

A Cross Sectional Study on Quality of Life among Leprosy Affected Persons in Hyderabad

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Abstract

Background: Leprosy, a socially stigmatising disease is caused by *Mycobacterium leprae*. It is a chronic infectious disease mainly affecting the skin and the peripheral nerves. Because of the stigma which is due to lack of knowledge regarding the disease transmission and the disfigurement that is caused, there is an impact on the quality of life in various aspects including employment, marriage and social status.

Objectives: 1) To assess the quality of life among leprosy affected persons in Hyderabad, 2) To determine the factors influencing the quality of life among the study subjects.

Methods: A cross sectional study was conducted among 125 leprosy affected persons in a Rehabilitation Home in Hyderabad during August and September 2021. A semistructured questionnaire was used for assessing the sociodemographic factors. With informed consent, Quality of Life was assessed using predesigned WHOQOL-BREF questionnaire which has four domains including physical health, psychological, social relationship and environment. Data was entered and analysed using Microsoft Office Excel 2007 and Epi Info version 7.2.2.6.

Results: The mean age of the study population was 48.32 ± 16.16 . 56% of them were males and 44% were females. The mean scores of all four domains were computed and it was, physical health domain 53.83 ± 12.35 , psychological domain 43.54 ± 18.72 , social relationship domain 55.28 ± 24.9 and environment domain 51.1 ± 12.46 . The mean score of various domains among males was better than that of the females. On assessing the overall quality of life it was found that age, marital status, employment and disease duration are influencing the quality of life among leprosy affected persons.

Conclusion: Early diagnosis and treatment can avert the deformities and disabilities in such persons and can improve their quality of life. Care after cure is a must in leprosy.

Keywords: Leprosy, quality of life, WHOQOL-BREF

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Introduction

Hansen's disease (also known as leprosy) is an age-old disease, described in the literature of ancient civilizations. There were 208 619 new leprosy cases registered globally in 2018, according to official figures from 159 countries from the 6 WHO Regions.^[1] Globally, the prevalence rate corresponds to 0.2/10000 population.^[1] In India, the prevalence rate is 0.57/10000 population.^[2]

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* which is an acid-fast, rod-shaped bacillus with cigar bundle appearance. It is known to occur at all ages ranging from early infancy to old age. It is transmitted via droplets, from the nose and mouth, during close and frequent contact with untreated cases and it mainly affects the skin, the peripheral nerves, mucosa of the upper respiratory tract, and the eyes. If left untreated, leprosy can cause progressive and permanent damage to the skin, nerves, limbs, and eyes resulting in crippling of hands and feet, paralysis, and blindness. It is curable and if treated in the early stages can prevent disability.

Leprosy has been classified as one of the neglected tropical diseases.³ Although not a typical tropical disease, its association with poverty means that leprosy is particularly prevalent in tropical countries with large population groups living in poverty.^[3]

Social stigma has been a persistent feature of leprosy around the world. Stigma against leprosy appears to be as old as the disease itself. People afflicted have often been ostracized by their families and communities. The manifestations of stigma, and also the psychological and socioeconomic impacts, have been shown to have a significant impact on the quality of life (QoL) of persons affected by the disease.^[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. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.^[4]

A study done by Joseph GA et al reveals that quality of life decrease progressively in leprosy-affected persons.^[5] Women had a better QoL score than men in almost every domain. Given the secondary role of women in Indian rural society, this may simply imply an acceptance of their situation.⁵ In another study done by Govindharaj P et al shows that the physical disability, disease duration, and family income were influencing more on QoL.^[6]

The primary objective of our study is to assess the quality of life among leprosy affected persons using WHOQOL-BREF questionnaire. The secondary objective is to determine the socio demographic and other factors influencing the quality of life among leprosy affected persons.

Materials and Methods

A cross sectional study was conducted in Sivanada Rehabilitation Home, Hyderabad, India between August and September 2021. 125 patients who were present during our study period were included.

Leprosy affected persons who had completed treatment and had given informed consent for the study were included in the study. Patients who were less than 18 years of age, those who were severely ill or had any other medical conditions/ debilitating disease which may have an impact on Quality of Life and those who did not give informed consent were excluded from the study.

After taking permission from the Institutional Ethical Committee and the concerned authorities, interviews were conducted among leprosy affected persons. Information regarding socio demographic factors was collected using a semistructured questionnaire. Quality of Life was assessed using predesigned pretested WHOQOL-BREF questionnaire which has four domains. The WHOQOL-BREF contains a total of 26 questions. To provide a broad and comprehensive assessment, one item from each of the 24 facets contained in the WHOQOL-100 has been included. In addition, two items from the Overall quality of Life and General Health facet have been included. It is available in 19 different languages. The four domain scores denote an individual's perception of quality of life in each

particular domain. Domain scores were scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain was used to calculate the domain score. Mean scores were then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100. After the calculation of individual scores, raw scores are converted into transformed scores. Data was entered and analysed using Microsoft Office Excel 2007 and Epi Info version 7.2.2.6.

Study Area

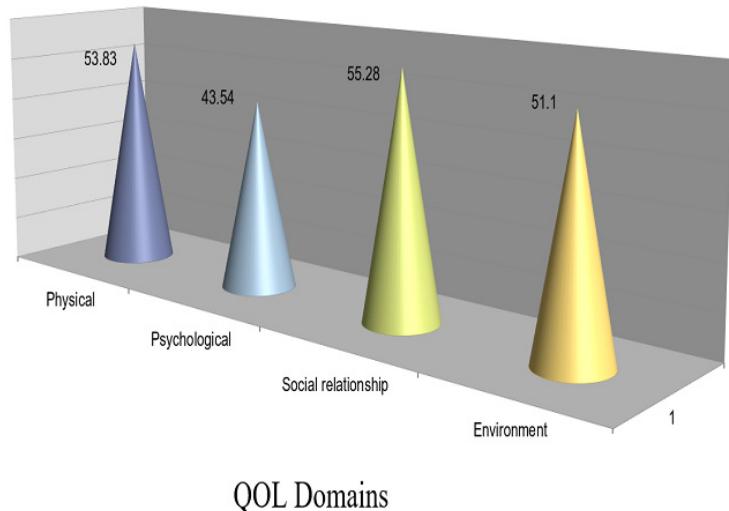


FIGURE 1: QUALITY OF LIFE-DOMAIN SCORES

TABLE 1: SOCIODEMOGRAPHIC DISTRIBUTION OF STUDY PARTICIPANTS

SOCIODEMOGRAPHIC VARIABLES		N	%
Sex	Male	70	56
	Female	55	44
Age	<60	82	65.6
	>60	43	34.4

Results

The mean age of the study population was 48.32 ± 16.16 . 56% of them were males and 44% were females. The mean domain scores of all four domains were computed as shown in figure1 and it was, physical health domain 53.83 ± 12.35 , psychological domain 43.54 ± 18.72 , social relationship domain 55.28 ± 24.9 and environment domain 51.1 ± 12.46 . Table 1 shows the sociodemographic characteristics of the study participants. Table 2 shows comparison of the baseline variables with overall QOL scores. The mean score of various domains among males was better than that of the females. On assessing the overall quality of life it was found that age, marital status, employment and disease duration had significance on the quality of life among leprosy affected persons.

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Education	Illiterate	91	72.8
	Primary	19	15.2
	Secondary	8	6.4
	Higher secondary	4	3.2
	Graduate	3	2.4
Marital status	Married	97	77.6
	Unmarried	20	16
	Widow	8	6.4
Disease duration	<40	108	86.4
	>40	17	13.6
Deformities	Present	114	91.2
	Absent	11	8.8
Employment	Employed	88	70.4
	Unemployed	37	29.6

TABLE 2: COMPARISON OF BASELINE VARIABLES WITH OVERALL QOL SCORES

VARIABLES		N	Mean (QOL domains)	P value
Sex	Male	70	217.6	0.6725
	Female	55	170.7	
Age	<60	82	205.7	0.0002
	>60	43	201.3	
Education	Literate	34	212.5	0.2312
	Illiterate	91	198.7	
Employment	Employed	88	210.2	0.0091
	Unemployed	37	181	
Marital status	Married	97	208.9	0.007
	Unmarried/ widow	28	176.1	
Disease duration	<40Years	108	209.3	0.001
	>40Years	17	153.1	
Deformities	Present	114	201.2	0.960
	Absent	11	202.1	
Surgical History	Yes	55	200.1	0.817
	No	70	202.5	

Discussion

Leprosy can be seen as having psychological, socioeconomic and spiritual dimensions that progressively dehabilitate the affected persons who are not properly cared for.^[7] Most of the patients in our study had some adverse impact on their QoL due to leprosy.

In the present study, all the study subjects were employed in jobs suitable for them within

the rehabilitation centre and were given a monthly pay of approximately 1500 to 2000 INR per month. Elderly people affected with leprosy were also given a pension of 2000 INR per month.

The present study revealed that men had a better QoL score than women in all the four domains. In contrary, a study conducted by Joseph and Rao et al found that QoL decreased progressively in person with leprosy and women had a better QoL score than men in all the four domains.^[5]

This study shows that younger persons had better QoL compared to elderly persons in all the four domains. A similar study conducted, by Dinesh *et al.*, in Tamil Nadu, India found similar findings only in the physical health and social relationship domains.^[8] In this study, the younger age, marital status, employment and disease duration had significant association with the QOL of the persons affected by leprosy.

Most of the study participants were worried about their disease condition. As they were living in the community built within the rehabilitation centre, they were grateful to the authorities. Considering the marital status, most of them were married within the community and were worried about their children being infected with lepra bacilli.

Early diagnosis and appropriate timely treatment will reduce the complications and minimize the activity limitation, consequently preventing the deterioration in the Quality of Life. The National Leprosy Eradication Programme, India, made a strategy to reduce stigma in leprosy mainly through information, education, and communication activities and spreading the awareness.^[9]

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Ethical Committee: ECR/300/Inst/AP/2013/RR-16

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