



Higher educational status, staying in joint family and early treatment initiation improves quality of life in leprosy: Experiences from and observational study at a tertiary centre in Eastern India

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ABSTRACT

Introduction

Leprosy is a chronic infectious disease with various risks of permanent and progressive disabilities as well as deformities. This can lead to social stigma and discrimination.

Methodology

A cross sectional institution based study was conducted among the patient of a leprosy clinic in a tertiary care center. WHOQOL-BREF questionnaire was used after taking consent from each study individual.

Results

Majority (69.8%) of the patients was male and 41.3% of the study population belonged to below poverty line. Majority (85.7%) of the study population were suffering from multi-bacillary type of leprosy. Though Majority (96.8%) of the patients was receiving MDT (multi drug therapy) regularly but still 33.33% of them were leading a poor quality of life. It has been seen that literacy, family type and time gap between starting of symptoms and initiation of treatment were significantly associated with quality of life.

Discussion

Different previous studies showed QOL (quality of life) was associated with factors like SES (socio economic status), literacy and male gender, the present study revealed higher literacy, staying in the joint family and early treatment initiation helped to improve the QOL.

Conclusion

Better QOL was associated with higher educational status, good family support and early initiation of treatment among the leprosy patients.

INTRODUCTION

Leprosy, a chronic infectious affliction, is a communicable disease that poses a risk of permanent and progressive disability. The associated visible deformities and disabilities have contributed to the

stigma and discrimination experienced by leprosy patients, even among those who have been cured. It is a chronic granulomatous immunological disorder caused by *M. leprae* primarily affecting the peripheral nerves and secondarily involving skin and mucosal

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membrane etc. It can also affect eyes and some internal organs. The disease is clinically suspected by one or more hypo-pigmented patches over skin surface. The overall global target to eliminate leprosy has been attained in 2000 and prevalence rate has been achieved due to improvement in management of cases, very low rates of relapse, high cure rates, absence of drug resistance and shorter duration of treatment with MDT.¹ Official figures from 115 countries show the global registered prevalence of leprosy at 189018 at the end of 2012 and during the same year, 232 857 new cases were reported.¹ The global statistics show that 220 810 (95%) of new leprosy cases were reported from 16 countries and only 5% of new cases are from the rest of the world.¹ India achieved elimination level of less than one case per 10,000 populations by 31st Dec 2005. The year 2012-13 started with 0.83 lakh leprosy cases on record as on 1st April 2012, with PR (prevalence rate) 0.68/10,000 and till then 33 States/ UTs had attained the level of leprosy elimination.² A total of 542 districts (84.7%) out of total 640 districts also achieved elimination by March 2012.² One State (Chhattisgarh) and One U.T. (Dadra & Nagar Haveli) in India has remained with PR between 2 and 4 per 10,000 populations. Three other States viz. Bihar, Maharashtra and West Bengal which have achieved elimination earlier have shown slight increase in P.R. (1-1.2) in the current year.² There is slight increase in new cases and prevalence during 2012-13 and current NLEP strategy shifted to carry out extensive house to house survey for new case detection and to treat

them with MDT to cut down the transmission potential in the future.²

The study was conducted to see the socio demographic profile and quality of life of leprosy patients attending the leprosy clinic of a tertiary centre in Eastern India.

METHODOLOGY

It was an observational descriptive institution based study with cross sectional design. The study was conducted in Leprosy Clinic of a tertiary care centre of Kolkata from August to October 2013. All persons aged more than 15 years, living with leprosy, attending the Leprosy Clinic at that tertiary care centre, constituted the study population. Severely morbid person and those who were registered less than 2 months before were excluded from the study. A Predesigned pre tested semi-structured schedule was used for collection of data. Informed verbal consent was taken from each participant and they were assured about the confidentiality of information. The WHOQOL-BREF (Field Trial Bengali Version)¹ used to assess the quality of life and health, contains four domain scores and has two individually scored items about an individual's overall perception of quality of life and health. It consists 26 items scored from 1 to 5 Likert scale. Four domain scores are scaled in positive direction with higher scores indicating a higher quality of life. Three items of the BREF are reversed before scoring (Q3, Q4 and Q26). Score of each domain as well as overall is considered good if score is more than 50% of the maximum attainable score both in domain and in total.

Table 1 Domain Wise Calculation of Raw Score

Domains	Equations for computing raw domain score
1. Physical	$(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18$
2. Psychological	$Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)$
3. Social relationship	$Q20 + Q21 + Q22$
4. Environmental health	$Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$

Next step involves transforming each raw score into a 0-100 scale using the formula shown below.¹

$$\text{Transformed scale} = \frac{\text{Actual raw score} - \text{lowest possible raw score}}{\text{Possible raw score range}} \times 100$$



Where 'Actual raw score' is the values achieved through summation, 'Lowest possible raw score' is the lowest possible value that could occur through summation and 'Possible raw score range' is the difference between the maximum possible raw score and the lowest possible raw score. The parameters taken in physical health domain are activities of daily living, dependence on medical substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, work capacity. The parameters in psychological health were bodily image and appearance, negative & positive feelings, self-esteem, spirituality/ Religion/ Personal beliefs, thinking, learning, memory and concentration. In social relationship domain, there are personal relationships, social support and sexual activity. In environment domain the parameters are financial resources, freedom, physical safety and security, health and social care: accessibility and quality, home environment, opportunities for acquiring new

information and skills, participation in and opportunities for recreation/ leisure activities, physical environment and transport. After collection, data were compiled and analyzed in SPSS version 16.

RESULTS

This study includes 63 diagnosed leprosy patients attending OPD of a leprosy clinic for follow up. Maximum no of patients were male (69.8%) and coming from rural areas (47.6%). Mean age of the study group was 41.76 (± 13.28) years. 47.6% of the patients were unemployed. Majority of the study population were married (74.6%). 66.7% of the study population have joint family. 41.3% of the study population belonged to below poverty line. 52.4% of them were found to be using at least one or more of the following: tobacco, betel nut, alcohol. Mean family income of the study population was Rs.6804.70 per month.

Table 2 Socio Demographic Variables of the Study Population (n=63)

Variables	Number	Percentage
Gender		
Male	44	69.8
Female	19	30.2
Residence		
Rural	30	47.6
Urban Slum	11	17.5
Urban – Non Slum	22	34.9
Type of Family		
Nuclear	21	33.3
Joint	42	66.7
Marital Status		
Married	47	74.6
Unmarried	12	19.0
Widow	2	3.2
Spouse Left	2	3.2
Working Status		
Unemployed	30	47.6
Unskilled	3	4.8
Skilled	13	20.6
Shopkeeper/Clerk/Farmer	15	23.8
Business	1	1.6
Professional	1	1.6
Socio-economic Status		
APL	37	58.7



BPL	26	41.3
Addiction		
Yes	33	52.4
No	30	47.6

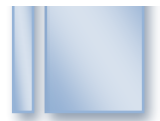
Majority of the patients were diagnosed by doctors (98.4%). Most of the patients (77.8%) were found to be without any deformity related to leprosy. 90.5% of the patients were not associated with any other diseases other than leprosy. Majority (96.8%) of the

patients were receiving MDT (multi drug therapy) regularly. 21% of the patients ignored about their ailments and delayed in seeking first treatment. Majority of the study population (85.7%) were suffering from multi-bacillary type of leprosy (Table 3).

Table 3 Disease and Treatment Related Information of the Study Population (n=63)

Variables	Number	Percentage
Diagnosed By		
Doctor	62	98.4
Others	1	1.6
Reasons for Delay		
Ignored	13	21
Lack of Knowledge	1	1.6
Misdiagnosed	4	6.4
Wrong Diagnosis and Treatment	7	11
Not Delayed	38	60
Type of Deformity		
None	49	77.8
Wrist Drop	1	1.6
Foot Drop	1	1.6
Planter Ulcer	11	17.5
Others	1	1.6
Associated Illness		
Diabetes Mellitus	1	1.6
Hypertension	1	1.6
COPD	1	1.6
Others	3	4.8
None	57	90.5
Type of Leprosy		
MB	54	85.7
PB	9	14.3
MDT Getting Centre		
Primary Centre	25	39.7
Secondary Centre	9	14.3
Tertiary Centre	29	46
Drug Supply		
Continuous	61	96.8
Intermittent	2	3.2

Mean and SD of the raw score of four domains of WHOQOL BREF were 22.38±3.34, 17.95±3.06,



9.76±1.96 and 26.40±3.71 respectively (Table 4). Mean and SD of the transformed score of four domains of WHOQOL BREF were 54.94 (±11.96); 50 (±12.93);

56.46 (±17.14) and 59.14 (±12.02) respectively (Table 5).

Table 4 Distribution of Mean and Standard Deviation of Raw Scores in four different domains according to WHOQOL – BREF Questionnaire

Domain No.	Mean Score	Standard Deviation
Domain 1	22.38	3.34
Domain 2	17.95	3.06
Domain 3	9.76	1.96
Domain 4	26.40	3.71

Table 5 Distribution of Mean and Standard Deviation of Transformed Scores in four different domains according to WHOQOL – BREF Questionnaire

Domain No.	Mean Score	Standard Deviation
Domain 1	54.94	11.96
Domain 2	50	12.63
Domain 3	56.46	17.14
Domain 4	59.14	12.02

33.33% of the leprosy patients studied was leading a poor quality of life. Logistic regression analysis was done between quality of life of the study population and different predictor variables. Literacy, family type and time gap between starting of symptoms and

initiation of treatment were significantly associated with quality of life. 44.1% of the outcome was explained by predictor variables ($R^2 = 44.1\%$) (Table 6).

Table 6 Relationship Between Quality of Life and Predictor Variables

Variables	B	S.E.	Wald	df	Sig	OR
Age	-0.003	0.031	0.008	1	0.930	0.997
Gender	1.641	1.200	1.871	1	0.171	5.161
Residence	-0.825	0.552	2.233	1	0.135	0.438
Family Type	1.645	1.014	2.634	1	0.015	5.183
Literacy	-0.182	0.101	3.271	1	0.050	0.833
Socio-economic Status	0.826	1.014	0.663	1	0.415	2.284
Marital Status	0.215	0.415	0.269	1	0.604	1.240
Addiction	0.469	1.072	0.191	1	0.662	1.598
Time Gap in Initiation of Treatment	0.145	0.065	4.929	1	0.026	1.157
Constant	-6.177	4.608	1.797	1	0.180	0.002

$R^2=44.1\%$

DISCUSSIONS

It was an observational, descriptive study, conducted on leprosy patients attending leprosy clinic of a tertiary centre in Eastern India. In this study majority of the patients were male (69.8%) and similar finding (61.9%) was observed in the study conducted by Felipe J. J. Reis et al⁶. Mean age of the current study

population was found to be 41.76 (±13.28) years and another study by Reis FJ, Cunha AJ et al conducted in Ghana the mean age of the study population was 43

(±11.0) years.⁶This difference is due to different study setting and different socio-economic characteristic of the study population. Majority of the study population (52.24%) was living in urban area and



belonged to joint family (66.7%). Majority of the study population (74.6%) was found to be married and similar finding (86.27%) was also found in another study conducted by M J Mankar et al in Maharashtra, India.⁵ Study findings of M J Mankar et al shows majority of the study population were sedentary workers but in current study we found majority of the study population were unemployed.⁵ Socio-economic status (SES) is an important predictor of the quality of life (QOL). In this study 41.3% of the study population were living below poverty line (BPL) and univariate analysis showed positive association between socio-economic status (SES) and QOL of the study population ($P=0.004$). Similar positive correlation between SES and quality of life score was observed in a similar study conducted by GA Joseph et al³. Literacy status of patients is an important predictor of QOL and in current study 19.05% of the patients were found illiterate. In a similar study by M J Mankar et al 52.94% of the study population were found illiterate⁵. In the current study multivariate analysis showed positive association between QOL and literacy status of the study population ($P=0.05$). In the current study maximum number of cases (85.7%) was suffering from Multi-bacillary leprosy (MBL) and similar finding (81%) was observed in the study conducted by Felipe J. J. Reis et al⁶, 33.2% of the patients were associated with visible deformity related to leprosy. Whereas similar study by Felipe J. J. Reis et al observed 20 male and 12 female patients were associated with visible deformity related to leprosy.⁶ This variation in the visible physical deformity among the study population in different study setting here due to early diagnoses and early initiation of treatment and better patient compliance and quality of patient care and support. In the current study only 9.5% of the study population were suffering from associated comorbidity. Only 9.5% of the study population were highly satisfied with the health services received in the tertiary centre. In this study 33.33% of the study population showed poor quality of life (QOL) and among them 13 male and 7 female patients showed poor quality of life (QOL). In a similar study conducted by GA Joseph et al showed women had higher quality of life scores than men in almost every domain.³ Another study conducted by M J Mankar et

al showed mean quality of life scores for male cases were lower than the female cases.⁵

However, there are many other confounding factors which could influence the treatment outcome and overall QOL among the leprosy patients. Treatment adherence, regular follow up visit, awareness related to the disease and its outcome, social stigma and discrimination could be important predictors. The overall nutritional status of the affected persons, loss of wage earning and out of pocket expenditures could be other responsible factors. Further longitudinal study considering all these confounders can be planned in future to get a better scenario regarding the overall QOL among the follow up patients of leprosy.

CONCLUSION

A cross sectional hospital based study to determine the factors affecting the quality of life among the follow up patient in a leprosy clinic showed that literacy status, family support in form of joint family and early initiation of treatment were the important responsible factors behind the better quality of life among the study subjects. So the study recommends that by improving literacy status, family support and early treatment initiation, QOL life can be further improved in the follow up patients of leprosy.

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