ORIGINAL RESEARCH ARTICLE

Quality of Life Among People with Leprosy-Related Disability In Tamil Nadu: A Cross-Sectional Study

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ABSTRACT

Background: Leprosy is one among the 20 conditions termed as Neglected Tropical Disease. Early diagnosis and treatment with multidrug therapy has made leprosy a curable disease these days. Even after all the improvements in managing the disease, the quality of life of affected individuals is still uncertain.

Materials and methods: A cross-sectional study was conducted among people with leprosy related disability residing in Chengalpattu district using a semi-structured questionnaire to access the quality of life and its association with socio-demographic variables. Simple random sampling technique was used to select 223 study participants. Data were analysed using IBM SPSS v 21. Fishers exact test and chi-square test were employed and statistical significance was set at p <0.05.

Results: Out of the 223 participants, 40.4% had poor quality of life score. Class V socio-economic status, lesser duration of disability and positive surgery history for deformity had a significant association with overall quality of life.

Conclusion: To conclude the findings of the current study, a huge prevalence of poor quality of life was noted that reflects the affected individual's deprived physical and mental health status. Early prevention of disabilities by rightful intervention at the right time and appropriate self-care should be ensured to improve the quality of life.

Keywords: leprosy, disability, quality of life, rehabilitation, deformity

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Introduction

Leprosy, often called as "The Hansen's disease," has been eliminated globally in the year 2000. However, India achieved elimination only in 2005.¹ By the year 2016, the leprosy elimination target of <1/10,000 population has been achieved in 551 districts out of a total of 669 districts in the country.² In spite of all the initiatives and programmes afforded by the governmental and non-governmental agencies, it is still evident that leprosy is a public health concern affecting different regions in the world. Owing to the novel corona virus disease (COVID-19) pandemic there was an additional 37% reduction in new leprosy case detection.³

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.4 Majority of the existing literatures from different parts of the world have contradicting results on the quality of life among individuals with leprosy. Few literatures had stated good Quality of Life among their participants as in Sinambela D et al⁵ (93.3%), Utama A et al⁶ (52.3%), Bottene I et al⁷ (63%) whereas many literatures have specified that participants have poor QOL as in Solanki AD et al⁸ (54%), Reis F et al⁹ (57.2%), Eyanoer P et al¹⁰ (41%), Umniyati H et al11 (55.5%) and so on. Such differences in the results might be due to regional variation, Questionnaire variation and also on the grade of leprosy disability. Adding to this, only a handful literatures are available on leprosy QOL studied among those with disabilities.

Hence to explore more about the disabled people, our study was directed to find Quality of Life (QOL) among the residents of Chengalpattu district with leprosy related disabilities. The outcomes of this study helps to understand the physical and mental component of the affected individual despite increased psycho-social support and vocational training activities implemented by the government under NLEP. The outcomes will also emphasize the need for increased community-based rehabilitation services to mitigate the effects of impairment.

METHODOLOGY

A cross sectional study was conducted in the leprosy colonies of Chengalpattu district (Thirumani and Paranur), Tamil Nadu, India from May 2021 to October 2022. Those people diagnosed with leprosy related disability grade 1 & 2 residing in the leprosy colonies aged 18 years and above, those who were the permanent residents of study setting were included in the study. Seriously ill and bedridden patients were excluded from the study. Considering the prevalence of 54% poor QOL with 7% allowable error at 95% confidence interval and 10% nonresponse rate, a sample size of 230 was arrived us-

ing the formula z^2PQ/d^2 .

The list of individuals with leprosy related disabilities residing in the Chengalpattu district was obtained from the Leprosy division. From the line list of 544 people with disability, 230 individuals were selected through computer generated random numbers. Out of 230 individuals approached, where 223 individuals gave consent and participated in the study. Previously validated short form-12 questionnaire in the local language (Tamil) was used to assess the QOL.13 The scoring for SF-12 QOL version 1 used in the present study has been recommended by Ware, John & Kosinski, M & Keller. 13 The summary scores range from a minimum of 0 to a maximum of 100. Higher the SF-12 scores, indicates the higher (better) quality of life.14 The QOL outcome was categorized into three groups namely High QOL (score ≥ 61), Normal QOL (score of 41 to 60) and Poor/impaired QOL (score ≤ 40). The cut-off for physical component score of QOL (PCS) was 39 and Mental component score of QOL (MCS) was 43. Scores below the respective cut-off were graded as poor PCS and MCS while the scores equal to or greater than the cut-off were graded Normal PCS and MCS.

Data analysis was done using IBM SPSS v 21. Qualitative variables were described in frequencies and percentage, quantitative variables were described in mean/standard deviation. Pearson Chi-square test and Fisher's exact test to determine the association amongst QOL and socio-demographic factors. The significance of the p-value for the present study was taken as p < 0.05.

RESULTS

The mean age of the participants was 63.12 ± 10.7 at enrolment (Table 1). The mean age at diagnosis of leprosy was 23.3 ± 11.6 . Only 27 participants had positive family history of leprosy among the 223 participated. Around 58% were employed when they were diagnosed with leprosy however, as disease progressed only 14% were able to work.

The mean duration of leprosy was 39.7 ± 14.5 years. The mean duration of disability was found to be 16.9 ± 11.7 years. All 223 participants were on one or other forms of rehabilitation. All those identified with deformity were on regular medical management. (Table 2)

Total 49%, 46% and 40.4% had poor PCS of QOL, MCS of QOL and overall QOL while 51%, 54% and 60.6% of the participants had normal PCS of QOL, MCS of QOL and overall QOL respectively.

Overall mean QOL score was 40.9 (sd 5.6) (Table 1).

Table 4, 5 and 6 shows association of physical component, mental component and overall QOL with socio-demographic characteristics of patients and various disease characteristics of leprosy.

Table 1: Socio-demographic characteristics of the study participants (n = 223)

Characteristics	Participants (%)
Age	
≤60 years	90 (40.4)
≥61 years	133 (59.6)
Gender	
Male	132 (59.2)
Female	91 (40.8)
Occupation (At present)	
Employed	32 (14.3)
Unemployed	191 (85.7)
Educational status	
Illiterate	80 (35.9)
Literate	143 (64.1)
Marital Status	,
Currently married	125 (56.1)
Never married	56 (25.1)
Divorced/separated/widow	42 (18.8)
Socioeconomic status (Modifie	ed BG Prasad)
Class I	16 (7.2)
Class II	16 (7.2)
Class III	34 (15.2)
Class IV	47 (21.1)
Class V	110 (49.3)
Type of family	
Nuclear	130 (58.3)
Joint	93 (41.7)

Table 2: Disease status-related details of the study participants (n = 223)

Characteristics	Participants (%)
Duration of Leprosy	
Mean (SD)	39.72 (14.46)
≤ 30 years	57 (25.6)
≥ 31 years	166 (74.4)
Duration of disability	
Mean (SD)	16.97 (11.67)
≤ 25 years	175 (78.5)
≥ 26 years	48 (21.5)
History of Surgery for deformity	
Yes	141 (63.22)
No	82 (36.78)
Grade of Disability at present	
Grade 1	13 (5.8)
Grade 2	210 (94.2)
Co-morbidities	
Present	77 (34.5)
Absent	146 (65.5)
Multimorbidity	
Yes	33 (14.8)
No	190 (85.2)
BMI (Asian classification)	
Underweight	115 (51.6)
Normal	89 (39.9)
Overweight	19 (8.5)
Obesity	0 (0)

Table 3: Prevalence of QOL among the study participants using the SF-12 questionnaire (n = 223)

QOL	Mean (SD)	
Physical Component Score	39.36 (8.04)	
Mental Component Score	42.49 (10.5)	
Overall QOL	40.9 (5.6)	

DISCUSSION

Most of the studies have utilized the WHOQOL-BREF tool for QOL assessment like in studies by Barakat M et al15, Utama A et al6, and Geetha K et al16 with a reported prevalence of 72%, 47.7%, and 17.8% respectively. Poor QOL is observed in 40.4% of the study participants which is similar to the 43% reported in the study by Eyanoer P10 in which the investigator utilized a researcher-designed questionnaire for the assessment of QOL. Likewise, Proto R et al17 and Bottene I et al7 have reported a prevalence of 95% and 37% poor QOL among their participants using the DLQI tool.

Comparatively, only a few studies have utilized the DLQI tool and SF-36 for QOL assessment among their participants. The variations in prevalence of QOL may be attributed due to geographical variation and differences in the study tools (Questionnaire) used. QOL in the present study had a significant statistical association with low socio-economic status which is similar to the findings reported by Govindharaj et al¹⁸, Pinto G et al¹⁹, Umniyati H et al¹¹ and Costa MD et al²⁰ which emphasis the role of financial support in assessing quality of life irrespective of the country were the study has been carried out.

QOL was also found having association with the duration of disability in the present study which was reported by Solanki AD et al⁸ and Govindharaj et al¹⁸ as well. Further, better QOL was seen among those who underwent surgery for deformity correction in the present study unlike that reported by Utama A et al⁶ and Lustosa A et al²¹ where physical disfiguration following surgery itself was cited as a reason for poor QOL.

PCS of QOL in the present study was not found to be statistically significant to age in contradiction to that reported by Govindharaj et al¹⁸ and Araujo D et al²² where a majority of their study participants were less than 60 years of age while the present study had a majority of the participants belonging to more than 60 years of age. This shows that age plays a significant role in determining younger population's QOL as it disturbs their education, occupation and standard of living. The present study displays that those with history of multimorbidity were found to have poor PCS of QOL however the studies by Araujo D et al²² and Barakat M et al¹⁵ mentioned that presence of more than two diseases itself acts as a driving factor for poor QOL among the participants.

MCS of QOL was found to be statistically significant with gender as reported by Araujo D et al²² and Pinto G et al¹⁹, unlike the present study where the association is not statistically significant. The reported difference might be because of the prevailing cultural and social differences among the study participants in different countries. MCS of QOL was found to have an association with disability duration, presence of co-morbidity, and multimorbidity in the present study. Few literatures have found that as the number

of disease conditions and years with disability indecreases.18,22 creases the mental health status of the participants

Table 4a: Association of Socio-demographic characteristics with PCS of QOL by Pearson Chi-Square analysis

Characteristics	PCS (n = 223)		Chi-square	Odds Ratio (95% CI)	p-value
	Poor (%)	Normal (%)	value		
Age					
≤ 60 years	43 (39.4)	47 (41.2)	0.073	0.9 (0.54 - 1.58)	0.787
≥ 61 years	66 (60.6)	67 (58.8)		Ref	
Gender					
Male	66 (60.6)	66 (57.9)	0.163	1.1 (0.65 – 1.90)	0.687
Female	43 (39.4)	48 (42.1)		Ref	
Occupation					
Unemployed	92 (84.4)	99 (86.8)	0.270	0.8 (0.38 - 1.73)	0.604
Employed	17 (15.6)	15 (13.2)		Ref	
Educational status					
Illiterate	34 (31.2)	46 (40.4)	2.032	0.6 (0.38 - 1.16)	0.154
Literate	75 (68.8)	68 (59.6)		Ref	
Marital Status					
Currently married	65 (59.6)	60 (52.6)	1.112	Ref	0.573
Never married	25 (22.9)	31 (27.2)		1.3 (0.71-2.52)	
Divorced/separated/widow	19 (17.4)	23 (20.2)		1.3 (0.65 - 2.64)	
Socioeconomic status					
Class I	9 (8.3)	7 (6.1)	7.373	Ref	0.117
Class II	9 (8.3)	7 (6.1)		1.0 (0.24 - 4.04)	
Class III	14 (12.8)	20 (17.5)		1.8 (0.55 - 6.10)	
Class IV	30 (27.5)	17 (14.9)		0.7 (0.23 - 2.30)	
Class V	47 (43.1)	63 (55.3)		1.7 (0.59 – 4.96)	
Type of family					
Nuclear	60 (55)	70 (61.4)	0.926	0.7 (0.45 - 1.31)	0.336
Joint	49 (45)	44 (38.6)		Ref	

Table 4b: Association of disease characteristics with PCS of QOL by Pearson Chi-Square analysis

Characteristics	PCS	PCS (n = 223)		Odds Ratio (95% CI)	p-value
	Poor (%)	Normal (%)	value		
Duration of Leprosy					
≤ 30 years	25 (22.9)	32 (28.1)	0.772	0.7 (0.41 - 1.39)	0.380
≥ 31 years	84 (77.1)	82 (71.9)		Ref	
Grade of Disability (at pr	esent)				
Grade 1	7 (6.4)	6 (5.3)	0.136	1.2 (0.40 – 3.79)	0.712
Grade 2	102 (93.6)	108 (94.7)		Ref	
Duration of disability					
≤ 25 years	88 (80.7)	87 (76.3)	0.644	1.3 (0.68 – 2.47)	0.422
≥ 26 years	21 (19.3)	27 (23.7)		Ref	
History of Surgery for de	formity				
Yes	62 (56.9)	79 (69.3)	3.695	0.58 (0.33 - 1.01)	0.055
No	47 (43.1)	35 (30.7)		Ref	
Co-morbidity					
Yes	32 (29.4)	45 (39.5)	2.522	0.6 (0.36 - 1.11)	0.112
No	77 (70.6)	69 (60.5)		Ref	
Multimorbidity					
Yes	22 (20.2)	11 (9.6)	4.904	2.3 (1.08 – 5.15)	0.026^*
No	87 (79.8)	103 (90.4)		Ref	0.020
BMI					
Underweight	51 (46.8)	64 (56.1)	5.635	Ref	0.060
Normal	44 (40.4)	45 (39.5)		0.8 (0.46 - 1.41)	
Overweight	14 (12.8)	5 (4.4)		0.2 (0.09 – 0.84)	

^{*}Statistically significant

Table 5a: Association of Socio-demographic characteristics with MCS of QOLby Pearson Chi-Square analysis

Characteristics	MCS (n = 223)		Chi-square	Odds Ratio (95% CI)	p-value
	Poor (%)	Normal (%)	value		
Age					
≤ 60 years	38 (37.3)	52 (43)	0.752	0.7 (0.45 - 1.35)	0.386
≥ 61 years	64 (62.7)	69 (57)		Ref	
Gender					
Male	65 (63.7)	67 (55.4)	1.599	1.4 (0.82 - 2.42)	0.206
Female	37 (36.3)	54 (44.6)		Ref	
Occupation					
Unemployed	89 (87.3)	102 (84.3)	0.394	1.2 (0.59 – 2.72)	0.530
Employed	13 (12.7)	19 (15.7)		Ref	
Educational status					
Illiterate	32 (31.4)	48 (39.7)	1.656	0.6 (0.39 - 1.21)	0.198
Literate	70 (68.6)	73 (60.3)		Ref	
Marital Status					
Currently married	55 (53.9)	70 (57.9)	0.566	Ref	0.753
Never married	28 (27.5)	28 (23.1)		0.7 (0.41 - 1.47)	
Divorced/separated/widow	19 (18.6)	23 (19)		0.9 (0.47 - 1.92)	
Socioeconomic status					
Class I	5 (4.9)	11 (9.1)	3.543	Ref	0.471
Class II	7 (6.9)	9 (7.4)		0.5 (0.13 - 2.48)	
Class III	18 (17.6)	16 (13.2)		0.4 (0.11 - 1.41)	
Class IV	25 (24.5)	22 (18.2)		0.4 (0.12 - 1.33)	
Class V	47 (46.1)	63 (52.1)		0.6 (0.19 - 1.87)	
Type of family					
Nuclear	65 (63.7)	65 (53.7)	2.279	1.5 (0.88 – 2.59)	0.131
Joint	37 (36.3)	56 (46.3)		Ref	

Table 5b: Association of disease characteristics with MCS of QOL by Pearson Chi-Square analysis

Characteristics	MCS (n = 223)		Chi-square	Odds Ratio (95% CI)	p-value
	Poor (%)	Normal (%)	value		
Duration of Leprosy					
≤ 30 years	23 (22.5)	34 (28.1)	0.896	0.7 (0.40 - 1.37)	0.344
≥ 31 years	79 (77.5)	87 (71.9)		Ref	
Grade of Disability (at present)					
Grade 1	5 (4.9)	8 (6.6)	0.294	0.7 (0.23 - 2.29)	0.587
Grade 2	97 (95.1)	113 (93.4)		Ref	
Duration of disability					
≤ 25 years	60 (58.8)	115 (95)	42.979	0.1 (0.03 - 0.18)	$\boldsymbol{0.0001}^*$
≥ 26 years	42 (41.2)	6 (5)		Ref	0.0001
History of Surgery for deformity					
Yes	59 (57.8)	82 (67.8)	2.345	0.6 (0.37 - 1.12)	0.126
No	43 (42.2)	39 (32.2)		Ref	
Co-morbidity					
Yes	51 (50)	26 (21.5)	19.902	3.6 (2.04 - 6.53)	$\boldsymbol{0.001}^*$
No	51 (50)	95 (78.5)		Ref	0.001
Multimorbidity					
Yes	26 (25.5)	7 (5.8)	17.044	5.5 (2.30 - 13.48)	$\boldsymbol{0.001}^*$
No	76 (74.5)	114 (94.2)		Ref	0.001
ВМІ					
Underweight	53 (52)	62 (51.2)	2.951	Ref	0.229
Normal	37 (36.3)	52 (43)		1.2 (0.68 - 2.10)	
Overweight	12 (11.8)	7 (5.8)		0.4 (0.18 - 1.35)	

*Statistically significant

Table 6a: Association of Socio-demographic characteristics with Overall QOLby Pearson Chi-Square analysis

Characteristics	Overall QOL (n = 223)		Chi-square	Odds Ratio (95% CI)	p-value
	Poor (%)	Normal (%)	value		
Age					
≤ 60 years	37 (41.1)	53 (39.8)	0.035	1.5 (0.61 - 1.81)	0.851
≥ 61 years	53 (58.9)	80 (60.2)		Ref	
Gender					
Male	56 (62.2)	76 (57.1)	0.573	1.2 (0.71 – 2.13)	0.449
Female	34 (37.8)	57 (42.9)		Ref	
Occupation					
Unemployed	78 (86.7)	113 (85)	0.127	1.1 (0.53 - 2.48)	0.722
Employed	12 (13.3)	20 (15)		Ref	
Educational status					
Illiterate	26 (28.9)	54 (40.6)	3.201	0.5 (0.33 - 1.05)	0.074
Literate	64 (71.1)	79 (59.4)		Ref	
Marital Status					
Currently married	52 (57.8)	73 (54.9)	0.196	Ref	0.907
Never married	22 (24.4)	34 (25.6)		1.1 (0.57 - 2.09)	
Divorced/separated/ widow	16 (17.8)	26 (19.5)		1.2 (0.56 - 2.37)	
Socioeconomic status					
Class I	6 (6.7)	10 (7.5)	34.720	Ref	0.071
Class II	5 (5.6)	11 (8.3)		1.3 (0.30 - 5.70)	
Class III	5 (5.6)	29 (21.8)		3.4 (0.86 - 13.93)	
Class IV	9 (10)	38 (28.6)		2.5 (0.72 - 8.80)	
Class V	65 (72.2)	45 (33.8)		0.4 (0.14 - 1.22)	
Type of family					
Nuclear	55 (61.1)	75 (56.4)	0.492	1.2 (0.70 - 2.09)	0.483
Joint	35 (38.9)	58 (43.6)		Ref	

Table 6b: Association of disease characteristics with Overall QOL by PearsonChi-Square analysis

Characteristics	Overall (Overall QOL (n = 223)		Odds Ratio (95% CI)	p-value
	Poor (%)	Normal (%)	value		
Duration of Leprosy					
≤ 30 years	25 (27.8%)	32 (24.1%)	0.390	1.2 (0.66 - 2.23)	0.532
≥ 31 years	65 (72.2%)	101 (75.9%)		Ref	
Grade of Disability (at pr	esent)				
Grade 1	5 (5.6%)	8 (6%)	0.021	0.9 (0.29 - 2.90)	0.886
Grade 2	85 (94.4%)	125 (94%)		Ref	
Duration of disability					
≤ 25 years	60 (66.7%)	115 (86.5%)	12.457	0.3 (0.16 - 0.60)	$\boldsymbol{0.001}^*$
≥ 26 years	30 (33.3%)	18 (13.5%)		Ref	0.001
History of Surgery for de	formity				
Yes	45 (50%)	96 (72.2%)	11.358	0.4 (0.22 - 0.67)	$\boldsymbol{0.001}^*$
No	45 (50%)	37 (27.8%)		Ref	0.001
Co-morbidity					
Yes	28 (31.1%)	49 (36.8%)	0.780	0.7 (0.43 - 1.36)	0.377
No	62 (68.9%)	84 (63.2%)		Ref	
Multimorbidity					
Yes	9 (10%)	24 (18%)	2.755	0.5 (0.22 - 1.14)	0.096
No	81 (90%)	109 (82%)		Ref	
BMI					
Underweight	40 (44.4%)	75 (56.4%)	5.791	Ref	0.055
Normal	38 (42.2%)	51 (38.3%)		0.7 (0.40 - 1.26)	
Overweight	12 (13.3%)	7 (5.3%)		0.3 (0.11 - 0.85)	

^{*}Statistically significant

CONCLUSION

This study adds extra evidence to the magnitude of problems that many leprosy-affected people still deal with even after treatment completion. In addition to the existing standard leprosy treatment guidelines, an integrated scaffold consisting of screening, diagnosis and management protocols for leprosy related physical and mental health issues should be added to improve their QOL. Apart from this, ensuring availability of multidisciplinary leprosy care approach at primary healthcare level in endemic districts with active participation from various specialities like surgery, dermatology, orthopaedics, psychiatry, ophthalmology and physiotherapy will also improve the QOL. Further research on early disease detection and efficient management techniques for leprosy and related-disability should be encouraged to improve the quality of life among the diseased.

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