

Quality of Life of People Affected with Leprosy Disability Living in Purulia, West Bengal

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ABSTRACT

Objective: This study aimed to assess the quality of life of people affected with leprosy disability living in Purulia district of West Bengal.

Methods: A cross-sectional study was conducted among 50 people affected with disability associated with leprosy and an equal number of people without disability aged 18 years and above who were reported at Purulia Leprosy Mission Hospital, West Bengal. The World Health Organization quality of life (WHOQOL-BREF) Scale was used to measure quality of life. The scale had four domains; physical health, psychological health, social relationship and environmental health.

Results: Among the total respondents, 51% were male, 60% were between 20 - 40 years of age, 49% were literate, 39 were house wives and 75% of family income was up to 5000 thousand rupees. Disease duration was 1 to 3 yrs in 37%, 3 to 5 years in 34% and more than 5 years in 29%. There was a highly significant difference seen among the leprosy affected persons with disability and without disability in all the four domains. The persons with disability had lower quality of life than the persons without disability.

Conclusion: The study observed that the person affected by leprosy with disability had lower quality of life. Early detection and management would prevent the deformity and thus prevent deterioration in the quality of life of leprosy affected persons.

Key word: Leprosy, Quality of life, Stigma, Disability, WHOQOL-Bref

INTRODUCTION

Leprosy is a chronic infectious disease caused by mycobacterium leprae and still a public health problem in India. In India, a total of 127,334 new cases were detected during the year 2015-16, and 4.6% of them had grade 2 disabilities at the time of diagnosis. ^[1] Physical disabilities caused by the disease resulted in enormous psychological consequences and more possibility to get poor quality of life. ^[2-4] The leprosy and leprosy related disabilities may predispose people to develop psychological, economic and social

problems which have an adverse effect on quality of life. ^[5]

Quality of life is important to everyone particularly, health. World health organization (WHO) defines quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns; this definition considers the person's physical and psychological health, social relationships, personal beliefs, environment and their relationship with salient features of their

environment. [6] Hence, this study aimed to assess the quality of life of people affected with leprosy with disability.

METHODS

A cross-sectional study was conducted among 50 leprosy affected people with disability and an equal number of leprosy affected people without disability aged 18 years and above, who were reported at The Leprosy Mission Hospital, Purulia, West Bengal from April to June, 2017.

Participant eligibility: A person suffering from leprosy for at least for a year at the time of interview and those who were willing to participate and give informed consent were included. Those living in leprosy colonies were excluded.

A semi-structured questionnaire was formulated to collect the demographic and disease profile of the respondents. The quality of life was assessed using validated Bengali version of the WHOQOL-BREF, which consisted of 26 items on a 5-point Likert scale of the patient's past four weeks of perception of their quality of life. [7-9] The scale measured the broad domains: physical health, psychological health, social relationships, and environment health with a

higher score indicating a better quality of life.

The study was approved by Doctoral Research Committee members, Department of Sociology, Bharathidasan University and The Research Committee of The Leprosy Mission Trust India permitted to conduct study in one of its hospitals. Participation was voluntary and information was collected anonymously after obtaining written consent from each respondent by assuring confidentiality throughout the period of data collection. The collected data was entered and analysed using Microsoft Excel database. The descriptive statistics and independent 't' test was done to compare the quality of life between two study groups.

RESULTS

Table.1 describes the demographic details and disease duration of the study participants, among them 60% were between 20-40 years of age, 49% were literate, 39 were house wives and in 75%, the family income was up to five thousand rupees. Seventy one percent of them were having duration of disease in a varied level of 1-5 years.

Table.1: Demographic profile and disease duration of the respondents (n=100).

Status	No Disability (n=50)		With Disability (n=50)		Total (n=100)
	Frequency	Percent	Frequency	Percent	
Sex					
Female	22	44%	19	38%	41
Male	28	56%	31	62%	59
Age					
20 to 40	32	64%	28	56%	60
40 to 60	16	32%	16	32%	32
Above 60	2	4%	6	12%	8
Education					
Illiterate	26	51%	25	49%	51
Literate	24	49%	25	51%	49
Occupation					
Farmer	10	20%	16	32%	26
House wife	21	42%	18	36%	39
Labour	15	30%	12	24%	27
Others	4	8%	4	8%	8
Family income					
Up to 5000	35	70%	40	80%	75
Above 5000	15	30%	10	20%	25
Disease duration					
1 to 3 years	29	58%	8	16%	37
3 to 5 years	12	24%	22	44%	34
Above 5 years	9	18%	20	40%	29

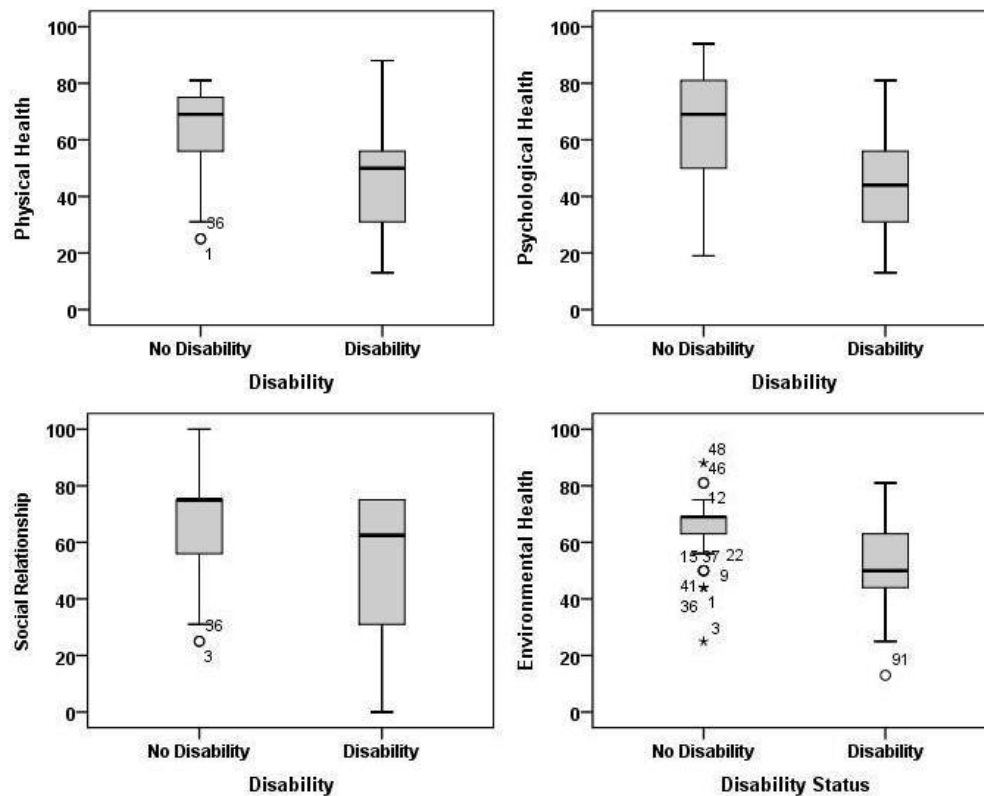


Figure 1: Comparison of Quality of life of respondents with disability and no disability.

Table.2: Independent 't' test -Differences in Quality of life by disability (n=100)

Domains wise Quality of life	N	Mean	Std. Deviation	t	df	p-value
Physical health						
No deformity	50	63.20	15.460	5.21	98	.00**
Visible deformity	50	46.44	16.704			
Psychological health						
No deformity	50	63.92	17.279	5.42	98	.00**
Visible deformity	50	46.04	15.662			
Social relationship						
No deformity	50	68.12	15.387	3.83	98	.00**
Visible deformity	50	53.04	23.225			
Environmental health						
No deformity	50	65.52	11.466	4.98	98	.00**
Visible deformity	50	52.66	14.191			

Note. **.Significant at <0.01

The leprosy affected person with disability had lower mean scores in all the four domains. The independent t test showed significant difference in quality of life from those with disability, in which significance between the two groups in all the four domains; Physical health domain [t (98) = 5.21, p = 0.00], Psychological health domain [t (98) = 5.42, p = 0.00], Social relationship domain [t (98) = 3.83, p = 0.00] and Environment health domain [t (98) = 4.98, p = 0.00]. The results revealed a lower quality of life in persons living with disabilities.

DISCUSSION

Multi-drug therapy (MDT) has been extremely successful in the treatment of leprosy. However, when there is a delay in diagnosis and initiation of treatment, nerve function impairment results in impairment and disability. [10,11] Stigma and discrimination occurs mainly due to physical disabilities in persons affected with leprosy and it leads to activity limitation and restriction in social participation, consequently impair the quality of life. [11,12]

The study findings further reveals that, the persons affected with leprosy disability had lower mean scores than the

person without disability in all the four domains; physical, psychological, social relationship and environmental health. In the same line Tsutsumi et al (2007) and Dinesh et al (2016) observed that the person affected with leprosy disability have poor quality of life. [13,14]

Leprosy predominantly affects the poor and marginalized people, moreover the family income have a stronger influence on the quality of life of persons affected with leprosy. [14-17] Similarly the study also shows that fifty percent of the persons affected with leprosy disabilities were in the productive age group of 20-40 years with young families and lower family income. Hence inferior the quality of life implies poor financial status, emotional and relationship problems and troubled family life.

Disability and leprosy are the two most stigmatized terms are instilled in the mind of people and in the society in a larger way. When these two strikes someone together, will fetch very series impact on their quality of life and lowers the morale of the affected person. The study observed that the quality of life was major concern for the people affected with leprosy disability than persons without disability. Early diagnosis and treatment will prevent disability and thus minimize the activity limitation, participation restriction and improve the quality of life.

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Contribution of Each Author

Mr. Pitchaimani Govindharaj was involved in study conceptualization and design, preparing the semi structural questionnaires, analysis and interpretation of data and preparation of the manuscript.

Dr. Sampathkumar Srinivasan was involved in study design, comments on the manuscript and finalized the manuscript for submission.

Dr. Joydeepa Darlong was involved in monitoring the study, getting approval from The Leprosy Mission Trust, India, New Delhi and comments on the manuscript.

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