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Strengthening Self Efficacy and Self Care Practices Among People Formerly Affected by Leprosy to Reduce Disability Risk

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Abstract Disability progression among people formerly affected by leprosy can occur due to permanent nerve damage involving the hands, feet, and eyes. Consistent self care can prevent or reduce secondary injury and disability. This community service program aimed to increase self efficacy and knowledge related to self care practices. A refresher program comprising education and motivational support was delivered to 20 participants who had a history of leprosy and varying levels of disability. Self efficacy and self care activities were assessed before and after the program. At baseline, conditions that support self efficacy were limited. After the intervention, improvements were observed across multiple elements of self care, particularly reduced wound odor, improved hand condition with cleaner and softer skin, and increased use of protective footwear and gloves during work activities. Participants reported that prior successful experiences with self care and support from peers, other people formerly affected by leprosy, and family members helped strengthen self efficacy and supported more consistent self care. These findings suggest that refresher education combined with social support can reinforce self care behaviors, which may help participants maintain daily self care practices.

1. INTRODUCTION

Disability remains a major concern for people formerly affected by leprosy. Even after completing multidrug therapy, individuals may still develop new disability or experience progression in disability grade due to leprosy related complications (dos Santos et al., 2020; Van Brakel et al., 2012). Limited education and inadequate knowledge can reduce adherence to appropriate wound care, which may contribute to worsening wounds and preventable complications (Cisneros et al., 2022). Leprosy can cause permanent peripheral sensory and motor nerve damage, which may result in disability. Disability in turn can have substantial consequences for quality of life, affecting physical function, psychological well being, social participation, and economic stability (Handaris et al., 2020; Rather, 2022).

Given these impacts, reducing the risk of disability progression should remain a priority for people formerly affected by leprosy and for those who support their long term care (Cisneros et al., 2022; dos Santos et al., 2020; Santoso et al., 2019). Evidence suggests that consistent, appropriate self care can help prevent secondary injury and reduce the likelihood of worsening disability grade (Nadhiroh et al., 2018; Susanto et al., 2022). However, effective self care is shaped by multiple individual and contextual factors. Santoso et al. (2019) highlighted low self acceptance among people affected by leprosy and emphasized the importance of social support. In addition, barriers such as low self efficacy, limited socioeconomic resources, and stigma may reduce engagement in routine self care practices (Beladina, 2023). Physical limitations and disability grade also influence independence in self care, which can further restrict a person's ability to maintain

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daily preventive behaviors (Handaris et al., 2020).

2. METHOD

This community service activity was conducted in Harapan Baru sub village, Sanggulan Village, Sebulu Sub district, Kutai Kartanegara District. The program involved 20 people formerly affected by leprosy who were identified using records provided by leprosy program staff at the Sebulu I Community Health Center.

The intervention consisted of a refresher course on self care techniques that was delivered using an adult learning approach. This approach was selected because participants had previously received self care information through several activities in the same area, including self care groups, education delivered by leprosy health workers, supervision activities, and leprosy screening programs. The refresher course was implemented in two sessions, with each session lasting approximately 60 minutes, and the sessions were delivered over a two month period.

Data were collected before and after the intervention using a Likert type scale ranging from 0 to 5 to measure self efficacy for performing self care practices. The instrument included items related to management of physical impairments, activity limitations, and participation restrictions, which correspond to the World Health Organization disability framework (WHO, 2007). Mean scores were calculated before and after the intervention. Pre and post intervention scores were compared using a paired t test with a 95 percent confidence level, and results are reported as the mean plus or minus the standard deviation.

The World Health Organization disability grading system classifies leprosy related impairment into three grades (Table 1). Grade 0 indicates no sensory loss and no visible impairment. Grade 1 indicates sensory impairment without visible deformity. Grade 2 indicates visible deformity or severe damage. For ocular involvement, Grade 0 indicates no eye impairment, Grade 1 indicates eye involvement with visual acuity better than 6/60, and Grade 2 indicates severe visual loss with visual acuity worse than 6/60 or functional impairment, for example lagophthalmos.

In Indonesia, leprosy disability is similarly categorized into Grades 0, 1, and 2 (Kementerian Kesehatan Republik Indonesia, 2019). Grade 0 indicates no disability due to leprosy. Grade 1 indicates sensory impairment without visible deformity or damage. Grade 2 indicates visible deformity or damage related to leprosy.

Self efficacy refers to an individual's belief in their ability to carry out actions needed to manage daily demands and achieve desired outcomes. In the context of leprosy, self efficacy reflects confidence in performing self care consistently and in seeking or using support when needed (Nurfajeria, 2022). In this community service activity, self efficacy for self care was assessed before and after the intervention using a Likert scale ranging from 0 to 5. Mean scores were calculated for each self care activity and were compared between pre intervention and post intervention assessments.

3. RESULT AND DISCUSSION

The self care refresher activities for people formerly affected by leprosy were conducted in two stages. The first stage took place on November 2, 2024, at the Sebulu I Community Health Center in Kutai Kartanegara Regency, East Kalimantan Province. This stage focused on confirming participant identity and disability grade and coordinating the community service plan with health center leadership and leprosy program staff.

The second stage was conducted on November 9, 2024, in Harapan Baru sub village, Sanggulan Village, Sebulu Sub district, Kutai Kartanegara District. This stage involved

Table 1 . WHO disability grading (Kementerian Kesehatan Republik Indonesia, 2019; Nicholls, 2007)

Grade	Degree of Impairment	Included	Excluded
Hands and Feet			
Grade 0	• No sensory impairment • No visible impairment	• Scars and healed ulcers, when sensation is normal	
Grade 1	• Sensory impairment present • No visible impairment	• Scars and healed ulcers, when sensation is impaired • Hand and feet following successfully reconstructive surgery • Muscle weakness without clawing	• Scars and healed ulcers when sensation is present • Minor skin cracks
Grade 2	• Visible impairment present	• Ulcers, severe cracks, severe atrophy	
Eyes			
Grade 0	• No eye impairment • No visible or vision impairment		
Grade 1	• Eye impairment present (vision: >6/60)	• Irregular or absent blink reflex	
Grade 2	• Severe visual impairment (vision: <6/60)	• Inability to count fingers at 6 meters • Presence of lagophthalmos	• Facial impairment do to lepromatous leprosy • Corneal opacitie • Uveitis

delivery of the refresher intervention to 20 participants who had a history of leprosy. The location map is presented in Figure 1.

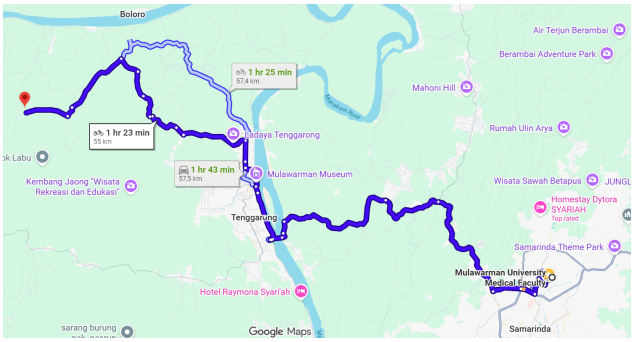

Figure 1 . Location map of Harapan Baru sub village, Sanggulan Village, Sebulu Sub district, Kutai Kartanegara Regency, East Kalimantan, Indonesia

Figure 2 . Self-care–based community service activities for people formerly affected by leprosy, illustrating participant training and an instructor-led demonstration of finger claw prevention techniques

Harapan Baru sub village has served as a residential settlement for people formerly affected by leprosy since the Tenggarong leprosy hospital closed in 1995. As shown in Table 2, most participants were male, accounting for 60 percent of the sample. Nearly one half were older than 50 years, accounting for 50 percent, while 35 percent were 40 to 50 years of age. With respect to disability, 65 percent had Grade 2 disability and 35 percent had Grade 1 disability, while none were classified as Grade 0. Regarding leprosy type, 60 percent had paucibacillary leprosy and 40 percent had multibacillary leprosy. The male to female ratio was 1.5 to 1.

Participant characteristics may have influenced baseline knowledge and skills and may also have shaped responses to the refresher intervention. Because most participants were older, some may have experienced greater physical limitations that could affect performance of self care tasks. At the same time, accumulated disability may increase motivation to adopt or maintain preventive self care practices. The predominance of Grade 2 disability suggests advanced impairment, which often requires ongoing support and repeated reinforcement of self care techniques. In addition, the relatively high proportion of paucibacillary cases suggests that some participants may have experienced less severe disease progression, which may be associated with better functional capacity for practicing self care after training.

Table 2 . Characteristics of participants formerly affected by leprosy in Harapan Baru sub village, Sanggulan Village, Sebulu Sub District, Kutai Kartanegara Regency, East Kalimantan, Indonesia

Respondent Characteristics	n=20	%
Sex		
Male	12	60
Female	8	40
Age		
<40 year old	3	15
40-50 year old	7	35
>50 year old	10	50
Grade of Disability		
Grade 0	0	0
Grade 1	7	35
Grade 2	13	65
Type of Leprosy		
Pausibacilar (PB)	12	60
Multibacilar (MB)	8	40

Source: Sebulu I Health Center record 2024

Participants' enthusiasm is shown in Figure 2. The home based self care refresher was delivered by resource persons from the Kutai Kartanegara District Health Office, a leprosy health worker from Sebulu I Community Health Center, and the research team.

Bhat et al. (2022) reported that people formerly affected by leprosy often experience substantial limitations in basic activities, and that dependence tends to increase with age and disability grade. Consistent with this evidence, our observations suggest that factors that support improvement in self efficacy among participants were limited, as shown in Table 3. People formerly affected by leprosy may require social support to strengthen self esteem and sustain engagement in self care practices (Jufriyanto et al., 2020; Nadhiroh et al., 2018).

Several studies have also suggested that functional ability may decline after completion of leprosy treatment. As a result, ongoing support, guidance, and education are often needed to help individuals perform self care consistently and to prevent worsening disability, which may require tailored approaches that account for physical limitations and social context (Bhat et al., 2022; Brouwers et al., 2011; Jatimi et al., 2020; Van Brakel et al., 2012). However, findings from Lau Simomo in North Sumatra differed from our observations, because many people formerly affected by leprosy in that setting reported good quality of life and did not experience depression (Zai, 2024). In addition, reconstructive surgery of the hands and feet can improve function, support ambulation, and increase self esteem or self confidence (van Veen et al., 2011).

As shown in Table 4, mean scores increased from pre test to post test across all self care items. The overall mean knowledge score increased from 2.64 plus or minus 0.36 before the training to 3.87 plus or minus 0.20 after the

Table 3 . Factors supporting self efficacy for implementing self care among people formerly affected by leprosy

Statement	n = 20			
	Yes	%	No	%
Have experienced successful self-care in the past (mastery experience)	13	65	7	35
Have seen the success of leprosy sufferers in managing their disability	8	40	12	60
Former leprosy patients' expectations of successful self-care are good	9	45	11	55
The whole family supports self-care activities	8	40	12	60
All family, neighbors, and health workers give appreciation when self-care is done regularly	5	25	15	75
Self-care activities do not interfere with the main job	14	70	6	30

training, which suggests a substantial improvement in participants' knowledge of hand and foot self care practices. The self care activity with the largest increase was the report of no odor after cleaning wounds or fissures on the hands and feet.

This activity can be time intensive because it typically involves soaking followed by cleaning using tools such as a brush and scissors. Removing nonviable tissue at the wound base can reduce bacterial load and support formation of healthy granulation tissue. Routine daily cleaning of wounds and areas of broken skin can also promote faster healing.

We found consistent improvement across all knowledge items, which indicates that the intervention enhanced participants' understanding of hand and foot self care. Post test scores were higher than pre test scores in each domain, reflecting increased awareness of wound hygiene, skin and joint care, odor reduction, and appropriate protective practices, for example the use of footwear and gloves, as shown in Table 4. Overall, the increase in mean scores supports a positive effect of the intervention on participants' knowledge and reported self care practices, as presented in Table 5.

Among people affected by leprosy who have reduced peripheral sensation in the hands and feet, the risk of unnoticed injury and subsequent wounds is high (Nicholls, 2007). For this reason, routine hand and foot care after daily activities is essential. Self care begins with careful inspection for new wounds because hypoesthesia can prevent individuals from noticing punctures, blunt trauma, or contact with hot objects. The next step is to maintain finger flexibility as a preventive measure against finger clawing. This can be performed by applying oil to the fingers, resting the hand on the thigh, and using the other hand to gently extend and align the fingers in a vertical position for 3 to 5 minutes. Preventing finger clawing is important because clawing reduces functional grip and limits the ability to perform tasks that require fine finger movements.

Protective measures during daily work are also critical. Using gloves and appropriate shoes or sandals while working at home or outside the home can reduce the risk of new injuries and wounds. However, our observations suggested that motivation to adopt these protective behaviors did not increase markedly, which may reflect habitual work practices and comfort preferences. In some rural settings, individuals may perceive gloves and footwear as uncomfortable or impractical for household work.

In addition, specialized footwear can be provided for people with foot drop to support toe clearance during walking and to improve gait safety. Ongoing follow up and rehabilitation for individuals who have completed leprosy treatment remain essential to prevent worsening disability and to support independence, autonomy, and quality of life (Silva et al., 2014).

Table 4 . Comparison of pre test and post test knowledge scores on hand and foot self care (n=20)

No.	Knowledge Items	Pretest	Posttest
1.	Hygiene of hand and foot wound	2.20(±0.61)	3.80(±0.61)
2.	Hand and foot skin becomes softer and less rough	2.25(±0.64)	3.70(±0.65)
3.	Fingers are more flexible and easier to move	2.80(±0.69)	3.85(±0.74)
4.	Feeling of odor due to the wound is reduced	2.15(±0.74)	3.90(±0.78)
5.	Wearing glasses is more comfortable	2.50(±1.00)	3.80(±0.76)
6.	Using footwear that fits your size	2.70(±0.97)	3.95(±0.68)
7.	Using gloves when working	3.90(±0.78)	4.10(±0.78)
	Overall	**2.64(±0.36)**	**3.87(±0.20)**

Table 5 . Comparison of knowledge score pretest and posttest (n=20)

Variable	Mean ± SD	Mean Difference ± SD	t	p-value*	95% Confidence Interval of the Differences	
					Lower	Upper
Pretest	2.64(±0.36)					
Posttest	3.87(±0.20)					
Pre-Post		-1.22 (±0.45)	-12.2	<0.001	-1.439	-1.017

*Paired t-test: p-value < 0.05

4. CONCLUSION

Following the refresher course on self care techniques, participants showed a meaningful improvement in self care activity scores, as reflected by an increase in the mean pre test score of 2.64 plus or minus 0.36 to a mean post test score of 3.87 plus or minus 0.20. These findings support the value of refresher education for strengthening hand and foot self care practices among people formerly affected by leprosy.

The program also indicated improvement in self efficacy for carrying out self care. Prior successful experiences with self care and support from peers and family members appeared to strengthen self efficacy and support more consistent practice. Self care interventions should be tailored to participant characteristics such as age, disability grade, and leprosy type, because these factors may influence confidence and the ability to apply skills learned during training. Ongoing education and health counseling are needed to help participants understand practical strategies to reduce the risk of secondary injury and disability progression. Periodic refresher sessions delivered through the community health center can help maintain motivation, reinforce skills, and encourage participants to support others in the community.

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CONFLICT OF INTERESTS

The authors declare no competing interests.

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