*International Research Journal of Social Sciences*_____ ISSN 2319–3565
Vol. **10(4),** 14-19, October **(2021)** *Int. Res. J. Social Sci.*

Case Study

Participation Restriction in Leprosy Patients - a case study

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Available online at: www.isca.in, www.isca.me
Received 24th March 2021, revised 1st August 2021, accepted 21st September 2021

Abstract

To assess the role of participation restriction and evaluate the prevalence of impairment and the effect of stigma among the people affected by Hansen's disease in the Kashmir valley. The assessment and evaluation were carried out among 120 leprosy patients suffering from leprosy in the Kashmir valley through adequate participation restriction scales. A comparative questionnaire was designed for two groups, Group I (for government leprosarium, Behral, Lalbazar) and Group 2 (for Kupwara, Ganderbal, Kangan and Budgam districts of Kashmir Valley). The result of the present study reveals that Grade I disability due to leprosy is higher and has the worst association with participation restriction than Grade II. In the study, it has been found that early diagnosis, effective treatment in disease and management of leprosy reaction can prevent participation restriction and are thus essential measures in preventing stigma related to it. The health services can play an important role to fight leprosy patients from the tag of stigma. The findings of the study revealed that participation restriction is directly related to the duration of the disease and has a negative correlation with education. Stigma has a significant role in aggravating the phenomena of participation restriction. Counselling through camping on Leprosy can overcome the myths related to leprosy and can abolish the roots of stigma.

Keywords: Stigma, Impairment, Disability, P-Scale.

Introduction

Leprosy, classified under the category of social diseases, besides being one among the oldest disease known to humankind is also one such infectious disease which triggers many complex problem particularly disability which is mainly due to the delayed detection followed with inadequate and insufficient medication with a result, it affects the quality of life viz –viz their participation in society and other associated factors which restricts its involvement in general. Leprosy caused by Mycobacterium tuberculosis though it is much resistant to culture. M. Leprae is an intercellular microorganism that usually infects the cooler part of the human body, which includes mainly the skin and the nerves of the body. As per dermatology lesions and peripheral nerves are the cardinal clinical feature of leprosy.

Leprosy is included in the list of Neglected Tropical Diseases (NTD)[1] which have an estimated global case of 7.44 billion, 18% of which have been found in India[2]. While for years India has been committed to multidrug therapy for leprosy, the highest percentage of new as well as prevalent cases of Leprosy as per both WHO-NTD and IHME have been reported in India[3]. WHO estimates that out of a total of 214,783 new reported cases of leprosy and 171,948 prevalent cases, 63% and 51% respectively are from India. IHME estimates that out of 523,245 reported cases of leprosy 32% are from India. Studies by Tsutsumi et al. and Lustosa et al. have proved that patients with Hansen's disease face numerous problems other than the disease itself[4,5]. Being a chronic infectious and communicable disease that poses a risk of permanent and progressive physical disability, it is further responsible for contributing the root cause of stigma and discrimination[6,7]. The associated visible deformities and disability have negatively contributed to the stigma and decimation experience by Leprosy patients even among those who have been cured. The patients remain trapped in the vicious circle of disease, impairment, stigma and also faces discrimination. In leprosy, physical impairment is considered to be the secondary effect in term of nerve damage which is caused due to chronic granulomatous inflammation because of Mycobacterium leprae and their impairment gives rise to certain disability such as participation restriction and social restriction due to impairment and disability in hands, feet, and eyes. The World Health Organization has classified impairments due to leprosy into three grades[8]. These are: i. Grade 0: No impairment; ii. Grade 1: Loss of sensation in hands and feet; and iii. Grade 2: Visible impairment.

As per International Classification of Functioning (ICF) (WHO, 2001), there are several categories and dimensions of disability such as structure of the body and its functioning and impairments thereof, activity (activity restriction) and participation (participation restriction). The ICF classification also emphasis the role of disability as per physical and social

environmental factors are concerned which are one way or other way affecting the disability outcomes. Further ICF has focused on the role of environment (physical, cultural, social, political) life of disabled patients rather than focusing on just disability itself as a mere medical or biological dysfunction.

Though besides knowing so much about the disease and its adverse effects, leprosy is diagnosed too late, unfortunately, when permanent physical impairment has already occurred. After the completion of the treatment, a significant proportion of leprosy patients sustain physical impairment and disability due to nerve damage and further require continuous health care (self) to limit any further secondary damage. In addition to the physical impairment, participation restriction triggers the social stigma and discrimination, leading to socio-economic loss[9]. Stigma due to disability is not the only phenomenon condition but there are several other components responsible for it[10]. These include self-stigma (shame and low self-esteem) or public stigma (general public prejudice), which are also factors for restrictions in social participation and discrimination.

As per the records, leprosy believed to have been disappearing since the introduction of dapsone in 1940 and more gradually after the introduction of MDT in 1980[11]. As per WHO, leprosy ranks one among the top in the list of NDT disease throughout the world. Though leprosy has shown downfall after the aggressive case findings and treatment campaigns in 2007, the execution in 1990 and 2000 with the result there was a significant reduction in new cases of leprosy during 2003 to 2009. However, as per the latest report[12], leprosy has a comeback in India; although India has shown a significant reduction in leprosy patients, undoubtfully India still holds more than half of the world's leprosy cases. As per the report submitted by the Directorate General of Health Services, the leprosy patients in India is approximately 1 case per 10,000 per year.

Methodology

In the present study stigma associated with Leprosy has been undertaken by measuring Participation restriction using participation scale (P-Scale)[13]. This scale though does not measure Stigma by itself but it measures the extent to which people participate in the social functions. The participation scale of 18 items is based on the terminology and conceptual framework of the International Classification of Functioning (ICF). The scale measures the level of social participation which are directly affected by stigma. Questions were asked in a private room free from disturbance and explanations wherever needed were provided to patients for their accurate responses.

The study has been carried out on two groups of patients - Group 1 has been taken from Government-run leprosarium and Group 2 from different districts of Kashmir Valley.

The socio-economic status was recorded based on Kuppuswamy Scale[14]. This scale was devised by Kuppuswamy in 1976 and consisted of a composite score that includes education and occupation of the family head and income per month of the family. This scale classifies the study populations into five SES. The scores for all three items are summed together to calculate the total score, and the socio-economic class are determined as follows: Upper (I) for score 26-29; Upper Middle (II) for scores 16-25; Lower Middle (III) for scores 11-15; Upper Lower (IV) for scores 5-10; and Lower (V) for scores 1-4. The head of the family's occupation and education are not changeable with time, but due to change in the Rupee's value, the income categories in the scale lose their scoring. As such, updated scales as per the changes in consumer price index (CPI) are made, thus making the socio-economic scale applicable to current populations[15].

The grading of participation was done as 0-12, 13-22. 23-32, 33-52 and 53-90 for cases with no significant, mild, moderate, severe and extreme restrictions respectively. The two groups were compared and results were analysed. The study also used WHO classification of grading for disability, which is as follows:

For hands and feet: i. Grade 0: For no anaesthesia, no visible deformity or damage; ii. Grade 1: For anaesthesia present but no visible deformity or injury; and iii. Grade 2: For visible deformity or damage present;

For eyes: i. Grade 0:For no eye problem due to leprosy, no evidence of visual loss; ii. Grade 1:For eye problem due to leprosy present, but vision not severely affected as a result (vision 6/60 or better, can count fingers at 6 meters); and iii. Grade 2:For severe visual impairment (vision worse than 6/60; inability to count fingers at 6 m) also includes lagophthalmos, iridocyclitis, corneal opacities.

Related work: Van Brakel el at. in a study to assess the fallout of role of impairment, activity, social participation, stigma and discrimination among the disabled patients due to leprosy[7]. They concluded that these are the most frequent problems faced among such patients and further stated that the severity of community stigma among the leprosy patients correlates with the severity of their participation restrictions.

Samy el at. in their study concluded that all the leprosy patients need to develop self-care to protect their limbs while performing any job, as prevention of any physical impairment and disability will help them to improve social and other participation[16].

Nicholls el at. while undertaking a study aimed to find out the risk factors among the leprosy patients which are responsible for their participation restriction explored screening tools to identify the patients who are at risk[17]. They concluded that physical impact, emotional response to the diagnosis, gender and education need to pay attention while dealing with the leprosy patients to help them avoid being victims of participation restriction.

Slim el at., in their study concluded that physical impairment (foot and eyes) significantly contribute to the limitation and participation restriction among the leprosy patients as compared to the hand impairment[18]. Their results indicate that leprosy patients living in non-endemic countries are considered the disabled and high prevalence of impairment, perceived substantial limitation in activities and their social participation is restricted.

The study of leprosy patients has put light on stigma, and it has been found that the critical factors of stigma in leprosy as measured by participation Score, which are education, socioeconomic status, presence and grade of deformity[19].

Being declared as a patient who belongs to Hansen's disease with irreversible physical damage and the trauma caused due to the stigma attached, very less work has been carried out so far in the state of Jammu and Kashmir.

Current Study: Very less research has been carried out on the effect of Stigma on leprosy patients in Jammu and Kashmir and as such stigma has never been taken as an essential factor in the treatment of leprosy patients. The present study has been made to calculate the level of participation restriction among the disabled leprosy patients and the role of the stigma associated with it, henceforth many other factors are also emphasized and impressed upon which are more or less responsible for its prevalence. The study has been carried by taking two groups of patients viz - group 1 has been made from Government-run leprosarium where they are being treated Indoor and this group consists of peoples who are part of different social environment from different parts of Jammu and Kashmir and the group 2 has been taken from Kupwara, Ganderbal, Kangan and Budgam districts of Kashmir Valley. The study cases have been distributed based on age, socio-economic, residence, level of education, disability grade and participation restrictions which have been studied in each group.

Results and discussion

In the two groups, all cases were older than 25 years of age. Maximum patients in Group 2 have age in the range of 25 to 50 years. In the case of Group 1, the age of maximum patients was more than 40 years. As shown in Table-1, the combined mean age of the two groups was 43 years and 3 months.

As shown in Table-2, the cases in group 2 had an average of 2.2 years of schooling compared to group 1, who had only 1.05 years of education. Almost 2/3rd of the evidence in group 1 had no education at all.

As shown in Table-3, all cases belonged to upper-middle-class in group 2, while as in group 1 had evidence for the lower-middle and upper-lower social class as per Kuppuswamy scale.

Table-1: Distribution by age.

Group	Mean Age (Years)	Youngest (Years)	Oldest (Years)	Age < 20 Years	Age 20-40 Years	Age > 40 Years
Group 1	55.3	30	75	0	3	30
Group 2	31.2	26	47	0	23	5
Combined	43.25	26	75	0	26	35

Table-2: Distribution by the level of literacy.

Group	Mean Education (Years of Schooling) +/-S. D	No Schooling	Primary School	Middle School	High School	12th	Graduation	Total
Group 1	1.05 +/-0.6	54	6	0	0	0	0	60
Group 2	2.20 +/- 1.2	45	15	0	0	0	0	60
Total	1.60 +/- 1.7	99	21	0	0	0	0	120

Table-3: Distribution by socio-economic status.

Group	Upper Class	Upper Middle Class	Lower Middle Class	Upper Lower Class	Lower Class	Total
Group1	0	0	34	26	0	60
Group2	0	60	0	0	0	60
Total	0	60	34	26	0	120

As shown in Table-4, group 1 included patients most of the urban background while in group 2 patients were mainly of rural areas.

As can be seen in Table-5, in group 1, patients had a longer mean duration of illness (43.4 years), while as in group 2, patients had a lesser mean duration of illness (4.2 years). The difference is statistically significant as indicated by both t-test and non-parametric test.

As shown in Table-6, patients from both groups had a disability in hands/feet and eyes as per the WHO classification scale. Grade 2 disability was found in 54 and 14 patients, respectively in group 1 and group 2 while as grade 1 disability was found in 6 and 46 patients, respectively in group 1 and group 2.

Table-7 shows the found participation scores studied across two groups for identifying restrictions and its association with factors like education, socio-economic status and grade of disability. It has been found that group 1 has a high mean score of participation restriction (63.8) in comparison to group 2 (16.6). Further, it has been found that participation restriction was significantly different in the two groups.

Table-8 shows the distribution by the severity of participation restriction. Severe participation restriction is present in most patients in group 1, while as in group 2 patients, participation restriction is comparably very less.

As can be observed from Table-9, grade 2 disability is related to participation restriction in all patients from both the groups alarming its risk factor for participation restriction.

As can be observed from Table-10, the highest participation restriction has been found in patients belonging to the lower middle class, followed by the upper lower class and upper-middle class.

Table-4: Distribution by residence.

Group	Rural	Urban	Total
Group 1	18	42	60
Group 2	56	4	60
Total	74	46	120

Table-5: Distribution by the duration of disease (n is 60 for each group).

Group	Longest (Years)	Shortest (Years)	More than 5 Years	Less than 1 Year	1-5 Years	Mean (Years)	S. D.	p-Value
Group 1	52	6	30	0	4	43.4	*24.32*	
Group 2	13	1	6	8	20	4.2	*4.9*	*0.034*
Combined	52	1	36	8	24	23.8		

Table-6: Grading of disability as per WHO classification.

Group	Grade 1 Patients	Grade 2 Patients	Total
Group 1	6	54	60
Group 2	46	14	60
Total	52	68	120

Table-7: Participation score (n is 60 for each group).

Group	Mean Score	Highest Score	Lowest Score	Restriction (score >=13)	No Restriction (score <=12)	Mean	S. D.	p-Value
Group 1	63.8	79	6	54	6	63.8	27.6	
Group 2	16.6	31	0	14	46	16.6	12.7	0.042
Total	40.2	79	0	68	52			

Table-8: Distribution by the severity of restriction.

Group	No significant Restriction	Mild Restriction (score:13-22)	Moderate Restriction (score:23-32)	Severe Restriction (score: 33-52)	Extreme Restriction (score:53-90)
Group 1	6	8	16	26	4
Group 2	46	12	2	0	0
Total	52	20	18	26	4

Table-9: Relationship between participation restriction and grade of disability.

Participation Restriction	Group 1		Group 2		Combined	
	Grade 1 Disability	Grade 2 Disability	Grade 1 Disability	Grade 2 Disability	Grade 1 Disability	Grade 2 Disability
Yes	0	54	0	14	0	68
No	6	0	64	0	26	0

Table-10: Participation restriction according to socio-economic status.

Participation Restriction	Upper Class	Upper Middle Class	Lower Middle Class	Upper Lower Class	Lower Class	Total
Yes	-	14	32	22	-	68
No	-	46	2	4	-	52
Total	-	60	34	26	-	120

Conclusion

The participation restriction has been found directly related to the duration of disease and the grade of disability of leprosy patient. The longer the period of the disease or higher the grade of the disability, the higher is the participation restriction. The participation restriction is negatively correlated with education. The higher the education of patients, the lesser is the participation restriction. The necessary measures in prevention of disability due to leprosy would require early diagnosis of nerve damage. Further, necessary action at community, family and health centers by way of proper care and education needs to strengthen. Prevention of disability is most important to be taken into account to prevent social stigma and restrictions resulting after that. The study concludes that early diagnosis, effective treatment in disease and its management, and prevention of significant disability can improve social participation. Further, Education of patients and the public through campaigns can overcome the myths related to leprosy and can abolish the roots of stigma and participation restriction.

References

1. WHO-NTD. (2013). Neglected Tropical Diseases. *URL:*https://www.who.int/neglected_diseases/diseases/en/

2. Hotez, P. J., Bottazzi, M. E., Franco-Paredes, C., Ault, S. K., & Periago, M. R. (2008). The neglected tropical diseases of Latin America and the Caribbean: A review of disease burden and distribution and a roadmap for control and elimination. *PLoS neglected tropical diseases*, 2(9), e300.

3. IHME (2021). Institute for Health Metrics and Evaluation. *www.healthdata.org*

4. Tsutsumi A., Izutsu T., Islam A. M., Maksuda A. N., Kato H. and Wakai S. (2007). The quality of life, mental health, and perceived stigma of leprosy patients in Bangladesh. *Soc Sci Med*, 64(12), 2443-53.

5. Lustosa A. A., Nogueira L. T., Pedrosa J. I., Teles J.B. and Campelo V. (2011). The impact of leprosy on health-related quality of life. *Rev Soc Bras Med Trop*, 44(S), 621-6.

6. Brouwers C., Van Brakel W. H. and Cornielje H. (2011). Quality of life, perceived stigma, activity and participation of people with leprosy related disabilities in South East Nepal. *Disability, CBR and Inclusive Development*, 22(1).

7. Van Brakel W. H. , Sihombing B., Djarir H., Beise K., Kusumawardhani L., Yulihane R., et al. (2012). Disability in people affected by leprosy: the role of impairment,

activity, social participation, stigma and discrimination. *Glob Health Action*, 5(1), 183-194.

8. WHO. (2001). International classification of functioning, disability and health: ICF. World Health Organization. https://apps.who.int/iris/handle/10665/42407.

9. Withington S. G., Joha S., Baird D., Brink M. and Brink J. (2003). Assessing socio-economic factors in relation to stigmatization, impairment status, and selection for socio-economic rehabilitation: A 1-year cohort of new leprosy cases in north Bangladesh. *Lepr Rev*, 74(2), 120-32.

10. Adhikari B., Kaehler N., Chapman R. S., Raut S., Roche P. (2014). Factors Affecting Perceived Stigma in Leprosy Affected Persons in Western Nepal. *PLOS Neglected Tropical Diseases*, 8(6), e2940. *https://doi.org/10.1371/journal.pntd.0002940*.

11. Moura, S. H. L., Grossi, M. A. F., Moura, A. C. L., Lehman, L. F., Gomes, A. C., Santos, E. D., ... & Rocha, M. O. C. (2018). Evaluation of physical impairment and psychosocial disorders in new leprosy patients before and after multidrug therapy in a referral hospital in Belo Horizonte, Minas Gerais, Brazil: The value of rating scales in the assessment of disabilities. *Indian Journal of leprosy*, 90(1), 47-59.

12. Wire. (2019). Leprosy is making a comeback in India, but the govt wants to deny it. URL: https://thewire.in/health/leprosy-is-making-a-comeback-in-india-but-the-govt-wants-to-deny-it dated 04-Jan-2019.

13. Van Brakel, W. H., Anderson, A. M., Mutatkar, R. K., Bakirtzief, Z., Nicholls, P. G., Raju, M. S., & Das-Pattanayak, R. K. (2006). The Participation Scale: measuring a key concept in public health. *Disability and rehabilitation*, 28(4), 193-203.

14. Sharma, R. (2012). Kuppuswamy's Socioeconomic Status Scale–revision for 2011 and formula for real-time updating. *The Indian Journal of Pediatrics*, 79(7), 961-962.

15. Bairwa, M., Rajput, M., & Sachdeva, S. (2013). Modified Kuppuswamy's Socioeconomic Scale: Social Researcher Should Include Updated Income Criteria, 2012. *Indian journal of community medicine*, 38(3), 185–186. *https://doi.org/10.4103/0970-0218.116358.*

16. Nandgaonkar, H. P., Mancheril, J., Ebenezer, J., & Samy, A. A. (2002). Activities of Daily Living (ADL) Assessment: a measure for grading activity limitation in Leprosy patiens. *The Indian Journal of Occupational Therapy*, 34(3).

17. Nicholls, P. G., Bakirtzief, Z., Van Brakel, W. H., Das-Pattanaya, R. K., Raju, M. S., Norman, G., & Mutatkar, R. K. (2005). Risk factors for participation restriction in leprosy and development of a screening tool to identify individuals at risk. *Leprosy Review*, 76(4), 305-315.

18. Slim, F. J., van Schie, C. H., Keukenkamp, R., Faber, W. R., & Nollet, F. (2010). Effects of impairments on activities and participation in people affected by leprosy in The Netherlands. *Journal of rehabilitation medicine*, 42(6), 536-543.

19. Singh et al. (2009). A study on patients using p-scale. Association of participation restriction to socio economical class and grade of deformity.