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Research Article

Physical Problems and Social Stigma Faced by Leprosy Patients in a Hospital of Lalitpur

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ABSTRACT

Leprosy is one of the critical health problem in the developing countries which affects physical, social and psychological aspects of human being. The study aimed to identify the physical problems and social stigma faced by leprosy patients in a hospital of Lalitpur focusing on prevalent myths and physical deformities caused by the disease. A descriptive cross-sectional research design and non-probability purposive sampling technique was used to conduct this study through interviewer administered questionnaire among 109 leprosy patients at Anandaban hospital and Patan's Clinic. The study assessed public attitudes toward leprosy patients using the Explanatory model interview catalogue stigma scale (EMIC) and identified disfigurement and ulcer by direct observation and disability using the WHO disability grading tool. Data analysis was done using SPSS version 16. Inferential statistics Mann Whitney U and (chi-square tests) was used at 5% level of significance. The findings revealed that a significant portion of respondents were aged 40-59 years. Most respondents reported physical problems, predominantly grade 1 disability. Many patients disclosed their condition to relatives, over half kept it secret, and a substantial majority experienced shame or embarrassment. Nearly half of the respondents perceived higher stigma. There was a significant associations of physical problems with age, occupation, and disease duration. The study emphasizes the importance *of raising awareness at all community levels and the knowledge regarding medical advances of the leprosy to mitigate disease concealment, low self-esteem and shame or embarrassment and address the associated social stigma.*

Keywords: Disfigurement, Disability, Leprosy patients, Physical problems, Social stigma

INTRODUCTION

Mycobacterium leprae, an acid-fast, rod-shaped bacillus, is the infectious agent that causes leprosy, often referred to as Hansen's disease. Leprosy is a community-based infectious disease that can cause problems for people, including economic difficulties (Siregar & Ratnawati, 2018), social life changes (Yudanagara, 2020), psychological issues resulting from a failure to adjust to deteriorating health conditions (Jatimi, Yusuf, et al., 2020), and permanent physical disability (Rismayanti et al., 2017).

Leprosy is treatable, and disability can be avoided with early diagnosis and treatment. In addition to the clinical representation that typically follow infection, the stigma attached to leprosy is more detrimental than the illness itself. It has been discovered that stigma is linked to the emergence of ulcers, visual abnormalities, and false beliefs about the illness. Any impairment, restriction on activities, or limitation on participation that affects an individual is referred to as a disability (Adhikari et al., 2014).

Studies reveal that even those who have been cured of leprosy can still experience stigma and discrimination due to their condition (Lusli et al., 2015). The social burden on individuals with disabilities is primarily due to persistent and long-standing social stereotypes, often exacerbated by visible attributes like deformities, impairment, and disabilities. In a qualitative study carried out in Eastern Nepal, it was discovered that visible indicators of leprosy, such as moist wounds, ulcers, and reactions on the skin receiving treatment, were stigmatizing factors (Marahatta et al., 2018). Hence, Leprosy is still stigmatized and considered a social sickness rather than just a medical one, even though it is fully curable and medications are readily available at health centers. The World Health Organization (WHO) reported a significant increase in newly diagnosed leprosy cases in 2018, with 2,08,619 new cases detected from 127 countries having the highest leprosy burden in South-East Asia region, including 3,282 cases in Nepal, which nearly broke the WHO's elimination target (The Himalayan Times, 2020).

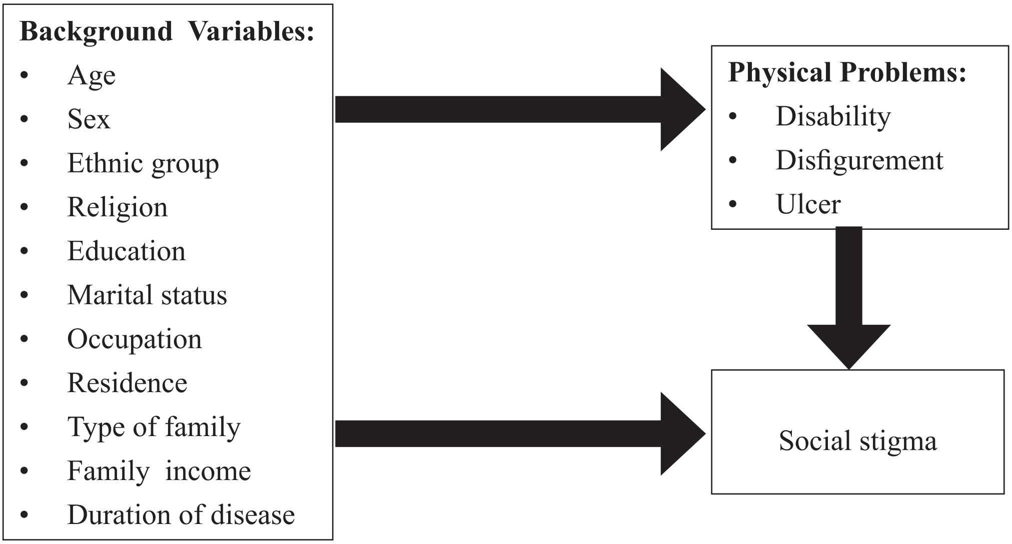
Since ancient times, stigma surrounding the contagious disease leprosy has led to negative perceptions and subsequent stigmatization. The primary factors contributing to the stigma associated with leprosy include the disease's outward symptoms, such as damage to the hands, feet, or eyes, as well as cultural and religious beliefs, ignorance, and fear. Chronic stress can have a detrimental effect on both physical and mental health because of these unfavorable outcomes and the fear of stigma. Health-related stigma can lead to people delaying or avoiding seeking treatment or care due to fear of stigmatization (Noordende et al., 2021). As per the research conducted in Eastern Nepal to identify the impact of leprosy among married women the problems faced by them are forms of stigma and discrimination, rejection, abuse, divorce, or loss of employment can lead to reduced self-esteem and loss of respect from communities (Noordende et al., 2016).

Different articles concluded that leprosy has still become the chronic disease causing physical problems and social stigma to the patients despite of many medical advantages and awareness too. There are only few published works that discuss the effects of leprosy on those who have it. So, researchers felt there is need to identify the problems faced by the leprosy patients. It is crucial for offering support against stigma, discrimination, and isolation, as well as for promoting the holistic well-being. Therefore, the research team is curious to learn about the real physical problems and social stigma that leprosy patients deal with.

Conceptual framework shows the interrelationship between independent variables such as age, sex, ethnic group, religion, education, Marital status, occupation, residence, family type, family income and duration of disease with dependent variables on physical problem and social stigma faced by leprosy patients. Independent variables may influence directly or indirectly on the physical and social problems faced by leprosy patients.

Figure 1

Conceptual Framework on Physical Problems and Social Stigma Faced by Leprosy Patients



DATA AND METHODS

Descriptive cross-sectional research design and non- probability purposive sampling technique was used to find out the physical problems and social stigma among leprosy patients in a hospital of Lalitpur. This study was conducted at Anandaban Hospital located in Godawari-06, Lalitpur which was established in 1957. It is a 80 bedded leading leprosy referral hospital serving patients from across the country. All the leprosy patients who were hospitalized and who visited OPD at Patan's clinic (every Wednesday) and Anandaban Hospital during the data collection time period were included in the study. The total sample size was 109.

On the basis of research objectives, structured Interviewer administered questionnaire was used for data collection. For identifying disfigurement and ulcer, direct observation was done by researcher. Questions related to background information, disfigurement and ulcer were made by researcher herself and disability tool of WHO was used to identify grade of disability. The Explanatory module interview catalogue tools (EMIC) scale was adopted to identify perceived stigma faced by leprosy patients. The research instrument was divided into three parts.

Part I: Questions related to background information: This part consisted of 10 items which includes age, sex, ethnicity, residence, education, marital status, religion, occupation, type of family and family income.

Part II: Questions related to disfigurement and ulcer and disability: This part consisted of 7 questions in which 6 multiple choice questions to assess disfigurement, ulcer and separate disability tool of WHO was used to identify the Grade of disability.

Part III: Likert scale related to perceived social stigma. The EMIC scale was adopted which consisted of 15 questions with 4 points likert scale consisting of (0) No, (1) Uncertain, (2) possibly, (3) Yes. Question no. 2 was in negative form, therefore reverse scoring was done. It has been classified to measure the perceived stigma in leprosy by the International Federation of Anti-Leprosy Association (ILEP) (Voorend et.al., 2011). The higher the score, the higher the level of perceived stigma.

The internal consistency of the instruments, as measured by Cronbach's α, was very good for all, ranging from 0.83 to 0.96 (Brakel et. al., 2011).

Validity of part I of the tool was maintained by extensive literature review, seeking opinion of subject experts as well as consulting with research advisor, teachers and peer review. Pre-testing of the instruments was done in 10 % (i.e. 10 respondents) of total sample.

Approval was obtained from the research committee of Pokhara Nursing Campus. Request letter for data collection was submitted to medical director of Anandaban Hospital of Godawari-06, Lalitpur and formal written permission was taken for data collection. Written informed consent was taken from every patient before data collection. Data was collected by researcher herself through face to face interview using interviewer administered questionnaire. Confidentiality was maintained by not disclosing the information given by the patients. About 20 – 25 minutes was taken to interview each respondent and each day 10 – 12 respondents were interviewed. Data was collected from 2024/01/28 to 2024/02/09 AD.

After data collection, all collected data were checked and organized for the accuracy and completeness. Data was kept in order for editing and coding. The collected data was reviewed, organized, edited, coded and entered in SPSS (Statistical Package for Social Sciences) version 16. Data was analyzed using descriptive statistic frequency, percentage, mean and standard deviation and inferential statistics chi-square test and Man Whitney test was used at 5% level of significance. As the stigma score were continuous data and were not normally distributed, Mann Whitney U test was used. Chi square test was used to assess association between physical problems and background variables and Mann Whitney U test was used to assess the difference in total perceived stigma score among different variables.

RESULTS AND DISCUSSION

Out of total of 109 leprosy patients, (36.7%) of patients were within the age range of 40-59 years. Overall mean and standard deviation of age of those patients was 48.30±17.53. Majority of the leprosy patients were males (69.7%) and (35.8%) were Brahmin/chhetri. Concerning the religion (78.8%) of total population were Hinduism and (53.2%) were literate. Most of them were married which was about (78.9%). Regarding occupation of the respondents (49.5%) were engaged in Agriculture. Among them (71.6%) belong to joint family and (63.3%) of respondents were from rural areas. About (48.6%) of them had lower family income i.e. < 4850 (Table 1).

Table 1

Socio-Demographic Characteristics of Respondents (n= 109)

Characteristics	Number	Percent
Age in Years		
< 20	3	2.8
20-39	32	29.3
40-59	40	36.7
60-79	34	31.2
Mean±48.30, SD±17.53, min =18 max = 79		
Sex		
Male	76	69.7
Female	33	30.3
Ethnicity		
Brahmin/Chhetri	39	35.8
Janajati	27	24.8
Madhesi	27	24.8
Dalit	11	10.1
Muslim	3	2.8
Others	2	1.7
Religion		
Hindu	86	78.8
Buddhist	9	8.3
Christian	9	8.3
Kirant	2	1.8
Muslim	3	2.8
Education level		
No (illiterate)	51	46.8
Basic level	36	33.0

Secondary level	15	13.8
Higher education	7	6.4
Marital status		
Married	86	78.9
Unmarried	22	20.2
Widow/widower	1	0.9
Occupation		
Agriculture	54	49.5
Unemployed	17	15.6
Homemaker	11	10.1
Student	9	8.3
Labor	7	6.4
Business	6	5.5
Service	5	4.6
Family type		
Joint	78	71.6
Nuclear	31	28.4
Residence		
Rural	69	63.3
Urban	40	36.7
Family income (NPR)		
< 4850	53	48.6
4851-14550	39	35.8
14551-24350	5	4.6
24351-36550	6	5.5
36551-48750	4	3.7
48751-97450	1	0.9
>97451	1	0.9

The highest duration of illness was (33.0%) which belonged to range of 20 years and above. Majority of the respondents had a physical problems which was about (72.5%). Firstly affected lesions of leprosy person seen in Hands/foots (83.5%) and (63.3%) of patients had presence of disfigurement or deformities. Approximately, (37.6%) had developed their first disfigurement or deformities before the first visit at hospital. More than half of the respondents (62.4%) had presence of ulcer, mainly ulcer was seen in foots (82.3%). Among them (73.6%) of ulcer had foul smelling and (71.6%) had experience difficulty in walking due to leprosy. Similarly, (49.6%) of the leprosy patients had Grade 1 disability while having Grade 0 disability was (28.4%) and Grade 2 was (22.0%) (Table 2).

Table 2

Physical Problems of Leprosy Patients (n=109)

Characteristics	Number	Percent
Duration of disease (Years)		
< 1	12	11.0
1-4	28	25.7
5-19	33	30.3
≥ 20	36	33.0
Physical problems		
Yes	79	72.5
No	30	27.5
Lesions first seen in		
Hands/or foot	91	83.5
Other body parts	11	10.1
Facial region	7	6.4
Presence of disfigurement or deformities		
Yes	69	63.3
No	40	36.7
First disfigurement or deformities		
Before the first visit	41	37.6
During the treatment	25	22.9
After the treatment	3	2.8
Presence of ulcer		
Yes	68	62.4
No	41	37.6
Body Parts having ulcer (n = 68)		
Foots	56	82.3
Hands	12	17.7
Foul smelling ulcer (n = 68)		
Yes	50	73.6
No	18	26.4
Difficulty in walking		
Yes	78	71.6
No	31	28.4
Disability grading		
Grade 0	31	28.4
Grade 1	54	49.6
Grade 2	24	22.0

About half of the patients (50.5%) kept the disease condition knowing from others and (81.7%) of leprosy patients disclosed the condition to the close ones. Similarly, (73.4%) think less of yourself because of this problem. Likewise, (78%) of the leprosy patients had shame or embarrassment and about (29.4%) felt about social problems to their children in community due to leprosy. Among 109 leprosy affected persons, the median score of perceived stigma was 15, Q1 was 12 and Q3 was 20.5 while it ranged from 3-38, and nearly half of the respondents (45.9%) perceived higher stigma (Table 3).

Table 3

Social Stigma Faced by Leprosy Patients (n=109)

Items	No No. (%)	Uncertain No.(%)	Possibly No.(%)	Yes No.(%)
Keep others from knowing if possible	43 (39.4)	2 (1.8)	9 (8.3)	55 (50.5)
Disclosed to the close person about this condition	15 (13.8)	1 (0.9)	4 (3.7)	89 (81.7)
Think less of yourself because of this problem	17 (15.5)	3 (2.8)	9 (8.3)	80 (73.4)
Shame or embarrassment due to leprosy	18 (16.4)	3 (2.8)	3 (2.8)	85 (78.0)
Less respect from others because of this problem	61 (56.0)	16 (14.6)	11 (10.1)	21 (19.3)
Contact with you would have bad effects on others	48 (44.0)	14 (12.8)	33 (30.4)	14 (12.8)
Others have avoided you because of this problem	62 (56.9)	21 (19.5)	10 (9.4)	16 (14.2)
Others might refuse to visit your home	81 (74.3)	11 (10.1)	9 (8.3)	8 (7.3)
Others would think less of your family	70 (64.2)	16 (14.7)	11 (10.1)	12 (11)
Social problems to your children in community	32 (29.4)	14 (12.8)	31 (28.4)	32 (29.4)
Disease causes problems in getting married (unmarried only)	2 (10.5)	6 (31.6)	6 (31.6)	5 (26.3)
Disease causes problem for your marriage(married only)	69 (76.6)	-	6 (6.7)	15 (16.7)
Causes marriage problems to your family	32 (29.4)	21 (19.3)	31 (28.4)	25 (22.9)
Asked to stay away from work or social groups	100 (91.8)	2 (1.8)	2 (1.8)	5 (4.6)
Decided on self to stay away from social group	84 (77.1)	1 (0.9)	4 (3.7)	20 (18.3)

Others presume you have other health problem	37 (33.9)	52 (47.7)	9 (8.3)	11 (10.1)

There was significant association between physical problems of leprosy patients with age of respondents, occupation and duration of disease. Those patients whose age was more than 49 years, unemployed and those who had more than 20 years of duration of illness had more physical problems by ulcer, disfigurement and disability than their counterparts (Table 4).

Table 4

Association Between Physical Problems of Leprosy Patients and Background Variables (n=109)

Physical Problems				
Variables	Yes No. (%)	No No. (%)	χ^2	p value
Age (Years)				
≤ 49	29(36.7)	50 (63.3)	18.908	<0.001
>49	25 (83.3)	5 (16.7)		
Sex				
Male	59 (77.6)	17 (22.4)	3.344	.067
Female	20 (60.6)	13 (39.4)		
Ethnicity				
Brahmin/chhetri	28 (71.8)	11 (28.2)	.014	.905
Others	51 (72.9)	19 (27.1)		
Religion				
Hindu	63 (73.3)	23 (26.7)	.124	.725
Others	16 (69.6)	7 (30.4)		
Education status				
Illiterate	41 (80.4)	10 (19.6)	3.010	.083
Literate	38 (65.5)	20 (34.5)		
Marital status				
Currently single	15(19.0)	64 (81.0)	.770	.380
Others	8 (26.7)	22 (73.3)		
Occupation				
Unemployed	71 (89.9)	8 (10.1)	8.494	<0.001
Employed	20 (66.7)	10 (33.3)		
Family type				
Joint	58 (74.4)	20 (25.6)	.487	.485
Nuclear	21 (67.7)	10 (32.3)		
Residence				

Urban	28 (70.0)	12 (30.0)	.194	.659
Rural	51 (73.9)	18 (26.1)		
Family income (NRS)				
≤ 4850	41 (77.4)	12 (22.6)	1.232	.267
> 4850	38 (67.9)	18 (32.1)		
Duration of disease (Years)				
< 20	39 (57.4)	29 (42.6)	20.730	<0.001
≥ 20	40 (97.6)	1 (2.4)		

p-value significant at < 0.05 $\chi 2$: chi square

There was no any significant difference in social stigma with the selected variables (Tale 5).

Table 5

Difference in Social Stigma with Background Variables (n = 109)

Variables	Number	Median scores	Quartile		p value
			Q^1	Q^3	
Age (year)					
≤ 49	54	15	12.7	20	.727
>49	55	15	10	22	
Sex					
Male	76	15	11.2	20.7	.579
Female	33	15	12	21.5	
Ethnicity					
Brahmin	39	14	12	21	.664
Others	70	15	12	20	
Religion					
Hindu	86	15	12	21	.797
Others	23	14	11	18	
Education status					
Illiterate	51	15	12	20	.424
Literate	58	14.5	10.7	21	
Marital status					
Currently single	23	14	13	21	.826
Others	86	15	11.7	20	
Occupation					
Unemployed	91	15	12	21	.143
Employed	18	14	12	16	
Family type					

Joint	78	14	12	19.2	.133
Nuclear	31	17	12	23	
Residence					
Urban	40	14	11	21	.603
Rural	69	15	12	20	
Family income (NRS)					
≤ 4850	53	14	11	21	.738
> 4850	56	15	12	20	

Mann Whitney U Test; p-value significant at < 0.05

There was no any significant difference in social stigma with physical problems and duration of disease (Table 6).

Table 6

Difference in Social Stigma with Physical Problems and Duration of Disease (n = 109)

Variables	Number	Median scores	Quartile		*p* value
			Q1	Q3	
Physical problems					
Yes	79	15	12	22	.568
No	30	15	12.7	19	
Duration of disease (Years)					
< 20	68	15	12.2	19	.925
≥ 20	41	15	9.5	22.5	

Mann Whitney U Test; p- value significant at < 0.05

DISCUSSION

Descriptive statistics were used to describe the socio-demographic, physical problems and social stigma faced by leprosy patients. Difference in total perceived stigma score using EMIC between different categorical variables were analyzed using Mann Whitney U test since these scores were not normally distributed. The study was conducted to identify the physical problems and social stigma faced by leprosy patients. The study found that (36.7%) of leprosy patients were aged 40-59 years, with a mean age of 48.30±17.532. Most patients were males (69.7%), followed by Hinduism (78.9%).

The study found that (72.5%) of respondents had physical problems, with over half having disfigurement or deformities (63.3%). This is slightly higher than a study done by (Adhikari et al. 2014) in Green Pasture Hospital where patients having disfigurement or deformities was about (51.1%). Around one third of respondents (37.6%) had their first disfigurement or deformities before their first hospital visit. The majority of patients had lesions which was firstly seen on hands or feet (83.5%), which is consistent with a study in Indonesia by (Brakel et al.,2012) where lesions and disfigurement was mainly seen in Feets/Hands. Also similar with the study conducted in India where disfigurement was mainly seen in hand (44.48%), followed by feet 39.76%, and face 15.74% respectively (Rathod et al.,2019).

More than half of the respondents (62.4%) had presence of ulcer. This finding is nearly similar with research done in Green pasture hospital by (Adhikari et al., 2014) where percentage of having ulcer is higher (55.6%). Most of patients (82.3%) had foot ulcers, (73.6%) having foul odor. Nearly two third (71.6%) experienced difficulty walking due to leprosy. Similarly, (49.5%) of leprosy patients had Grade 1 disability, while 28.4% had Grade 0 disability and 22.0% had Grade 2 disability, aligning with (Rodrigues et al.'s 2016) findings that Grade 1 disability is higher than other disabilities (63·6%). Findings is also similar with the study conducted at Gujarat India where grade 1 disabilities was higher (21.25%) and (6.31%) had Grade 2 or more severe deformity (Rathod et al.,2019). In contrast the study conducted at west Bengal, India Grade 2 disability was higher which was about (61.7%) whereas Grade 1 disability was (26.2%) and Grade 0 disability was (12.1%) respectively (Banerjee et al.,2022).

The perceived stigma towards individuals affected by leprosy is a significant indicator of societal attitudes and stereotypes. Community people are particularly concerned about concealing the disease (51.2%) after diagnosis (Adhikari et al., 2013). Consistent with a study done in Eastern Nepal, leprosy affected individuals used concealment as a strategy to maintain social integrity, as stereotypical views on the disease remained dominant. Concealing the disease (65.9%), disclosure (40.7%) and shame and embarrassment (37%) due to leprosy was also a major concern for leprosy affected persons attending Green pastures hospital, Nepal (Adhikari et al.,2014). Similarly, concealment was major finding in an Indonesian study where almost 40% of the community participants perceived that leprosy affected person would conceal the disease (Brakel et al., 2012). Self-Stigma against themselves experienced by leprosy sufferers is triggered by disturbances in the self-concept component (Mahanani & Idris, 2020).

This study also reveals that majority of the patients does not want others from knowing that they are affected from leprosy. And half of patients (50.5%) kept the disease condition knowing from others, most of the patients disclosed the condition to the close ones (81.7%). This study shows that (78%) of the leprosy patients has shame or embarrassment due to leprosy. This is quiet similar to (Adhikari et al., 2014) where (65.9%) of Leprosy affected persons intended to conceal their disease, (40.7%) disclosed to the close person about this condition and (37%) experienced lowered self-esteem due to leprosy. The study indicates that fear after disclosure is a more significant aspect of EMIC compared to other aspects that are more related to real-life situations.

This study reveals that there was a significant association between the physical problems and background variables . Significant association seen in those having age more than 49 years, those who are unemployed and those having duration of disease more than 20 years (p value: <0.001). However, many of the study have not considered this socio-demographic variables. Therefore, no comparison of results could be conducted. Current study reveals that there was no significant difference in stigma with the background variables .This result was quiet similar to the study conducted at Green Pasture Hospital of Pokhara (Adhikari et al., 2014) where it represented that there was no any significant association between the socio-demographic variables except the level of education. The finding of the present study shows no any significant difference in social stigma with physical problems which is consistent with the study conducted at Green Pasture Hospital, Pokhara (Adhikari et al., 2014). Similarly, it was supported by another study done in Eastern Nepal (Brouwers et al, 2011).

CONCLUSIONS

The study concluded that majority of the respondents had physical problems including disfigurement, ulcer and disability. Nearly half of the respondents perceived higher stigma. There was significant association of physical problems with age, occupation and duration of disease. There was no any significant difference in social stigma with the selected variables and physical problems of leprosy patients. To reduce the physical problems and social stigma, it is essential to conduct awareness programs in community levels and the knowledge regarding the medical advances of the leprosy focusing on concealment, low self-esteem and shame or embarrassment.

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