

Quality of Life in Patients with Leprosy using WHOQoL-Bref Questionnaire: A Pilot Study

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Quality of life (QoL) is a subjective measure which includes physical, psychological and social health and its relationship with the environment. Leprosy results in progressive damage to peripheral nerves in untreated or inadequately treated patients leading to nerve impairment and visible disabilities which may affect the quality of life. A descriptive cross-sectional study was conducted in a tertiary care centre among patients with leprosy over a period of six months, and quality of life status was evaluated using the WHOQoL Bref questionnaire based on four domains, namely physical, psychological, social and environmental. A total of 50 patients (males: females - 36:14) in the age group of 19-69 years were evaluated. Most patients (64%) belonged to the borderline tuberculoid spectrum. Patients with a disability accounted for 16% (8 out of 50) of the total cases. The psychological domain was the most commonly affected domain among patients. Females had lower scores than males in all domains. Elderly patients, patients with lepromatous leprosy and those with facial involvement had lower scores. Domain outcomes in lepra reactions were lower than in other types of leprosy. The study observed that leprosy in the ageing population, women and patients with severe forms of leprosy, associated with disabilities, have poorer quality of life.

Keywords : QOL, Leprosy, WHO-Bref Questionnaire, India

Introduction

Leprosy is a chronic infectious disease caused by *Mycobacterium leprae* that mainly affects the skin and peripheral nerves (Garbin et al 2015). It results in progressive damage to peripheral nerves in untreated or inadequately treated patients, leading to nerve impairments and visible disabilities resulting in limitation of physical activities, social exclusion and a lower

quality of life in some patients (Reis et al 2013).

The Quality of life (QoL) is a highly subjective multidimensional concept which includes physical health, psychological health, level of independence, social relationships, personal beliefs, and the relationship with one's environment (Savassi et al 2014, WHO 1998, Govindharaj et al 2018).

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The World Health Organization (WHO) defines QoL 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 (WHOQoL-Bref 1998). Although leprosy is a disease associated with significant stigma and

discrimination, there are a relatively small number of quality of life studies on leprosy conducted in Indian patients as compared to other dermatoses. Among the various indices used to study QoL, only a few studies have used WHOQoL-Bref to evaluate individuals affected by leprosy, its sequelae, neurolysis and lepra reactions (Reis

Table 1 : Scoring domains of the WHOQoL-BREF

Physical Health (domain 1 or d1)	• To what extent do you feel that physical pain prevents you from doing what you need to do?
	• How much do you need any medical treatment to function in your daily life?
	• Do you have enough energy for everyday life?
	• How well are you able to get around?
	• How satisfied are you with your sleep
	• How satisfied are you with your ability to perform your daily living activities?
	• How satisfied are you with your capacity for work?
Psychological (domain 2 or d2)	• How much do you enjoy life?
	• To what extent do you feel your life to be meaningful?
	• How well are you able to concentrate?
	• Are you able to accept your bodily appearance?
	• How satisfied are you with yourself?
	• How often do you have negative feelings such as blue mood, despair, anxiety, depression?
	• How satisfied are you with your personal relationships?
Social relationship (domain 3 or d3)	• How satisfied are you with your sex life?
	• How satisfied are with the support you get from your friends?
	• How safe do you feel in your daily life?
Environmental (domain 4 or d4)	• How healthy is your physical environment?
	• Have you enough money to meet your needs?
	• How available to you is the information that you need in your day-to-day life ?
	• To what extent do you have the opportunity for leisure activities?
	• How satisfied are you with the condition of your living place?
	• How satisfied are you with your access to health services?
	• How satisfied are you with your transport?
	• How satisfied are you with your transport?

et al 2013, Savassi et al 2014, WHO 1998, Govindharaj et al 2018, Costa et al 2012, Santos et al 2015). As prevention of disability remains one of the focus of leprosy programs, our aim was to analyse how these disabilities affect the QoL and whether the site of involvement of lesions or their disabilities affected QoL in leprosy patients.

The present study was based on the World Health Organization Quality of Life (WHOQoL-Bref) questionnaire, and it aimed to describe the QoL of leprosy patients based on age and clinical pattern of leprosy.

Material and Methods

A descriptive, cross-sectional study was conducted in the department of dermatology, Goa medical college over a period of six months after approval of the institutional Ethics Committee. The study population included all consecutive patients over 18 years who were diagnosed with leprosy or on treatment for leprosy and also included those who had completed multidrug therapy (MDT). Patients with diabetic neuro-

pathy, traumatic nerve injury, excessive alcohol intake, and cognitive or physical deficit interfering with the analysis were excluded.

After obtaining informed consent, the participants were interviewed using a questionnaire concerning their demographic details and examined to classify the type of leprosy using Indian classification, and the extent of disabilities was noted. The Quality of life status of the participants was evaluated using the WHOQoL-Bref questionnaire (WHOQoL-Bref 1998). The WHOQoL-Bref version questionnaire (WHOQoL-Bref) compares persons or groups through the assessment of four main domains: physical health (seven questions), psychological health (six questions), social relations (three questions) and environment (eight questions) (Table 1). The sum of the raw scores of each of the four domains were calculated. The raw scores of each domain were then converted into the transformed score in a scale from 4 to 20 and domain scores were converted to a 0–100 scale as per the WHOQoL

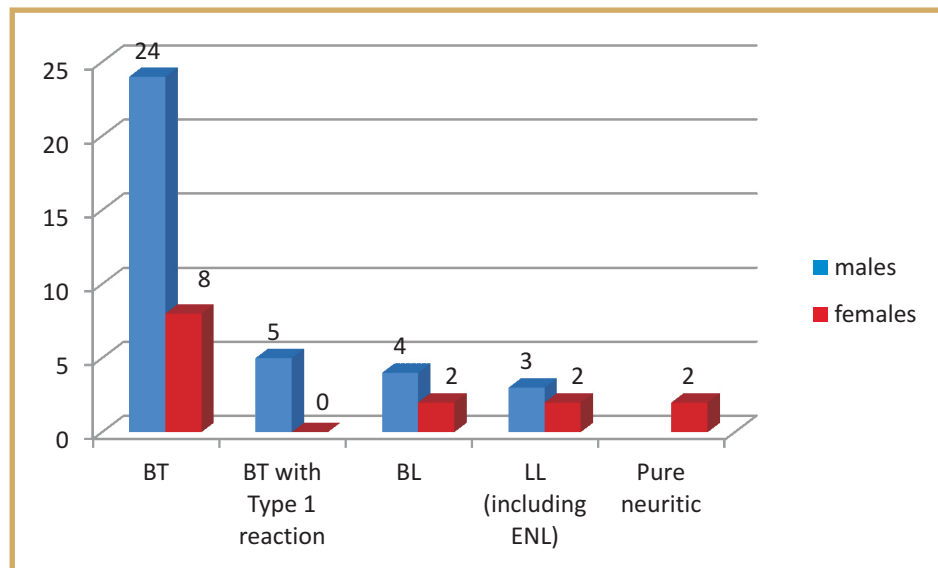


Fig. 1 : Distribution of patients according to the type of leprosy

Table 2 : Demographic characteristics of the patients

Variables	N=50
Male N (%)	36 (72%)
Females N (%)	14 (28%)
Age: Mean (range in years)	36.3± 11.11 (19-69)
Type of Leprosy N (%)	
Borderline tuberculoid (BT)	32 (64%)
BT with reaction	5 (10%)
Borderline lepromatous	6 (12%)
Lepromatous	5 (10%)
Pure neuritic	2 (4%)
WHOQoL-Bref domains (mean± std dev)	
Physical	63.28 ± 9.41
Psychological	61.28 ± 13.01
Social	78.12 ± 15.9
Environmental	66.34 ± 13.6

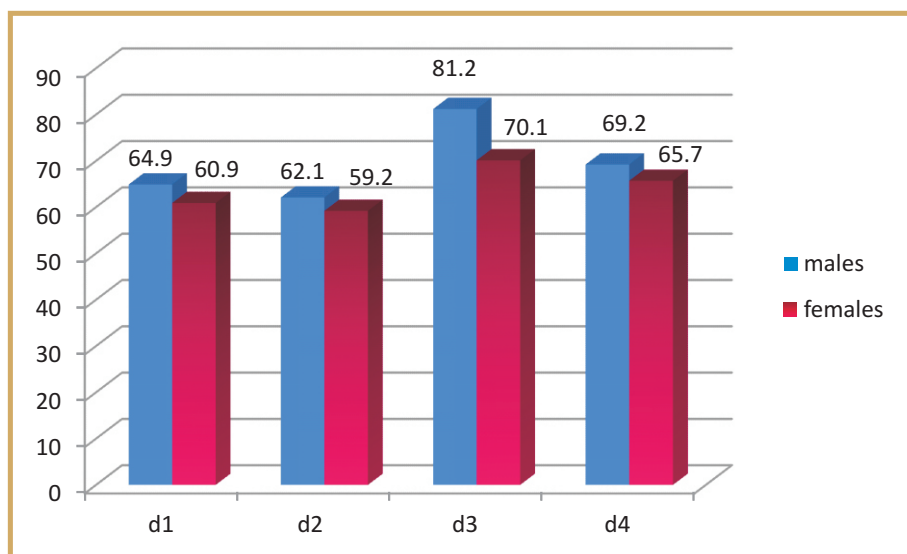


Fig. 2 : Gender based differences in the domain scores [d1-physical health, d2- psychological health, d3- social relationship, d4- environment]

guidelines. A lower score indicates a lower quality of life, and a higher score represents a higher quality of life. The final domain scores of QoL

were analysed using Mann-Whitney or the Kruskal-Wallis tests. A p-value <0.05 was considered significant.

Results

Fifty patients who fulfilled the inclusion criteria were included in our study. Most patients were males (72%). The mean age of the study group was 36.3 ± 11.1 years (Table 2). Most patients belonged to the age group of 18-40(70%). There was not much difference in the mean ages between males and females (36 and 39 years respectively). Most patients in the study group were borderline tuberculoid leprosy (64%). The distribution of patients according to the type of leprosy is given in Fig. 1. Out of the five patients with lepromatous leprosy, three had LL with type 2

reactions. Patients with a disability accounted for 16% (8 out of 50) of the total cases.

The mean scores for the WHOQoL-Bref domains were: 63.28 for physical (d1), 61.28 for psychological (d2), 78.12 for social (d3) and 66.34 for the environment domains (d4) (Table 2).

The quality of life scoring with respect to various domains is given in Table 3. Women had poor scores in all domains, and the difference in the social relationships (domain 3) between the male and female gender was significant ($p = 0.021$) (Fig. 2 & Table 3). Patients above 60 years had lower scores in all domains as compared to the

Table 3 : Quality of life scoring with respect to various domains

Variables	Physical (d1)		Psychological (d2)		Social (d3)		Environmental (d4)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Gender								
Female	13.71	1.684	13.43	2.027	15.00	2.961	14.43	2.174
Male	14.25	1.422	13.92	2.116	16.00	2.151	14.61	2.233
P-value	0.334		0.297		0.021		0.670	
Age								
18-40	14.20	1.302	14.14	1.768	16.77	2.001	14.86	2.171
41-60	14.25	1.712	13.58	2.429	16.25	3.223	14.25	2.261
>60	12.33	2.309	10.33	0.577	12.67	2.887	12.33	0.577
p value	0.696		0.018		0.187		0.276	
Patterns of leprosy								
BT	14.53	1.295	14.81	0.965	17.47	1.367	15.53	1.704
BT with Reactions	14.00	1.000	11.80	1.095	15.40	1.949	12.40	1.342
BL	13.50	1.761	12.50	3.082	13.67	3.445	13.33	2.733
LL	12.00	1.414	10.40	1.517	13.40	3.286	11.80	0.447
PN	14.50	0.707	14.50	0.707	17.50	2.121	15.00	0.000
p value	0.028		0.000		0.006		0.000	
Disability								
Facial involvement	13.17	1.465	11.83	2.065	14.44	2.915	12.61	1.614
Claw hand	13.80	1.095	12.60	1.673	16.00	2.550	13.40	1.517
Lower limb involvement	13.18	1.448	12.18	2.677	14.9	2.721	12.54	2.416
p value	0.338		0.150		0.220		0.537	

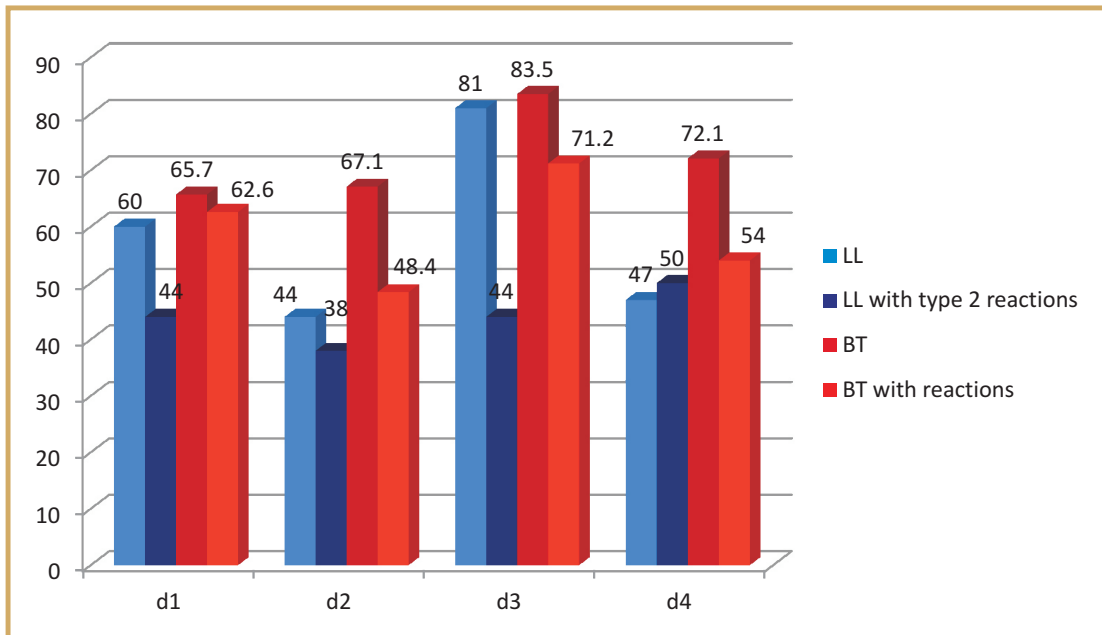


Fig. 3 : Domain score difference between BT and LL and Type 1 and Type 2 reactions [d1-physical health, d2- psychological health, d3- social relationship, d4- environment]

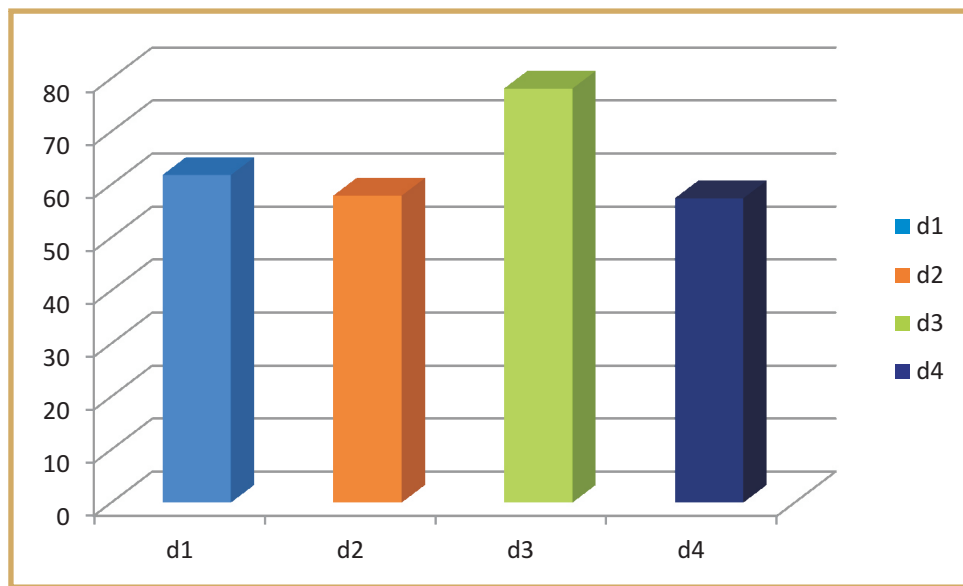


Fig. 4 : Domain scores in patients with disability [d1-physical health, d2- psychological health, d3- social relationship, d4- environment]

other age groups. The psychological domain scores were the lowest among the four domain scores in all three age groups. There was statistical significance in the psychological domain among the three age groups ($p=0.018$) (Table 3). Among the patterns of leprosy, the social relationship domain scores were higher as compared to other domains and most psychological domain scores were lower compared to the other domains (Table 3). All patients with lepromatous leprosy had lower scores in all domains compared to other types of leprosy. BT leprosy patients had higher scores in most domains compared to other types of leprosy. All the four domain scores were statistically significant (physical domain p -value 0.028, psychological domain p -value 0.000, Social domain p -value 0.006, environmental domain p -value 0.000). The domain outcomes in patients with both Type 1 and Type 2 lepra reactions were lower than BT leprosy and lepromatous leprosy (Fig. 3). Depending on the site of involvement, though, there was no statistical difference among the three groups, however, patients with facial lesions of leprosy had poorer quality of life scores (Table 3). Among the patients with disabilities, the social domain had the highest scores in all patients with disability, while the psychological domain and environmental domains had the lowest scores in patients with a claw hand and trophic ulcer, respectively (Fig. 4).

Discussion

Leprosy affects the quality of life due to the social stigma and physical disabilities associated with the condition (Das et al 2020, Joseph & Rao 1999). There are various tools to measure the effect on physical, mental, and social wellbeing and stigma among patients with leprosy. Some scales are domain-specific or disease specific like 'the Participation scale' which analyses social participation for use in rehabilitation, stigma reduction and

social integration programmes, or the Salsa scale which stands for 'Screening of Activity Limitation and Safety Awareness, and is a questionnaire that measures activity limitation in peripheral neuropathy as seen in leprosy and diabetes or the SARI stigma scale (van Brakel et al 2006, SALSA Collaborative Study Group 2007, Dadun et al 2017).

Also, there are some indices which are non disease-specific, like the DLQI (dermatology life quality index) or WHOQoL-Bref. The Dermatology Life Quality Index (DLQI) is a ten-question questionnaire used to measure the impact of skin disease on the quality of life of an affected person and is the one of most commonly used indexes in dermatology (Finlay & Khan 1994). The WHOQoL brief version questionnaire (WHOQoL-Bref) compares persons or groups through the assessment of four main domains: physical health, psychological health, social relationships, and environment, in which higher scores indicate better QoL. This instrument was developed as a short version of the WHOQoL-100 for use in situations where time is restricted. It is a generic and multi-dimensional tool that assesses other QoL aspects in addition to biomedical issues (Reis et al 2013, Savassi et al 2014, Skevington et al 2004).

Leprosy patients may suffer feelings of denial, anger, depression, frustration, emptiness, or anxiety. These behaviours and feelings vary in intensity, duration and expression (Garbin et al 2015). Studies have shown that the factors associated with a higher stigma were illiteracy, perceived economical inadequacy, change of occupation due to leprosy, lack of knowledge about leprosy, perception of leprosy as a severe disease and a disease which is difficult to treat (Adhikari et al 2014). Quality of life is affected in both males and females with variations among different studied populations. Study by Govindhraj et al (2018) showed almost

similar QoL among both males and females in all four domains. In some studies males had lower scores in all domains, and the environmental domain was significantly more affected score (Reis et al 2013). A study by Joseph & Rao (1999) indicated that women had higher quality of life scores than men in almost every domain, and this perhaps implied a greater readiness among women to accept their situation, in line with their secondary role in Indian rural society. While in our study, females had lower scores as compared to males, more significantly in the social domain, reflecting an effect in personal relationships and support system. These differences in the scores among females may probably due to differences in the demographic profiles or social and cultural attributes in the studied populations. Also, improved healthcare, education, economic status, access to information through social media and raised expectations are bound to lead to changes in people's perceptions of their quality of life as against conventional factors associated with higher stigma such as illiteracy, low socio-economic status.

In our study, increasing age decreased the domain scores and elderly patients predominantly had lower scores in all four domains as compared to younger patients, and psychological domain was significantly affected. This probably reflected increased anxiety and fear associated with disease and the inability to enjoy life. Similar findings were noted in other Indian studies too (Govindharaj et al 2018, Dinesh et al 2016).

Among the various domain scores, in our study, we found that the psychological domain and physical were the two lowest scoring domains (Table 1) compared to the other domains with respect to most variables. This is in agreement to a study conducted in Bangladesh which showed lower outcomes in psychological and physical domains (Nardi et al 2012) But this data is, in

contrast, to a study in Brazil by Santos et al (2015) where in patients with leprosy had lower physical and environmental domain outcomes. These variations indicated towards increased stress about the disease or the physical disabilities caused by it and lack of employment opportunities thereof in the south Asian population. Study on mental health in leprosy by Garbin et al (2015) reported that 69% of the respondents complained of depression, 38.3% of patients reported that they were no longer vain, 27.7% were afraid of dying, and 92.6% were afraid of experiencing disease sequelae. These regional differences may be due to the cultural and socioeconomic characteristics of patients being enrolled in the studies.

The social relation outcomes had a higher score in most study groups as compared to other domains probably because of the higher awareness about the disease in the studied population and the support of the family. But there was a significant gender difference in the social domain as discussed earlier. Similar finding was noted by Saha et al (2015) where 93% and 82% of the patients did not face discrimination in high prevalent and low prevalent areas, respectively.

The domain scores varied with the type of leprosy. The paucibacillary types of leprosy had higher scores, while the multibacillary forms and reactions had lower scores. The psychological domain was affected in types of leprosy associated with disabilities like type 1 reactions and lepromatous leprosy. Patients with lesions over the face had a lower domain score as compared to even claw hand or foot drop or trophic ulcer. This indicated increased stigma associated with physical appearance especially concerning facial features. Patients with a disability had lower scores in the psychological domain and environmental domain, probably indicating additional stress associated with disability and an inability

to do their daily activities. Similar findings were associated with higher stigma as in other studies (Adhikari et al 2014, Santos et al 2015). Patients with lepromatous leprosy, lepra reactions, patients with facial lesions and claw hands had lower scores in the psychological domain.

The limitations of our study was a small sample size as well as shorter duration of study. The study was conducted in a tertiary care centre thereby the result may not be reflective of the larger community. Also, as this was a cross-sectional study and involved leprosy patients in various stages of treatment, the QoL before and after completion of therapy could not be analysed. In addition, other factors like cultural, urban location with better access to education and health care measures, which may affect the QoL, were not analysed.

Conclusion

In conclusion, the study observed that leprosy, particularly in the aging population, women, and patients with severe forms of leprosy and leprosy patients with disabilities, had poorer quality of life. Analysis from QoL studies may help plan appropriate interventional and rehabilitation programmes in the target population.

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