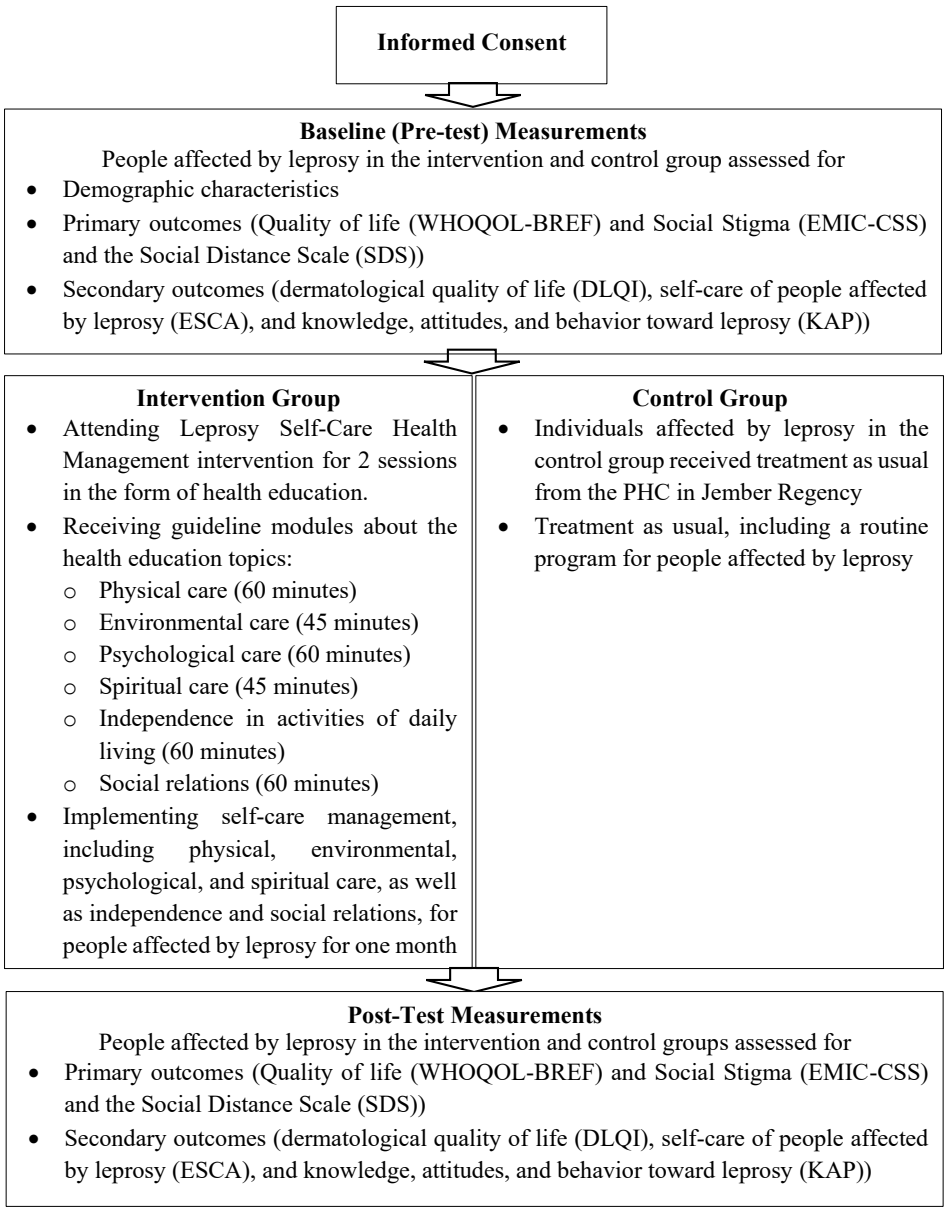

Figure 3. The Leprosy Self-Care Health Management Procedure

Instruments

The study's instruments included a form assessing demographic and clinical characteristics (1), QoL (2), social stigma and social distance (3), the Dermatology Life Quality Index (4), exercise of self-care agency among persons affected by leprosy (5), and knowledge, attitudes, and practices related to leprosy (6). The demographic questionnaire collected information on individuals affected by leprosy, including age, gender, ethnicity, educational level, occupation, and family role. Additionally, data related to leprosy were collected on the type of leprosy, participation in leprosy self-help groups, history of drug use, presence of disabilities (in eyes, hands, and feet), duration of leprosy, duration of treatment, and access to the PHC.

The Indonesian version of the WHOQOL-BREF was used to assess the QoL of individuals affected by leprosy.[17] More elevated scores indicate a better QoL. Moreover, a score ≥ 60 represents good QoL, thereby further stratifying the overall QoL assessment.[18] Likewise, social stigma was assessed using the Explanatory Model Interview Catalog Community Stigma Scale (EMIC-CSS) and the Social Distance Scale (SDS).[19] The EMIC-CSS measures how social stigma is perceived across different approaches, whereas the SDS evaluates personal perceptions of stigma. The Indonesian versions of the EMIC-CSS and SDS demonstrated strong internal consistency, with Cronbach's alpha coefficients of 0.83 and 0.87, respectively.[19] The EMIC-CSS questionnaire comprises 15 items; higher total scores denote more severe stigma. In addition, the SDS questionnaire comprises seven items representing different degrees of social distance, with higher scores reflecting a greater social distance.[19]

This study also examined the impact of dermatological QoL, estimated using the Dermatology Life Quality Index (DLQI),[20] which has been translated into Indonesian and has good validity (correlation coefficients 0.310–0.699) and reliability (Cronbach's alpha 0.858).[21] Scores range from 0 to 30, with higher scores indicating a better QoL. The ability of persons affected by leprosy to perform self-care was measured using the Exercise of Self-care Agency (ESCA),[22, 23], with a total ESCA score ranging from 0 to 140, where higher scores demonstrate greater self-care capacity.[22] Further, the original English version of the ESCA was translated into Indonesian for this study by the research team for cultural appropriateness before use. Finally, knowledge, attitude, and practice questionnaires were included in the perception study toolkit on Infolep (2022), the International Knowledge Center for Resources on Leprosy.[24] The questionnaire has 15 questions, scored from 0 to 9, and is completed using an interview-based approach. The Knowledge, Attitude, and Practice (KAP) questionnaire was adapted and translated into Indonesian using a method similar to ESCA.

Statistical Analysis

The characteristics of persons influenced by leprosy were analyzed using descriptive statistics. Paired and independent t-tests were then utilized to assess QoL before and after the intervention in each group and to examine the impact of leprosy self-care health management between groups after the intervention ($P < 0.05$). Furthermore, a normality test using the Kolmogorov-Smirnov method was performed for all outcome variables. The results revealed that the QoL (WHOQOL-BREF) data were normally distributed. In contrast, the data for social stigma (EMIC-CSS), social distance (SDS), DLQI, ESCA, and KAP were not normally distributed ($P < 0.05$). Therefore, the Wilcoxon signed-rank and Mann-Whitney U tests were employed for these non-normal variables for within-group and between-group comparisons, respectively.

This study also examined several factors associated with QoL among participants, including demographic characteristics, social stigma (EMIC-CSS and SDS), dermatological QoL, self-care practices, and knowledge, attitudes, and behaviors toward leprosy. Data used in this analysis were from pre-tests of the control and intervention groups. These potential factors, at a threshold of *P*-value less than 0.25 in bivariate analysis (using the Kendall-Tau, Pearson Correlation, and Spearman's Rho test), were entered into our multivariable linear regression models. Multiple linear regression was used to investigate the variables associated with QoL among individuals affected by leprosy in the rural areas of Indonesia. Moreover, an adjusted odds ratio (AOR) with a 95% confidence interval (CI) was utilized, and the level of significance was set at $P < 0.05$. Ultimately, the obtained data were analyzed using SPSS, version 29.

Ethical Considerations and Ethical Approval

This study considered ethical feasibility, and participation was voluntary. All participants had the autonomy to decide whether to participate in the research process. In addition, the researcher described the purpose and research stage, and participants who agreed to participate provided verbal and written consent forms. Additionally, the researcher ensured the confidentiality of respondents' detailed information. This study was approved by the Research Ethics Committee of the Faculty of Dentistry, Universitas Jember, Indonesia (Ethical approval No. 2592/UN25.8/KEPK/DL/2024).

Results

Overall, 89 persons affected by leprosy (51.7% intervention and 48.3% control groups) were identified for inclusion in this study. Of the participants in this study, 56.2% were male, with an average age of 45 years. In addition, more than half of the persons affected by leprosy (61.8%) were Madura ethnic. Most individuals influenced by leprosy had an elementary school education (43.8%) and did not work (31.5%). Additionally, about 48.3% of participants were husbands/fathers in their family.

Further, most caregivers of persons affected by leprosy were female (82.0%) and had an average age of 39 years. Furthermore, most caregivers were participants' partners (40.4%), and 48.3% were unemployed. Concerning leprosy,

95.5% of cases were multibacillary, and 42.7% of people impacted by leprosy had disability grade 2, with a mean disability score of 5. Approximately 83.1% of individuals affected by leprosy participated in self-help groups and had 5.1 km to access primary healthcare. Regarding leprosy, the mean duration since first diagnosis and the mean duration of treatment at the time of the study were 17 months and 7 months, respectively. However, nearly 74.2% of persons influenced by leprosy had no history of drug withdrawal. The baseline demographic findings are presented in Table 1.

Table 2 presents the baseline demographic and clinical characteristics of the participants in the intervention and control groups. The baseline comparison showed that the two groups were comparable with respect to most characteristics, including gender, ethnicity, occupation, and type of leprosy. However, there were significant baseline differences between the groups in terms of several variables, including age of persons affected by leprosy ($P=0.008$), education level ($P=0.003$), leprosy disability grade ($P=0.002$), and leprosy disability score ($P=0.001$). Among caregiver characteristics, significant baseline differences were also observed with regard to gender ($P=0.034$) and the relationship to the person affected by leprosy ($P=0.007$).

The Effect of Leprosy Self-Care Health Management

A comprehensive comparison of primary and secondary outcomes between the intervention and control groups is provided in Table 3. For the primary outcome, QoL, no significant difference was found between the two groups at baseline ($P=0.057$). However, post-intervention, the intervention group demonstrated a significantly higher mean QoL score than the control group ($P=0.001$). Within-group changes, q QoL in the intervention group considerably increased from a mean of 64.72 ± 19.58 to 83.49 ± 15.82 ($P<0.001$). In contrast, no significant change was observed in the control group (from 72.38 ± 17.86 to 73.09 ± 16.30, $P=0.145$). For community stigma and social distance, there were no significant differences between the groups at either baseline ($P=0.720$ and $P=0.491$, respectively) or post-test ($P=0.482$ and $P=0.910$, respectively). However, the within-group analysis of the intervention group revealed a significant reduction in both community stigma scores (from 12.3 ± 8.62 to 10.4 ± 7.57, $P=0.026$) and social distance scores (from 8.2 ± 5.84 to 6.5 ± 4.63, $P=0.001$). Conversely, no significant changes occurred in the control group for these variables (Table 3).

Regarding the secondary outcomes, there were no significant between-group differences in terms of DLQI at baseline ($P=0.080$) or at post-test ($P=0.678$). The within-group analysis showed no significant change in the intervention group ($P=0.292$), but a slight, significant improvement was observed in the control group ($P=0.011$). Regarding ESCA, the two groups significantly differed at baseline, with the intervention group having a lower mean score ($P<0.001$). Post-intervention, this between-group difference remained significant ($P=0.030$). Within-group changes confirmed that the intervention group experienced a remarkable improvement in self-care ability (from 110.1 ± 21.41 to 121.4 ± 15.62; $P=0.002$), whereas the control group demonstrated no change ($P=0.861$). Finally, for the KAP score, no significant between-group differences were found at baseline ($P=0.063$) or post-test ($P=0.192$). Nevertheless, the within-group analysis indicated that both the intervention group (from 6.7 ± 1.64 to 8.3 ± 1.76, $P=0.001$) and the control group (from 7.4 ± 2.03 to 7.8 ± 1.72, $P=0.019$) experienced significant increases in their KAP scores (Table 3).

Determinants of Quality of Life Among Persons Affected by Leprosy

According to the multivariable linear regression results (Table 4), factors with significant and substantial contributions to adverse mental health outcomes were those associated with mental health services and prescriptions. Leprosy disability grade decreased by approximately 4.9 units ($\beta=-4.921$; 95% CI: -9.060, -0.782) in the QoL among persons affected by leprosy, followed by knowledge, attitude, and practices about leprosy ($\beta=1.953$; 95% CI: 0.350, 3.556), dermatological disease on QoL ($\beta=-1.555$; 95% CI: -2.031, -1.078), and community stigma ($\beta=-0.399$; 95% CI: -0.758, -0.041). All these factors were negatively associated with QoL, but not with knowledge, attitudes, or practices regarding leprosy.

Discussion

Our findings indicated that self-care health management for leprosy positively affected key outcomes, most notably the QoL and self-care abilities. The results further revealed a significant difference in the QoL improvement among persons affected by leprosy between groups. However, social stigma and social distance were effective only in the intervention group before and after the intervention for leprosy self-care health management. Self-care ability among participants considerably increased more across groups for intervention participation, but not for the QoL in dermatological diseases. In addition, knowledge, attitudes, and practices regarding leprosy increased in the intervention group at the follow-up after leprosy self-care health management. The findings of this study also identified that leprosy disability grade, knowledge, attitude, and practices, dermatological disease on the QoL, and community stigma were predictors of the QoL among individuals affected by leprosy.

Low levels of understanding about leprosy can lead to missed disease progression and poorer treatment adherence.[25] Improving the knowledge of leprosy patients can be achieved by providing detailed explanations of their condition during medical visits. In addition, this enhancement of knowledge, attitudes, and practices regarding leprosy can be effectively facilitated through primary healthcare services, particularly in screening, early diagnosis, and family-level treatment.[26] In this study, self-care health management was implemented

Table 1. Characteristics of Persons Affected by Leprosy and Correlation With the Quality of Life

Characteristics	Total		Intervention Group (n=46)		Control Group (n=43)		*P*-Value (r-Value)
	n	%	n	%	n	%	
People affected by leprosy: Characteristics							
Gender, n (%)							
Male	50	56.2	26	56.5	24	55.81	0.490 (-0.074)[b]
Female	39	43.8	20	43.5	19	44.19	
Education level, n (%)							
Not attending formal school	13	14.6	9	19.6	4	9.3	0.003** (0.218)[b]
Elementary school	39	43.8	21	45.7	18	41.86	
Secondary school	18	20.2	10	21.7	8	18.6	
Senior high school	17	19.1	6	13.0	11	25.58	
Bachelor degree	2	2.2	0	0	2	4.65	
Ethnic							
Madura	55	61.8	21	45.7	34	79.07	0.059 (-0.202)[b]
Java	34	38.2	25	54.3	9	20.93	
Occupations							
Unemployment	28	31.5	12	26.1	16	37.22	0.084 (0.133)[b]
Agriculture sector	24	27.0	14	30.4	10	23.25	
Entrepreneur	14	15.5	3	6.5	11	25.58	
Students	7	7.9	6	13.0	1	2.32	
Others	16	18.0	11	23.9	5	11.63	
Roles in the family							
Father/husband	43	48.3	23	50.0	20	46.52	0.386 (0.070)[b]
Mother/wife	32	36.0	16	34.8	16	37.2	
Children	14	15.7	7	15.2	7	16.28	
Type of leprosy							
Multibacillary	85	95.5	43	93.5	42	97.67	0.839 (0.022)[b]
Paucibacillary	4	4.5	3	6.5	1	2.32	
History of drug withdrawal							
Have	23	25.8	18	39.1	5	11.63	0.121 (-0.163)[b]
Did not have	66	74.2	28	60.9	38	88.37	
Leprosy disability grade							
Grade 1	27	30.3	17	37.0	10	23.26	0.002** (-0.251)[b]
Grade 2	38	42.7	17	37.0	21	48.84	
Grade 3	24	27.0	12	26.1	12	27.90	
Join a self-help group							
Did not join	15	16.9	13	28.3	2	4.65	0.973 (-0.004)[b]
Join a self-help group	74	83.1	33	71.7	41	95.35	
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**	
Age (years)	45.35	16.813	44.46	19.302	46.30	13.832	0.008** (-0.278)[a]
How long has it been affected by leprosy (months)	17.85	25.156	17.59	27.946	18.14	22.114	0.487 (-0.075)[a]
The duration of medical treatment (months)	7.82	7.519	7.91	6.840	7.72	8.264	0.207 (-0.135)[a]
Distance home from PHC (in km)	5.125	3.680	5.48	4.454	4.75	2.618	0.993 (0.0001)[a]
Leprosy disability score	5.06	3.530	4.65	3.713	5.49	3.312	0.001** (-0.340)[a]
Caregiver of people affected by leprosy characteristics							
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**	
Age (years)	39.81	14.518	41.2	14.835	46.3	13.832	0.698 (0.042)[a]

Table 1. Continued.

	N	%	N	%	N	%	
Gender, n (%)							
Male	16	18.0	6	13.0	10	23.26	0.034* (-0.227)[b]
Female	73	82.0	40	87.0	33	76.74	
Occupations							
Unemployment	43	48.3	20	43.5	23	53.49	
Agriculture sector	15	16.9	11	23.9	4	9.3	
Entrepreneur	11	12.3	4	8.7	7	16.28	0.081 (-0.138)[b]
Students	1	1.1	-	-	1	2.32	
Others	19	21.3	11	23.9	8	18.61	
The relationship with persons affected by leprosy							
Parents	15	16.9	11	23.9	4	9.3	
Couple	36	40.4	16	34.8	20	46.5	
Brothers/sisters	6	6.7	1	2.2	5	11.6	0.007** (-0.187)[b]
Children	28	31.5	16	34.8	12	27.9	
Grandparents	1	1.1	1	2.2	0	0	
Grandchild	3	3.4	1	2.2	2	4.7	

Note: SD: Standard deviation; PHC: Public health center. Baseline characteristics were compared between groups. [a]Mann-Whitney U test; [b] Chi-square test or Fisher's exact test where appropriate. $^{*}P<0.05$; $^{**}P<0.01$.

Table 2. Spearman's Rho Correlation Coefficients Between Stigma, Secondary Outcomes, and the Quality of Life Among Persons Affected by Leprosy

Variables	Median	Min-Max	Quality of Life (WHOQOL-BREF)	Social Stigma (EMIC-CSS)	Social Distance (SDS)	Dermatological Disease on the Quality of Life (DLQI)	Self-Care Ability (ESCA)	Knowledge, Attitude, Practice About Leprosy
Quality of life (WHOQOL-BREF)	68.75	19.79 – 107.29	1					
Social stigma (EMIC-CSS)	13.00	0 - 30	-0.288**	1				
Social distance (SDS)	7.00	0 - 21	-0.241*	0.334**	1			
Dermatological disease on the quality of life (DLQI)	7.00	0 – 26	-0.617**	0.329**	0.280**	1		
Self-care ability (ESCA)	119	56 – 179	-0.073	0.238*	0.210*	0.064	1	
Knowledge, attitude, practice about leprosy	7.00	2 - 11	0.203	0.021	-0.291**	-0.059	-0.117	1

Note: Values represent Spearman's rho correlation coefficients. Analysis using the Spearman-Rho test. $^{*}P<0.05$, $^{**}P<0.01$.

in PHC to directly engage the community and enhance their knowledge and self-care practices related to leprosy care. The results confirmed a significant improvement in knowledge, attitudes, and practices regarding leprosy in the intervention group before and after participation in the self-care health management programs. While the control group demonstrated improvements in these areas, the intervention group experienced an increase that was four times greater than that of the control group. This suggests that knowledge and attitudes regarding leprosy can be improved through awareness initiatives involving community volunteers (e.g., health cadres and community health workers[27]), as in this research.

Knowledge of leprosy is significantly related to self-care practices.[28] Self-care health management is an intervention that focuses on educating individuals and guiding them in self-care practices. Moreover, promoting self-care among persons affected by leprosy enhances their practical and intellectual skills through repeated guidelines and hands-on care practices.[29] Additionally, interventions that provide direct education and training to people affected by leprosy, including teaching and encouraging regular self-care practices, can contribute to preventing, managing wounds, and avoiding disabilities.[30] By directly providing education and support for self-care and health management to persons affected by leprosy, this intervention may remarkably improve self-care skills. Self-care ability has a prominent and significant influence on QoL. Additionally, social support plays an essential role in boosting the QoL for persons affected by leprosy.[31] Current research indicates notable differences in self-care ability between the groups before and after the intervention. The improvement in self-care ability among persons affected by leprosy is influenced by their self-care skills and health literacy, which are integral parts of self-care health management.[31]

Self-care health management programs did not significantly affect the QoL of persons affected by leprosy, which contradicts the findings of earlier studies, indicating that self-care interventions could effectively alleviate skin condition-related issues among individuals with neglected tropical diseases.[32] The discrepancy may

Table 3. Comparison of Mean Scores Among Individuals Affected By Leprosy in the Intervention and Control Groups

Variable		Groups		*P*-Baseline	*P*-Between
		Control (Mean ± SD)	Intervention (Mean ± SD)		
Quality of life (WHOQOL-BREF)	Pre-test	72.384 ± 17.862	64.719 ± 19.577	0.057[a]	0.001**[a]
	Post-test	73.086 ± 16.296	83.492 ± 15.816		
	P-within	0.145[b]	<0.001**[b]		
Social stigma (EMIC-CSS)	Pre-test	11.2 ± 8.21	12.3 ± 8.62	0.720[c]	0.482[c]
	Post-test	11.4 ± 6.53	10.4 ± 7.57		
	P-within	0.776[d]	0.026*[d]		
Social distance (SDS)	Pre-test	7.8 ± 6.06	8.2 ± 5.84	0.491[c]	0.910[c]
	Post-test	6.8 ± 4.27	6.5 ± 4.63		
	P-Within	0.204[d]	0.001**[d]		
Dermatological disease on quality of life (DLQI)	Pre-test	7.5 ± 6.96	9.6 ± 6.43	0.080[c]	0.678[c]
	Post-test	8.7 ± 6.78	9.2 ± 6.91		
	P-within	0.011*[d]	0.292[d]		
Self-care ability (ESCA)	Pre-test	132.4 ± 31.40	110.1 ± 21.41	<0.001[c]	0.030*[c]
	Post-test	131.9 ± 27.19	121.4 ± 15.62		
	P-within	0.861[d]	0.002**[d]		
Knowledge, attitude, practices about leprosy	Pre-test	7.4 ± 2.03	6.7 ± 1.64	0.063[c]	0.192[c]
	Post-test	7.8 ± 1.72	8.3 ± 1.76		
	P-within	0.019*[d]	0.001**[d]		

Note: SD: Standard deviation. [a] Independent t-test; [b]Paired t-test; [c]Mann Whitney U-test; [d]Wilcoxon Rank-test; *$P<0.05$; **$P<0.01$.

Table 4. Multivariable Linear Regression Analysis of Quality of Life Among Persons Affected by Leprosy

Characteristics	B	*P*-Value	95% CI		R-Square
			Lower	Upper	
Leprosy disability grade	-4.921	0.020*	-9.060	-0.782	0.527
Community stigma (EMIC-CSS)	-0.399	0.029*	-0.758	-0.041	
Dermatological disease on quality of life (DLQI)	-1.555	0.001**	-2.031	-1.078	
Knowledge, attitude, and practices about leprosy	1.953	0.018*	0.350	3.556	

Note: Excluding variables due to $P>0.05$ (Age ($P=0.809$); Disability score ($P=0.753$); Duration of medical treatment ($P=0.149$); Social distances (SDS) ($P=0.884$); Ethnic ($P=0.057$); Education ($P=0.278$); Occupation ($P=0.306$); Occupation of caregiver ($P=0.774$); Gender of Caregiver ($P=0.101$); Relationship with caregiver ($P=0.548$). *$P<0.05$; **$P<0.01$.

be due to the current study's 4-week follow-up period, whereas previous research examined self-care practices over 6 months. The lack of a significant effect on the DLQI is likely attributable to the short follow-up period, as skin changes often require more time to manifest. This is supported by a randomized controlled trial performed by Mukherjee et al, which evaluated a trophic ulcer treatment over 10 weeks and reported a sharp decline in DLQI scores in their treatment groups.[33] This indicates that longer-duration interventions are likely needed to produce measurable improvements in skin-related QoL. Consequently, this study highlights that the DLQI is strongly and significantly correlated with QoL among persons affected by leprosy.[34] This research revealed that individuals affected by leprosy faced challenges due to the distance from their homes to PHC facilities, with an average of 5.48 km (the intervention group) and 4.75 km (the control group). At a shorter distance, the control group showed significant changes in dermatological disease-related QoL. Research in Sumba, Indonesia, reported challenges in leprosy care, including the difficulty of providing services in remote areas, extensive travel times, and diagnostic issues that require patients to be referred between health services for proper diagnosis.[35]

Self-leprosy health management does not have a considerable effect on social stigma and social distance; this may be due to the high level of support received by individuals affected by leprosy who are cared for at home by family and friends.[31] People affected by leprosy face stigma from their community because of the consequences of leprosy (e.g., disability and abnormalities), leading them to conceal their illness to avoid discrimination.[36] Although no considerable difference in statistics was found in social stigma and social distance between groups in this study, there was a marked decrease in social stigma and social distance scores, with reductions of 1.9 and 1.7 points, respectively, for the intervention group after participating in the self-leprosy health management program. The decline in stigma in the intervention group was related to a significant increase in knowledge levels, which is

consistent with the results of some studies, indicating a strong negative correlation between perceived stigma and the desire to maintain social distance from people with leprosy.[37,38] Information, education, and communication interventions are effective in reducing leprosy-associated stigma.

While our intervention resulted in a considerable reduction in stigma scores within the intervention group, this effect was not significant in the between-group analysis, which might be attributable to the short 4-week duration. This hypothesis is supported by evidence from longer-duration interventions. For instance, the findings of a study by Agarwal et al using a peer-support intervention over 3 months revealed a highly significant reduction in mean stigma scores ($P<0.001$).[39] Similarly, a systematic review by Willis et al highlighted a two-year counseling program that reported a sharp decrease in self-stigma ($P<0.001$).[40] Moreover, another intervention in Indonesia by Dadun et al, which combined peer counseling with socioeconomic development, was also effective in significantly reducing stigma.[41] Overall, these findings suggest that while short-term educational programs can initiate change, longer and more comprehensive interventions are likely required to produce a robust and statistically significant impact on deeply ingrained social stigma.

Individuals affected by leprosy experience the disease's effects across multiple dimensions. Biophysically, persons influenced by leprosy may endure various signs and symptoms, functional impairments, and disabilities, in addition to complications arising from the treatment of leprosy reactions.[42–44] Similarly, numerous persons affected by leprosy convey mental and emotional health difficulties, including negative emotions, low self-esteem, feelings of hopelessness, and suicidal thoughts.[42–44] Furthermore, people affected by leprosy often experience social and socioeconomic challenges, such as changes in their social environment, employment, and economic instability, stigmatization, and disruptions in relationships with family and support networks.[42–44] This aligns with the study results, indicating that the QoL among persons affected by leprosy is closely related to stigma, the severity of their dermatological conditions, and their knowledge and attitudes toward leprosy. The findings revealed that the leprosy disability grade had the most significant QoL; those with lower disability grades reported 4.9 times higher QoL than those with more significant impairments. Leprosy poses a risk of causing deformities, disabilities, and functional limitations, which are linked to higher psychosocial and mental health challenges, resulting in a lower QoL.[6, 45, 46]

The findings of this study revealed that self-care health management programs have a positive and significant impact on the QoL for persons affected by leprosy in the intervention group compared to those in the control group. A key outcome of this study was that the self-care health management program could significantly improve participants' QoL. This result is strongly supported by existing literature. The mechanism for this improvement is likely linked to enhanced self-care capabilities, as demonstrated in a large study by Xu et al, demonstrating that self-care ability has a significant direct positive effect on the QoL among individuals affected by leprosy.[31] Furthermore, our results conform to the broader evidence on psychosocial interventions. A systematic review by Bonkass et al confirmed that various psychosocial approaches, including educational and counseling interventions, are consistently effective in improving QoL among this population.[47] For example, studies included in their review, such as Dadun et al, showed that peer counseling significantly improved QoL scores ($P=0.036$).[41] Similarly, a proof-of-concept study by Agarwal et al reported that a 3-month peer support intervention led to a remarkable increase in mental well-being ($P<0.001$), a core component of the overall QoL.[39] Our study reinforces this body of evidence, confirming that structured self-care education is an effective strategy for improving the well-being of persons affected by leprosy.

To adapt to their long-term disease conditions, individuals affected by leprosy need to change their behaviors through self-care management.[48] Self-care health management provides health education guidelines for people influenced by leprosy, and the use of manuals with self-care instructions significantly improves the QoL, particularly with respect to pain and social functioning.[7] Research indicates that family-based interventions focused on self-management positively affect disability management, address stigma, and enhance family QoL.[49] Additionally, self-care interventions contribute to improving wound prevention and management among people affected by leprosy.[30] Therefore, this study indicated that self-care health management for leprosy is a promising intervention that improves the QoL among individuals influenced by leprosy.

Our study evaluated the impact of leprosy self-care health management on both primary and secondary outcomes. Given the relatively short follow-up period, the effectiveness of physical measurements (e.g., those of dermatological conditions) may not have changed significantly. However, this study included a comparison group, which provides additional evidence to support its findings.

Strengths and Limitations of the Study

This study had several strengths, including the use of a control group, which enables a more robust evaluation of the intervention's effects than a single-group design. Furthermore, the intervention was based on a structured module and measured a comprehensive set of outcomes, including the QoL, stigma, and self-care capacity, using validated instruments.

However, several limitations should be acknowledged. First, the study employed a quasi-experimental design without randomization, which may not fully control for confounding variables. Moreover, significant baseline

differences were observed between the groups in terms of self-care ability (ESCA), which could have influenced the outcomes. Additionally, the follow-up period was relatively short (four weeks). This duration may have been insufficient to capture significant changes in outcomes that require more time to manifest, such as improvements in DLQI. Finally, the study was conducted in a single regency in Indonesia, which may limit the generalizability of the findings to other populations or settings.

Conclusion

The findings of this study demonstrated that the self-care management of leprosy improves the QoL and self-care skills among people affected by the disease. Importantly, the leprosy self-care health management significantly impacted social stigma, social distance, knowledge, attitudes, and practices about leprosy within the intervention group over a four-week follow-up period. It can be concluded that leprosy self-care health management programs can noticeably improve primary and secondary outcomes among persons influenced by leprosy. Leprosy self-care health management programs can effectively improve primary and secondary outcomes among individuals affected by leprosy. This study has offered valuable insights into the potential benefits of this self-care management strategy for persons affected by leprosy, caregivers, and healthcare providers, highlighting its role in promoting community health and improving the QoL for people impacted by leprosy.

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Competing Interests

The authors declare they have no conflict of interests. All authors have read and agreed to the published version of the manuscript.

Data Availability Statement

The data that support the findings of this study are available upon reasonable request from the corresponding author. It should be noted that the data are not publicly available due to privacy or ethical restrictions.

Ethical Approval

This study was approved by the Research Ethics Committee of the Faculty of Dentistry, Universitas Jember, Indonesia, under ethical approval No. 2592/UN25.8/KEPK/DL/2024. All participants were informed about the study objectives, procedures, confidentiality, voluntary participation, and their right to withdraw at any stage without any consequences.

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