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PARTICIPATORY EMPOWERMENT OF SELF-CARE GROUPS FOR PERSONS AFFECTED BY LEPROSY WITH DISABILITIES

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ABSTRACT

Disability and stigma among persons affected by leprosy remain important public health challenges, particularly for those living with permanent impairments. These conditions can limit physical functioning, social participation, economic independence, and overall quality of life. This community engagement program aimed to improve knowledge of self-care and disability prevention, as well as enhance the quality of life of persons affected by leprosy through a community-based empowerment approach. The program was conducted in Harapan Baru Sub-village, Sebulu Village, Kutai Kartanegara Regency, East Kalimantan, Indonesia, from May to August 2025. A total of 25 persons affected by leprosy participated, including 76% with grade 2 disability and 24% with grade 1 disability. The intervention consisted of health education, self-care training, and empowerment activities designed to promote independence and improve quality of life. Knowledge and quality of life were assessed before and after the intervention using a structured questionnaire and the Assessment of Quality of Life–4 Dimensions (AQoL-4D) instrument. The results showed improvements in both knowledge and quality of life following the intervention. The proportion of participants with high self-care knowledge increased from 4% to 36%, while the proportion with low knowledge of disability prevention decreased from 48% to 32%. Quality of life also improved, as indicated by a reduction in the proportion of participants with a high level of quality-of-life impairment from 40% to 12%. In contrast, the proportions of participants with moderate and low levels of impairment increased from 40% to 56% and from 20% to 32%, respectively. Community-based empowerment interventions that integrate health education, self-care training, and community participation can improve knowledge and quality of life among persons affected by leprosy. Sustained support from relevant stakeholders is needed to maintain independence, reduce stigma, and enhance the well-being of persons affected by leprosy.

Keywords: Leprosy-related disability; self-care knowledge; quality of life; community empowerment

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ABSTRAK

Kecacatan dan stigma pada penyintas kusta masih menjadi tantangan kesehatan masyarakat karena dapat membatasi fungsi fisik, partisipasi sosial, kemandirian ekonomi, dan kualitas hidup. Kegiatan pengabdian kepada masyarakat ini bertujuan meningkatkan pengetahuan tentang perawatan diri dan pencegahan kecacatan serta meningkatkan kualitas hidup penyintas kusta melalui pendekatan pemberdayaan berbasis masyarakat. Kegiatan dilaksanakan di Dusun Harapan Baru, Desa Sebulu, Kabupaten Kutai Kartanegara, Kalimantan Timur, pada Mei–Agustus 2025. Sebanyak 25 penyintas kusta berpartisipasi, terdiri atas 76% dengan cacat tingkat 2 dan 24% dengan cacat tingkat 1. Intervensi meliputi pendidikan kesehatan, pelatihan perawatan diri, dan kegiatan pemberdayaan untuk meningkatkan kemandirian serta kualitas hidup. Pengetahuan dan kualitas hidup diukur sebelum dan sesudah intervensi menggunakan kuesioner terstruktur dan instrumen Assessment of Quality of Life-4 Dimensions (AQoL-4D). Hasil menunjukkan adanya peningkatan pengetahuan dan kualitas hidup setelah intervensi. Proporsi peserta dengan tingkat pengetahuan tinggi mengenai perawatan diri meningkat dari 4% menjadi 36%, sedangkan peserta dengan pengetahuan rendah mengenai pencegahan kecacatan menurun dari 48% menjadi 32%. Pada aspek kualitas hidup, proporsi peserta dengan gangguan kualitas hidup tinggi menurun dari 40% menjadi 12%, sementara kategori gangguan sedang meningkat dari 40% menjadi 56% dan kategori gangguan rendah meningkat dari 20% menjadi 32%. Intervensi pemberdayaan berbasis masyarakat yang mengintegrasikan pendidikan kesehatan, pelatihan perawatan diri, dan keterlibatan masyarakat efektif meningkatkan pengetahuan dan kualitas hidup penyintas kusta. Dukungan berkelanjutan dari berbagai pemangku kepentingan diperlukan untuk mempertahankan kemandirian, mengurangi stigma, dan meningkatkan kesejahteraan penyintas kusta.

***Kata Kunci**: Kecacatan Kusta; Pengetahuan; Kualitas Hidup; Pemberdayaan Masyarakat*

INTRODUCTION

Leprosy disability remains a persistent public health problem(WHO, 2023). Disability is a major consequence for persons affected by leprosy (PALs) due to untreated nerve damage, and it not only limits physical activities but also affects quality of life, psychological well-being, social participation, and economic productivity(Jatimi, Yusuf, & Andayani, 2020; Nadhiroh, Dharmawan, & Murti, 2018; Putri et al., 2022; Rusnah, Buntoro, Handoyo, & Oematan, 2025; Zai, 2024). The Indonesian Ministry of Health in 2023,reported 14,376 leprosy cases with a disability rate of 5.7 per 100,000 population, far above the national target of less than 1 per 100,000(WHO, 2023). In 2023, a total of 130 new leprosy cases were reported across all districts and municipalities of East Kalimantan Province. Despite the national elimination target, nine villages in Kutai Kartanegara Regency remain classified as leprosy high-risk areas, including Harapan Baru Subvillage in Sanggulan Village, Sebulu Regency(Dinkes, 2023).

Dusun Harapan Baru, a resettlement area established after the closure of Tenggarong Leprosy Hospital in 2012, is relatively isolated from the main village, limiting access to healthcare and community participation. Currently, 19 former patients live with grade 2 disability involving visible impairments of hands, feet, or eyes, and 14 with grade 1 disability marked by numbness and wounds(Dinkes, 2023). Most do not practice proper wound care due to barriers such as low motivation, lack of assistive devices, financial difficulties, transportation constraints, and limited support from health workers.

These conditions show that disability among people affected by leprosy in Harapan

Baru is still an important problem even after completing treatment. Many former patients have limited self-care practices and low participation in community activities due to disability and stigma. This situation may increase the risk of recurrent wounds, worsening disability, and poor quality of life. In addition, there has been no community-based empowerment program focusing on self-care and quality of life improvement in this area. Therefore, an empowerment intervention is needed to improve knowledge, self-care practices, and quality of life among people affected by leprosy with disabilities.

Many former leprosy patients have low participation in community activities or employment in agriculture, plantations, and construction due to disability and stigma. Stigma, driven by low public knowledge, education, and cultural perceptions, contributes to discrimination and exclusion(Astutik & Gayatri, 2018; van Brakel et al., 2012). In addition to medical challenges, social and economic issues remain significant(Dadun et al., 2019). Data from Sebulu I Primary Health Center show that although most work independently, only a small proportion engage in activities together with the broader community.

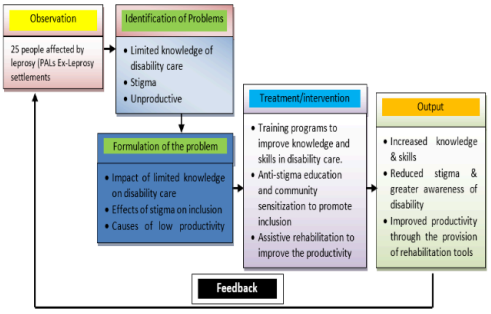
Leprosy-related disability can be prevented or reduced through early detection, treatment, management of reactions, and consistent self-care(Dahiru, Iliyasu, & Aliyu, 2022; Paula et al., 2019). However, adherence to self-care remains low, influenced by limited knowledge, education, motivation, access to health services, and family support, as well as the limited role of health workers in encouraging behavior change. Persistent stigma further reduces the willingness of former patients to seek medical evaluation, worsening disability and restricting opportunities for work and social integration(Silva, Ferreira, Ferreira, & Ribeiro, 2014). This community service program aims to improve knowledge and self-care capacity among persons affected by leprosy with disabilities, while enhancing their quality of daily life. Through these efforts, the program seeks to support increased independence, productivity, and overall well-being within the community.

METHOD

The community service activity began with consultations involving the head of the primary health center and leprosy health officers to obtain an overview of the condition of persons affected by leprosy, including stigma, educational level, socioeconomic status, and other related issues. In collaboration with participants, these challenges were reformulated into guiding questions addressing knowledge gaps, the influence of stigma on social inclusion, and the underlying factors contributing to unproductivity. Guided by this shared problem identification, interventions were designed and implemented in the form of training sessions to strengthen disability self-care skills, anti-stigma education, and community awareness activities.

These efforts aimed to foster social inclusion, promote assistive rehabilitation, and enhance productivity. The participatory action approach was implemented among a total of 25 persons affected by leprosy (PALs) residing in former leprosy settlements. The outcomes of these actions included increased knowledge and skills, reduced stigma, and greater community awareness of disability inclusion, as well as enhanced independence through improved productivity by providing rehabilitation tools (figure 1).

Figure 1. Problem-Solving Framework



(Source: Modified from Logic Model, 2025)

The evaluation of the disability prevention training for persons affected by leprosy was conducted using a knowledge questionnaire developed by the researchers based on the training materials. The instrument consisted of 15 brief statements with dichotomous response options (true = 1, false = 0). The items were organized into three main domains: basic understanding of disability prevention (5 items), self-care techniques (5 items), and application in daily life (5 items). The total score ranged from 0 to 15, with higher scores indicating greater knowledge. For analytical purposes, the knowledge levels were categorized as follows: low (0–59), moderate (60–79), and high (80–100).

The instrument used to assess the participants' quality of life was the Indonesian version of the Assessment of Quality of Life-4D (AQoL-4D), which has been validated for use in Indonesia (Achmad, Husna, Priyandani, & Zairina, 2023). The questionnaire consists of 12 items representing four core dimensions: independence, social relationships, mental well-being, and senses. Each item is rated on a four-point Likert scale, ranging from *never* (1), *rarely* (2), *sometimes* (3), to *often* (4). An overall quality of life score was calculated by summing all item responses, yielding a total score ranging from 12 to 48. The total score was then transformed into a 0–100 scale. For categorical analysis, overall quality of life was classified into three levels based on the tertile approach commonly applied in previous studies: low (0–33), moderate (34–66), and high (67–100).

RESULT AND DISCUSSION

Table 1. Characteristics People Who Had Experienced Leprosy

Characteristics		N	%
Sex	Male Female	9 16	36 64
	Mean age:50.2 year		
Aged	≤ 50 y.o >50 y.o	11 14	44 54
Type of Leprosy	Pausi-Bacilary (PB)	7 18	28 72
	Multi-Bacillary (MB)		
Degree of Disability	0 1 2	0 6 19	0 24 76

(Source: Primary Data, 2025)

A total of 25 persons affected by leprosy participated in this community service program. Most participants were female (64%), aged over 50 years (56%), had multibacillary (MB) leprosy (72%), and presented with grade 2 disability (G2D) (76%) (Table 1). The high proportion of G2D indicates that the majority of participants had visible impairments that may affect daily functioning and social participation, reflecting a substantial disability burden among the target community in Harapan Baru.

This pattern is consistent with findings from other leprosy rehabilitation settings, such as Donorojo Leprosy Rehabilitation Village in Indonesia, where 77.5% of residents were reported to have G2D, and the Kindia rehabilitation center in Guinea, which reported 48.7% G2D and 27% (Aishia & Wiarsih, 2017; Sy Savané et al., 2024). These proportions are considerably higher than those observed in general community settings, where grade 2 disability among new cases typically ranges between 10–30%(WHO, 2023). The high burden of disability in this program setting may be related to delayed diagnosis, limited access to rehabilitation services, prolonged disease duration, and the cumulative impact of stigma and social exclusion that hinder timely health-seeking behavior(Nadhiroh et al., 2018; Rather, 2022).

Table 2. Level of Knowledge on Disability Care among Persons Affected by Leprosy

Statements	Pretest			Postest		
	Low	Moderate	High	Low	Moderate	High
Understanding of disability prevention	12(48%)	10(40%)	3(12%)	8(32%)	12(48%)	5(20%)
Self-care techniques	11(44%)	12(48%)	2(8%)	9(36%)	7(28%)	8(32%)

Statements	Pretest			Postest		
	Low	Moderate	High	Low	Moderate	High
Application in daily life	15(60%)	9(36%)	1(4%)	6(24%)	10(40%)	9(36%)

(Source: Primary Data, 2025)

The intervention included health education and self-care training focusing on disability prevention and daily self-care practices (Figure 2). Table 2 shows improvements in participants' knowledge after the intervention. For disability prevention, the proportion of participants with high knowledge increased from 12% before the intervention to 20% after the intervention, while those with low knowledge decreased from 48% to 32%. Similar improvements were observed in self-care techniques, where the proportion of participants with high knowledge increased from 8% to 32%, and those with low knowledge decreased from 44% to 36%.

Knowledge regarding the application of self-care in daily life also improved. Participants with high knowledge increased from 4% before the intervention to 36% after the intervention, while participants with low knowledge decreased from 60% to 24%. These findings suggest that health education and practical training helped participants better understand the importance of regular self-care in preventing further disability and maintaining physical function.

Table 3. Quality of Life among Persons Affected by Leprosy

Domain	Pretest			Postest		
	Low (0-33)	Moderate (34–66)	High (67–100)	Low (0-33)	Moderate (34–66)	High (67–100)
All Dimensions (independence, social relationships, mental well-being, and senses)	5 (20%)	10 (40%)	10 (40%)	8 (32%)	14 (56%)	3 (12%)

(Source: Primary Data, 2025)

Quality of life also showed positive changes following the intervention (Table 3). Before the program, 40% of participants were classified in the high impairment category, indicating considerable limitations in daily life. After the intervention, this proportion decreased to 12%. At the same time, the proportion of participants in the moderate category increased from 40% to 56%, and those in the low impairment category increased from 20% to 32%. From a practical perspective, these findings highlight the importance of community-based rehabilitation and continuous psychosocial support to sustain improvements and prevent relapse into higher levels of impairment(Aishia & Wiarsih, 2017; Cisneros et al., 2022; Susanto et al., 2022).

The improvement in quality of life may be related to increased knowledge and self-care capacity gained during the program (Figure 2). Better understanding of disability prevention and self-care can help participants manage their condition more effectively, reduce the risk of recurrent wounds, and improve confidence in daily activities. These findings indicate that community-based education and self-care empowerment can contribute to better well-being among people affected by leprosy with disabilities.

The limited improvement in knowledge among former leprosy patients, as presented in Table 1, may be influenced by several contributing factors. Persistent stigma related to leprosy can reduce self-confidence and limit active participation in health education activities, thereby affecting the absorption of information delivered during the program(Astutik & Gayatri, 2018; Handaris, Rosmaharani, & Rodiyah, 2021). In addition, psychosocial barriers and low engagement in learning activities may further constrain knowledge improvement despite educational interventions(Kinanti & Alinda, 2024; Rusnah et al., 2025).

Quality of life (QoL), in addition to knowledge, self-care practices, stigma reduction, and productivity, was assessed using a simplified self-reported scale covering

physical, psychological, social, and environmental domains(Brouwers et al., 2011). Prior to the intervention, 40% of participants reported high levels of life impairment, particularly related to limitations in mobility, social participation, and emotional well-being. After the program, this proportion decreased to 12%, indicating improved independence in daily functioning, increased self-confidence, and better social acceptance.

These improvements were strongly supported by the provision of rehabilitation aids, including prosthetic limbs, walking sticks, muscle-strengthening devices, and reconstructive surgery for leprosy-related nerve damage (Figure 3). These assistive and rehabilitative measures helped reduce physical barriers, alleviate anxiety related to disability progression, and encouraged participants to re-engage in social and economic activities(van Veen et al., 2011).

The observed improvement in knowledge and wound care practices in this program supports previous evidence that training combined with provision of self-care tools plays a critical role in preventing secondary impairments and maintaining functional independence(Choudhury, 2021). In line with findings from similar community-based interventions in India, improved disability management was associated with increased confidence and reduced dependence on health services, which is particularly relevant in settings with limited access to healthcare facilities (Bhat, Khan, Vaida, Hassan, & Banday, 2022).

Furthermore, the reduction in stigma through community sensitization activities demonstrated a measurable improvement in social inclusion. The increase in perceived community acceptance from 4% to 36% reflects the effectiveness of structured educational and awareness interventions in reshaping community perceptions of leprosy. This finding aligns with previous evidence indicating that stigma is largely driven by misinformation and low awareness, and that active community engagement can significantly reduce discriminatory attitudes(Astutik & Gayatri, 2018).

Figure 2. Providing self-care tools to prevent disability progression in former leprosy patients

(Source: Primary Data, 2025)

Importantly, the improvement in quality of life from 20% to 32% of participants reporting good QoL highlights the positive impact of the integrated intervention implemented in this community service program. By simultaneously addressing physical, psychological, and social barriers through self-care training, assistive device provision, and community engagement, the program contributed to increased independence, self-esteem, and social participation among participants(Santoso, Nurdina, & Nurwijayanti, 2019).

However, sustaining these improvements requires continued post-program support. Regular follow-up by health workers, ongoing involvement of family members, and strengthened livelihood opportunities are essential to maintain self-care practices and social inclusion over time(Jufriyanto, Yusuf, & Mundakir, 2020). Without these supportive mechanisms, there is a potential risk of decline in self-care adherence and re-emergence of social exclusion(Paula et al., 2019).

Figure 3. The process of making prosthetic legs for former leprosy sufferers

(Source: Primary Data, 2025)

Overall, the results showed that health education and self-care training contributed to improvements in participants' knowledge and quality of life. Increased knowledge regarding disability prevention and self-care may help people affected by leprosy apply appropriate self-care practices in their daily lives and reduce the risk of further disability. The improvement in quality of life observed after the intervention suggests that participants became more confident and independent in managing their condition(Silva et al., 2014). These findings highlight the importance of community-based empowerment programs and the need for continuous support from health workers, families, and local stakeholders to sustain positive outcomes and encourage long-term self-care practices among people affected by leprosy(Jufriyanto et al., 2020).

CONCLUSION

This community service program demonstrates that the participatory approach effectively improves disability care knowledge, self-care practices, social participation, and quality of life among persons affected by leprosy. The implementation of training activities, assistive device provision, and community sensitization has contributed to increased self-reliance and reduced stigma within the community. Overall, the program shows positive outcomes in strengthening both individual capacity and community support systems. The sustainability of these achievements requires continued collaboration between health workers, families, and community stakeholders to ensure long-term empowerment and social reintegration of persons affected by leprosy.

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