

A Survey to Estimate Adherence to Self-Care Practices among Leprosy Patients with Peripheral Neuropathy Undergoing Physiotherapy

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In India, leprosy has shown a remarkable decline in prevalence; however, longterm disability persists. Patients undergoing physiotherapy are prescribed exercises and advised following selfcare measures to prevent sensory and motor complications. Despite these interventions, adherence to selfcare remains understudied. This study aims to determine adherence to self-care practices among leprosy patients with peripheral neuropathy who are undergoing physiotherapy. A cross-sectional survey was conducted among 70 leprosy patients with peripheral neuropathy undergoing physiotherapy in tertiary hospitals in Sangli, Maharashtra. A paper-based questionnaire on self-care behaviours related to peripheral neuropathy was administered. Domain-wise and question-wise analysis was performed. Overall, 57 (81.43%) of patients showed fair self-care, while only 13(18.57%) demonstrated good selfcare. Adherence to sensory selfcare was satisfactory for basic hand, foot care and footwear inspection, but very few patients practiced adequate rest and offloading on foot wounds. For motor neuropathy, 28(40%) of patients did not perform all prescribed exercises, including stretching, mobility, and strengthening. The study highlights the importance of adherence to self-care practices among leprosy patients. Addressing these gaps is critical to preventing disability. Strengthening patient education and awareness, especially regarding home exercise routines, should be prioritized to enhance self-care and reduce longterm complications.

Keywords: Leprosy, Self-care, Rehabilitation, Peripheral Neuropathy, Cross-sectional Studies

Introduction

Leprosy, also known as Hansen's disease, is a chronic infectious disease caused by *Mycobacterium leprae* (Hannan et al 2022). This bacterium targets schwann cells in peripheral nerves, leading to nerve damage that impairs sensory and motor functions, thereby causing diverse neurological complications (Bhat & Prakash 2012). Leprosy patients suffer from

physical disorders such as lagophthalmos, mutilation, blindness, secondary infections in wounds, and physical anomalies. If not treated early, it leads to disabilities (Sarker et al 2015).

According to the Press Information Bureau Government of India report, prevalence of leprosy in India has fallen from 57.2 per 10,000 population in 1981 to just 0.57 in 2025 (PIB 2025). This significant decline can be attributed

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to the multiple Government-led programs along with significant support by several national and international non-governmental organizations that provide awareness, preventive measures, treatment, and rehabilitation to slow down the progression of the disease and reduce disability. Despite advances in multidrug therapy, many individuals continue to experience leprosy-related disabilities that limit their functional abilities and social participation. These challenges are often compounded by social stigma, gaps in treatment, and shortcomings in health services (Hasina 2022). A retrospective study conducted in Southern India found that two-thirds of leprosy patients presented with deformities or disabilities, indicating persistent issues related to access to early and appropriate management (Spandana et al 2024). Whether these problems arise from ignorance, lack of awareness, or other contributing factors warrants further investigation.

Effective management of leprosy requires not only pharmacological treatment but also active patient engagement through self-care and physiotherapy. Physiotherapy plays a crucial role in addressing both sensory and motor neuropathy by providing interventions like sensory re-education, stretching, strengthening, and preventive techniques (Hassan & Zafar 2023). Self-care practices—including wound inspection, soaking, oiling, protecting limbs from injury, and stretching—are vital to prevent complications such as stiffness, contractures, and further limb damage (Dos Santos et al 2022).

Integrating physiotherapy with consistent self-care has been shown to maintain function, reduce disability, and improve quality of life among people affected by leprosy. Moreover, such combined approaches promote limb protection and functional independence (Darlong 2021). Patients undergoing physiotherapy treatment

are prescribed with exercises and advised self-care measure to prevent sensory and motor complications. Despite these interventions, adherence remains understudied.

Understanding the current self-care behaviours of leprosy patients undergoing physiotherapy is essential to know the prevalence, deformities, and quality of life (Serrano-Coll et al 2016). Therefore, the current study aims to determine the adherence to self-care measures among leprosy patients with peripheral neuropathy who are undergoing physiotherapy treatment from Sangli district.

Materials and Methods

This cross-sectional study was carried in Richardson Leprosy Hospital, Miraj. After approval of Institute Ethics Committee (BV (DU) MC&H/Sangli/IEC/Phy-39/25)), a total of 70 leprosy patients, having peripheral neuropathy and undergoing physiotherapy treatment were included through convenient sampling from the hospital's inpatient and outpatient physiotherapy department over a typical cross-sectional period of 3-6 months to capture available cases during routine clinic visits. The patients who could not comprehend questions and were not cooperative were excluded. Adherence to self-care was assessed using a paper-based questionnaire consisting of 18 questions. A series of questions were selected from the WHO guidelines. The questions were segregated into motor or sensory section. The questions were then presented and approved by the panel of expert physiotherapists and research advisory committee of the department (World Health Organization 2006). The sensory domain consisted of self-care about skin, wound, and precautions taken while holding hot/ cold objects. The motor domain consisted of adherence to exercises. All the answers were in the form of Yes/ No. Yes, scored 1 and No was scored 0. The adherence was classified as; Poor

Self-Care from 0-6 score; Fair Self-Care from 7-12 score and Good Self-Care from 13-18 score.

Data was entered into Microsoft Excel and analyzed. Descriptive statistics such as frequency, percentage, mean, media, mode, standard deviation, and range were used to summarize the findings.

Results

The demographic characteristics of the patients are presented in Table 1. Most of our patients (51/70, 66%) were 18-60 years of age which are active earning years. Like most of earlier reports, 43/70 (61%) were males.

The overall self-care assessment revealed 57/70 (81.43%) of the participants exhibited fair self-care practices, whereas only 13 (18.57%) demonstrated good self-care practices (Table 2).

Table 3 shows the question wise analysis of patients' adherence related to sensory neuropathy. Adherence to self-care for sensory domain was largely satisfactory. The maximum self-care activity performed by the patients was soaking hands/feet in water and checking footwear daily for sharp objects or damage. It is, however, observed that a small number of patients do not take precautions during weight bearing practices (Table 3).

Table 1: Demographic characteristics of the patients (N=70).

Age Group(yrs)		No of patients	Percentage
31-40 yrs		8	11.43
41-50 yrs		21	30
51-60 yrs		22	31.43
61-70 yrs		15	21.43
71-80 yrs		4	5.71
Total		70	100
Mean's		54.6±10.3 (35-80 yrs)	
Gender	Male	43	61.43
	Female	27	38.57
Total		70	100

Table 2: Adherence to Self-care practices in leprosy patients having peripheral neuropathy.

Adherence Score	No of patients	Percentage
Poor Self-Care (0-6)	0	0
Fair Self-Care (7-12)	57	81.43
Good Self-Care (13-18)	13	18.57
Total	70	100

Table 3: Question wise analysis of adherence to self-care practices- Sensory Domain.

Questions	No of patients with Answer "YES" N= 70	Percentage
Q1: Have you told a health worker if your skin patches become red, painful, or swollen?	41	58.57
Q2: Do you soak your hands/feet in water every morning and evening for about 20 minutes?	57	81.43
Q3: After soaking, do you remove hard skin and apply oil or Vaseline to your hands/feet?	40	57.14
Q4: Do you use gloves or cloth to hold hot objects?	40	57.14
Q5: Do you wear soft shoes and avoid sandals with hard soles?	52	74.29
Q6: Do you check your footwear daily for sharp objects or damage?	56	80.00
Q7: Do you avoid holding your hands near fire when feeling cold?	45	64.29
Q8: Do you check your hands/feet daily for wounds, redness, or swelling?	42	60.00
Q9: When you have a foot wound, do you rest it by lying down or using crutches/stick?	27	38.57
Q10: Do you avoid walking barefoot or wearing tight or broken shoes?	47	67.14

Table 4: Question wise analysis of adherence to self-care practices- Motor Domain.

Questions	No of patients with Answer "YES" N= 70	Percentage
Q1: Have you noticed weakness or loss of feeling in your hands or feet?	40	57.14
Q2: Have you developed regular exercise habit?	44	62.86
Q3: Do you do hand exercises regularly to reduce stiffness or weakness?	40	57.14
Q4: Do you do these hand exercises at least three times a day?	36	51.43
Q5: Do you perform mobility exercises regularly?	41	58.57
Q6: Do you perform strengthening exercises regularly	35	50.00
Q7: Do you perform exercise to improve your grip?	38	54.29
Q8: Do you consistently follow your self-care routines?	39	55.71

Table 4 shows the question wise analysis of patients' adherence related to motor neuropathy.

The distribution of patients according to motor neuropathy revealed varying levels of self-care

knowledge. When compared to sensory domain 40% patients fail to perform all types of exercises that is stretching, mobility and strengthening exercises. The consistency of regular exercises also remained low (Table 4).

Discussion

The present study highlights varying levels of self-care knowledge among leprosy patients with sensory and motor neuropathy, indicating domain-specific strengths and gaps in self-care practices. The current study, most participants demonstrated only fair self-care practices $n=57$ (81.43%), with a limited proportion exhibiting good self-care $n=13$ (18.57%), aligning with similar study in 2022 who reported basic self-care knowledge but limited perseverance among leprosy patients. The previous study focused on psychosocial determinants while the present study provides domain-specific analysis identifying areas of both sensory and motor self-care practices (Hannan et al 2022).

The higher knowledge observed in skin and wound care, foot protection, and eye care in the present study agrees with previous study done by Darlong (2021) who noted that frontline self-care programs primarily emphasize wound prevention, protective footwear, and ocular care. These practices are often repeatedly reinforced during clinic visits, making them easier for patients to adopt. Both studies highlight that patients are more compliant with preventive measures related to visible complications, particularly foot ulcers. However, the lower knowledge scores observed in hand care, mobility modification, and off-loading practices during foot wounds in the present study 27 patients (38.57%) reflect similar gaps reported by Darlong, who attributed these deficiencies to inadequate training, limited resources, and insufficient emphasis on behaviour change strategies (Darlong 2021).

Furthermore, the moderate knowledge levels related to motor neuropathy and exercise-based self-care observed in the present study are comparable with findings from Susanto et al (2017). Both studies underscore the importance of early identification of neuropathy and consistent intervention.

Overall, the comparison with previous studies (Hannan et al 2022, Darlong 2021, Susanto et al 2017) suggests that although basic self-care knowledge among leprosy patients is present, significant gaps remain in functional and rehabilitative self-care domains. Addressing these gaps through enhanced patient education, regular supervision, family involvement, and community-based rehabilitation programs may improve adherence to self-care practices, reduce disability progression, and enhance quality of life for individuals affected by leprosy. Disability prevention, medical rehabilitation and self-care are important components of National Strategic Plan and Roadmap for eradication of leprosy (NSP 2023-2027). Our limited data, though cannot be generalised to all settings, provides a glimpse of challenges ahead.

In summary, comparing of our data with previous studies suggests that although basic self-care knowledge is present among leprosy patients, substantial gaps remain in functional and rehabilitative self-care areas. Addressing these through enhanced patient education, ongoing supervision, family involvement, and community-based rehabilitation can improve self-care adherence, reduce disability progression, and enhance quality of life for those affected by leprosy. It is important that the interventions should be evidence-based and may be implemented after proper studies in different geographical and institute-level settings.

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