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Pattern Of Disability and its Relationship with Disease Related Physical Involvement, Stigma, and Mental Health Status among People Living with Leprosy

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Abstract

Background: Leprosy continues to be a major cause of preventable disability, particularly in low-resource settings. While its physical impairments are well-documented, the relationship between disability, leprosy-related stigma, and mental health remains underexplored, especially in marginalized communities. This study aimed to assess the pattern of disability and its association with disease-related physical involvement, stigma, and mental health among people living in a leprosy colony in Nepal.

Materials and Methods: A cross-sectional descriptive study was conducted among 119 residents of Khokana Arogya Ashram, a sheltered colony for people affected by leprosy. Data were collected on socio-demographic and clinical profiles, stigma (SARI Stigma Scale), mental health status (Hospital Anxiety and Depression Scale – HADS), and disability (12-item WHO Disability Assessment Schedule 2.0 – WHODAS 2.0). Non-parametric statistical tests (Spearman correlation and Mann-Whitney U-test) were used to assess associations.

Results: The highest disability scores were noted in the "getting along" domain, while "mobility" had the lowest. Overall disability scores were significantly associated with age, lower education, leprosy-related ulcers, eye involvement, facial palsy, aesthetic disfigurement, and elevated HADS scores. However, there was no statistically significant association between stigma scores and disability.

Conclusion: Among people affected by leprosy in a segregated community, disability was more closely associated with physical impairment and mental health symptoms than with perceived stigma. These findings emphasize the need for comprehensive care approaches that address both physical and psychological aspects of disability in leprosy.

Key words: Leprosy, Disability, WHODAS 2.0, Stigma, Mental Health, HADS, Nepal

Introduction

Leprosy is a chronic infectious disease and a major cause of preventable disability. Though there is a significant reduction in global prevalence of leprosy, it still remains a major cause of morbidity owing to its associated long-term disabilities and sequelae.[1] Disability for a disease is an impairment in functioning at

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the body, person, or societal levels in different domains of life experienced by an individual.[2] International Classification of Functioning, Disability and Health (ICF) categories different dimensions of disability as body structure and function (and impairment thereof), activity (and activity restrictions) and participation (and participation restrictions).[3] Leprosy not only causes physical impairments and activity restrictions, but also lead to social stigma and discrimination leading to psychological trauma.[4] A study done in Indonesia among 1,358 people living with leprosy, showed that majority of the respondents had problems in all components of disability.[5]

In the context of Nepal, the prevalence rate of leprosy has been maintained at below 1 per 10,000 population since the declaration of country's goal towards its elimination. However, high case detection rate and pockets of endemic areas still exist.[6] A qualitative study with total of six focused group discussions (FGDs) with 43 participants from a community living close to a Leprosy Hospital and ten semi structured interviews (SSIs) with health care providers in Nepal showed that Leprosy was still perceived to be a feared condition, and concealed by people as it created potential discrimination. Different aspects like marriage, employment and social interaction were affected by the stigma which was strongly associated with leprosy-related visible deformity.[7]

There are many correlates of disability in case of people living with leprosy. However, there is dearth of literature in a niche population of leprosy patients living in a sheltered community setting from the Nepalese societal context. Also, having knowledge regarding the factors associated with disability in Leprosy would be important for guiding leprosy-related disability prevention or mitigation programs. The previously published work in the same data set found high prevalence of depression and anxiety with social and psychological effects of leprosy as major drivers of mental health problems.[8] It is important to distinguish whether the disability is due to mental health status or the physical status in this group of people living with leprosy. In this paper, we aim to explore the pattern of disability and its relationship with disease related physical involvement, stigma, and mental health status among people living with leprosy in a colony of leprosy patients.

Materials and Methods

This manuscript presents a secondary analysis of the same dataset described in the previous paper, however, the disability assessment and analysis was pre-specified in the original study protocol.[8] This was a cross-sectional descriptive study was conducted at Khokana Arogya Ashram, which is a colony where people with leprosy (above 18 years), having some disability and abandoned or marginalized by their family members live. All enumerative sampling technique was employed, and all the patients of leprosy staying in the colony were enrolled after taking informed consent. The participants who were not willing to give consent to the study, and children below 18 years of age were excluded. The study included 119 respondents and these was no missing data. The data was collected by two researchers going to each household of the community. using paper and pencil method. Ethical clearance was obtained from institutional ethics review committee of Patan Academy of Health Sciences with reference drs2112211584.

Data on socio-demographic details and clinical profile like age, gender, education, marital status and leprosy related physical impairment were taken. The mental health status was assessed using translated and validated Nepali version of The Hospital Anxiety and Depression Scale (HADS).[9] The different domains of stigma was assessed using 22 items Stigma Assessment and Reduction of Impact (SARI)- Stigma Scale.[10] WHODAS 2.0[11] was used to assess disability gives domain-specific scores for six different domains of functioning/ adult life tasks: Cognition – understanding & communicating (items 3 and 6); Mobility– moving & getting around (items 1 and 7); Self-care– hygiene, dressing, eating & staying alone (items 8 and 9); Getting along– interacting with other people (items 10 and 11); Life activities– domestic responsibilities, leisure, work & school (items 12 and 2); and Participation– joining in community activities (items 4 and 5). The WHODAS 2.0 does not attempt to determine whether disability is due to physical or psychological disorders. There are 36 and 12 items versions of the WHODAS 2.0 that can be completed by the patient, by their clinician, or by an informant. We have used the 12-item version in this study, which has shown to produce acceptable results when compared with the 32-item WHODAS 2.0. Response options for each item ranged from 1 to 5 to indicate the level of difficulty or a problem, i.e., none (1 point), mild (2 points), moderate (3 points), severe (4 points), and extreme or cannot do (5 points). The overall points for global disability therefore ranged from 12 (no disability) to 60 (complete disability), with higher results indicating a higher level of disability.[12] In addition, the individual scores in each domain were also calculated by adding up the results of the two relevant items.[13]

The two tools SARI-Stigma Scale and WHODAS 2.0 were translated from English to Nepali by bilingual expert. The Nepali version was be examined by the researchers for the content. After that the version was back translated into English by another bilingual expert (not the first one). The examination of back translation was again done by the researchers. Final version was made and any controversy in words was resolved by mutual consensus. The grammatical

correction was corrected by Nepali language expert. The Nepali questionnaire was administered by the researcher and was marked appropriately by them. In case of confusion some clarifications were done. The uniformity was maintained as both the researchers collecting data were medical interns competent in Nepali language.

The data were analysed using SPSS version 23.0 (Armonk, NY, IBM Corp). Descriptive statistics using mean, standard deviation, frequency and percentage were used to describe the basic demographic profile, leprosy related clinical characteristics, leprosy related stigma, and WHODAS 2.0 scores. Additionally, median and inter-quartile range was described for skewed data. The data was checked for normal distribution using the Kolmogorov–Smirnov test, and non-parametric tests were applied as the WHODAS 2.0 total and domain-wise scores had a skewed distribution. Thus, appropriate non-parametric inferential statistics (Spearman correlation, Mann Whitney U-test) was conducted to explore the relationship of disability among study participants with disease related physical involvement, leprosy specific stigma, and their mental health status (HADS score). The level of statistical significance was set at *p*-value <0.05 for all the tests.

Results

The data from a total of 119 participants was analysed. The mean age of study participants was 62.09 years [standard deviation (SD): 16.74], with number of females slightly higher than the males (63:56). The basic demographic and leprosy related clinical profile of study participants have been described in previous study.[8]

The mean and median stigma score was 17.88 (SD: 14.53) and 14.00 (IQR: 7.00-24.00) respectively. The mean and median total disability score was 25.06 (SD: 10.59) and 24.00 (IQR: 16.00-34.00) respectively. Table 1 described the pattern of leprosy-related stigma and disability among the study participants. The participants reported relatively lesser degree of disclosure concerns and experienced stigma on the SARI-stigma scale. However, they experienced higher degree of internalized stigma and anticipated stigma. The highest disability scores on the WHODAS 2.0 were reported for the getting along (interacting with other people) domain. Whereas, lowest disability scores on WHODAS 2.0 were reported for the mobility (moving and getting around) domain.

Table 1: Pattern of leprosy-related stigma and disability among study participants (N=119)

Leprosy-related Stigma profile:	Mean ± SD/ Median (IQR)
Experienced stigma	3.15 ± 7.11/ 0.00 (0.00-0.00)
Disclosure concerns	1.35 ± 3.10/ 0.00 (0.00-0.00)
Internalized stigma	7.67 ± 6.02/ 7.00 (2.00-12.00)
Anticipated stigma	5.70 ± 4.48/ 6.00 (0.00-9.00)
SD: Standard Deviation; IQR: Inter-quartile range.	
WHODAS 2.0 domain wise disability:	Mean ± SD/ Median (IQR)
Cognition	4.53 ± 2.58/ 4.00 (2.00-7.00)
Mobility	6.38 ± 2.93/ 7.00 (4.00-9.00)
Self-care	3.87 ± 2.26/ 3.00 (2.00-6.00)
Getting along	2.48 ± 1.26/ 2.00 (2.00-2.00)
Life activities	4.04 ± 2.07/ 4.00 (2.00-5.00)
Participation	3.75 ± 2.02/ 3.00 (2.00-5.00)
WHODAS 2.0: World Health Organization's Disability Assessment Schedule version 2.0 (12-items).	

Table 2 described the relationship of global and domain-wise disability with disease related physical involvement, stigma, and mental health status in people living with leprosy. Disability in cognition domain (understanding & communicating) was significantly associated with age (rs=0.36, p<0.01), education (Illiterate: 5.00 vs. Up to 10th standard: 2.50; U=1337.50, p=0.02), leprosy related eye involvement (Yes: 5.00 vs. No: 3.00; U=1246.00, p<0.01), leprosy related facial palsy (Yes: 7.00 vs. No: 3.00; U=448.00, p<0.01), and leprosy related aesthetics problem (Yes: 5.00 vs. No: 2.00; U=748.50, p<0.01).

Table 2: Relationship of disability with disease related physical involvement, stigma, and mental health status in people living with leprosy

Study variables	WHODAS-Cognition	WHODAS-Mobility	WHODAS-Self-care	WHODAS-Getting along	WHODAS-Life activities	WHODAS-Participation	WHODAS-Total
Age	0.36[a] (<0.01)*	0.15[a] (0.08)	0.35[a] (<0.01)*	0.11[a] (0.20)	0.25[a] (<0.01)*	0.32[a] (<0.01)*	0.34[a] (<0.01)*
Gender	1532.00[b] (0.20)	1746.00[b] (0.92)	1507.00[b] (0.14)	1507.00[b] (0.05)	1410.50[b] (0.05)	1456.50[b] (0.08)	1490.00[b] (0.14)
Education	1337.50[b] (0.02)*	1583.50[b] (0.39)	1251.00[b] (<0.01)*	1673.00[b] (0.63)	1461.00[b] (0.12)	1350.00[b] (0.02)*	1317.00[b] (0.02)*
Marital status	1593.00[b] (0.97)	1585.50[b] (0.93)	1585.00[b] (0.93)	1588.50[b] (0.93)	1509.50[b] (0.60)	1473.50[b] (0.46)	1578.00[b] (0.90)
Leprosy related limb involvement	272.50[b] (0.40)	268.00[b] (0.38)	230.00[b] (0.15)	325.50[b] (0.81)	241.50[b] (0.22)	277.50[b] (0.43)	237.00[b] (0.21)
Leprosy related ulcers	1151.50[b] (0.05)	1353.50[b] (0.49)	1194.00[b] (0.08)	1187.00[b] (0.02)*	1178.00[b] (0.08)	952.50[b] (<0.01)*	1101.00[b] (0.03)*
Leprosy related eye involvement	1246.00[b] (0.01)*	1402.50[b] (0.12)	1272.00[b] (0.01)*	1635.00[b] (0.73)	1308.50[b] (0.03)*	1205.50[b] (<0.01)*	1202.00[b] (<0.01)*
Leprosy related facial palsy	448.00[b] (<0.01)*	484.50[b] (<0.01)*	565.00[b] (0.01)*	689.00[b] (0.05)	508.50[b] (<0.01)*	449.50[b] (<0.01)*	393.50[b] (<0.01)*
Leprosy related loss of sensation	467.50[b] (0.77)	371.50[b] (0.20)	458.50[b] (0.69)	382.50[b] (0.11)	379.00[b] (0.23)	377.00[b] (0.21)	383.50[b] (0.26)
Leprosy related infertility	936.50[b] (0.69)	811.50[b] (0.19)	987.50[b] (0.98)	931.00[b] (0.55)	954.00[b] (0.79)	811.50[b] (0.18)	874.50[b] (0.41)
Leprosy related aesthetics problem	748.50[b] (<0.01)*	1067.00[b] (0.09)	900.50[b] (<0.01)*	1083.00[b] (0.03)*	690.00[b] (<0.01)*	920.00[b] (<0.01)*	761.50[b] (<0.01)*
Experienced stigma	0.09[a] (0.11)	-0.06[a] (0.47)	0.20[a] (0.02)*	-0.002[a] (0.98)	0.16[a] (0.06)	0.09[a] (0.29)	0.10[a] (0.27)
Disclosure concerns	0.10[a] (0.25)	0.04[a] (0.62)	-0.05[a] (0.54)	0.03[a] (0.74)	0.05[a] (0.52)	0.11[a] (0.22)	0.06[a] (0.48)
Internalized stigma	-0.10[a] (0.27)	-0.10[a] (0.26)	-0.04[a] (0.65)	0.07[a] (0.43)	0.01[a] (0.91)	0.02[a] (0.83)	-0.03[a] (0.68)
Anticipated stigma	-0.14[a] (0.11)	-0.05[a] (0.54)	-0.08[a] (0.37)	-0.04[a] (0.59)	-0.09[a] (0.30)	-0.02[a] (0.75)	-0.09[a] 0.30)
HADS-Total score	0.09[a] (0.31)	0.09[a] (0.32)	0.23[a] (0.01)*	0.12[a] (0.17)	0.18[a] (0.04)*	0.22[a] (0.01)*	0.19[a] (0.03)*

WHODAS: World Health Organization's Disability Assessment Schedule version 2.0 (12-items) domains; HADS: Hospital Anxiety Depression Scale; * p-value <0.05; a Spearman's correlation coefficient; b Mann Whitney-U test.

Disability in mobility domain (moving and getting around) was significantly associated with leprosy related facial palsy (Yes: 9.00 vs. No: 6.00; U=484.50, p<0.01).

Disability in self-care domain (hygiene, dressing, eating & staying alone) was significantly associated with age (r_s=0.35, p<0.01), education (Illiterate: 4.00 vs. Up to 10th standard: 2.00; U=1251.00, p<0.01), leprosy related eye involvement (Yes: 4.00 vs. No: 2.00; U=1272.00, p=0.01), leprosy related facial palsy (Yes: 4.00 vs. No: 2.00; U=565.00, p=0.01), leprosy related aesthetics problem (Yes: 4.00 vs. No: 2.00; U=900.50, p<0.01), experienced stigma (r_s=0.20, p=0.02), and HADS total score (r_s=0.23, p=0.01).

Disability in getting along domain (interacting with other people) was significantly associated with leprosy related ulcers (Yes: 2.00 vs. No: 2.00; U=1187.00, p=0.02), and leprosy aesthetics problem (Yes: 2.00 vs. No: 2.00; U=1083.00, p=0.03).

Disability in life activities domain (domestic responsibilities, leisure, work and school) was significantly associated with age (r_s=0.25, p<0.01), leprosy related eye involvement (Yes: 4.00 vs. No: 3.00; U=1308.50, p=0.03), leprosy related facial palsy (Yes: 5.00 vs. No: 3.00; U=508.50, p<0.01), leprosy related aesthetics problem (Yes: 4.00 vs. No: 2.00; U=690.00, p<0.01), and HADS total score (r_s=0.18, p=0.04).

Disability in participation domain (joining in community activities) was significantly associated with age (r_s=0.32, p<0.01), education (Illiterate: 4.00 vs. Up to 10th standard: 3.00; U=1350.00, p=0.02), leprosy related ulcers (Yes: 4.00 vs. No: 2.00; U=952.50, p<0.01), leprosy related eye involvement (Yes: 4.00 vs. No: 2.00; U=1205.50, p<0.01), leprosy related facial palsy (Yes: 5.00 vs. No: 3.00; U=449.50, p<0.01), leprosy related aesthetics problem (Yes: 4.00 vs. No: 2.00; U=920.00, p<0.01), and HADS total score (r_s=0.22, p=0.01).

Overall disability (WHODAS 2.0 total score) was significantly associated with age (r_s=0.34, p<0.01), education (Illiterate: 25.00 vs. Up to 10th standard: 21.00; U=1317.00, p=0.02), leprosy related ulcers (Yes: 24.00 vs. No: 20.00; U=1101.00, p=0.03), leprosy related eye involvement (Yes: 26.50 vs. No: 21.00; U=1202.00, p<0.01), leprosy related facial palsy (Yes: 33.00 vs. No: 21.00; U=393.50, p<0.01), leprosy related aesthetics problem (Yes: 26.00 vs. No: 18.50; U=761.50, p<0.01), and HADS total score (r_s=0.19, p=0.03).

Discussion

In the present study we aimed to study the pattern of disability in people living with leprosy and its relationship with leprosy related physical involvement, stigma, and mental health status in a colony of patients with leprosy. It was observed that study participants reported relatively lesser degree of disclosure concerns and experienced stigma; but higher degree of internalized stigma and anticipated stigma. The studies have been showing a higher degree of stigma among people living with leprosy and this stigma are similar among different cultures and countries.[14,15] The lesser degree of disclosure concern and experienced stigma in our study sample can be explained on the basis that they were living in a separate niche colony that served as a safe place for them. However, the findings regarding overall stigma are at par with that reported in the literature available from Nepal and abroad.[16,17]

The highest disability scores on the WHODAS 2.0 were reported for the getting along (interacting with other people) domain, and the lowest disability scores were reported for the mobility (moving and getting around) domain. It is a well-established fact that globally leprosy causes disability in various domains of life of the patient, which is increased by delayed diagnosis and multisystem involvement.[18,1,19,20]

The total disability score was significantly associated with age, education, leprosy related ulcers, leprosy related eye involvement, facial palsy, aesthetics problem, and depression or anxiety symptom severity (HADS total score) among study participants. The study from Brazil done among 275 leprosy patients have shown similar association with age and duration with disease.[21] Another study from China among 10644 leprosy patients have shown association of disability with age.[22] A study from India among 171 leprosy patients and 73 patients from Brazil has shown association of disability with education of patients.[19,23] The finding from our study regarding the association of disability with the features suggestive of leprosy related nerve involvement like ulcers, facial palsy, eye involvement and aesthetic problems is also in line with most of the published literature throughout the world.[22,24] The association of disability could also be diue to the higher prevalence of mental health issues independently in this population.

The interesting finding from our study was no association of different types of stigma with the disability scores in contrast to some other studies which had suggested that stigma was a major determinant of disability in patients of leprosy.[25,5] One of the reason for this could be that the study participants were living in a separate community where very few had job outside of there living place, leading to less disability associated with stigma. However, the mental health problems measured by HADS score had association with the disability among the participants similar to that reported in other prior studies.[26,27]

One of the unique characteristics of the present study is the recruitment of homogenous participants from a single-site, community of individuals affected by leprosy. Given the global decline in such segregated

communities due to improved treatment access and increased social integration, this study offers a rare opportunity to examine the different domains of disability among individuals living together in a leprosy-affected colony. However, certain limitations must be acknowledged. The study employed self-reporting tools where the bias can occur. And the use of WHODAS 2.0 scale which is a self-administered tool asking questions by the researcher might have led to socially desirable responses. Also, cross-sectional design cannot make any inference of causality between leprosy-related factors and disability. The overlap with the earlier study and this study being from the same data set could have led to reporting and duplication bias. Lastly, the single setting of this research and the population with mean age of 62.09 (SD= 16.74 years) may limit the broader applicability of its findings to the wider population of people affected by leprosy across Nepal.

Conclusion:

There is definite disability among the participants with leprosy living in a leprosy colony as seen from the WHODS 2.0 scale. The disability score was associated with age, education, leprosy related ulcers, leprosy related eye involvement, facial palsy, aesthetics problem and depression and anxiety scores but not associated with stigma scores.

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