

Health-Related Quality of Life Study of Leprosy Affected People of a Leprosarium of Northern India

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The quality of life (QoL) of leprosy-affected people (LAP) of a leprosarium at Srinagar, Jammu & Kashmir, India were assessed across sociodemographic, dermatology, and neurological factors using DLQI, WHOQOL-BREF, and DN4 questionnaires and statistically analyzed using IBM SPSS. QoL of LAPs measured through DLQI and WHOQOL-BREF was found to be low with most leprosy affected people having a significant effect of leprosy disease on their QoL, the highest affected domain was social relationship followed by psychological domain. QoL had a strong relationship with age, gender and type of leprosy disease; with progression in age the QoL impairments increased; more QoL impairments in females than males and multibacillary (MB) disease rather than paucibacillary (PB category) of leprosy that showed lesser QoL impairments. Females experienced more neuropathic pain than males, and quality of life in the social relationship followed by the psychological domain were worst affected and were found to have a strong correlation with age, gender, and disease category. QoL was also observed to be severely affected due to the pain and disability associated with the leprosy, and psychological, social, and environmental factors contributed to its reduction. A multi-front strategy towards improving the quality of life may include several measures such as early diagnosis and treatment; active surveillance and treatment of wounds to reduce the intensity of pain; organization of rehabilitation programmes; creating occupational opportunities and continued counselling to reduce diverse social and psychological complexities, and reintegration with the society to reduce social exclusion.

Keywords : Perceived Stigma, Enacted Stigma, Self-Stigma, Internalized Stigma, Participation Restriction, Psychological Aspects, Quality of Life, Leprosy Affected People, Kashmir, India

Introduction

Leprosy (also known as Hansen's disease) is a chronic infection with slow clinical progression often punctuated by hypersensitivity reactions that mainly affect the skin, the peripheral nerves, mucosa of the upper respiratory tract, and eyes, apart from some other structures (Basra et al 2008). The bacterium *Mycobacterium leprae*, an acid-fast, rod-shaped bacillus, also known as

Hansen's bacillus, causes this infection. As per more recent knowledge, the causative agents of leprosy in humans as well as in animals are the *Mycobacterium leprae* (*M. leprae*) and the more recently discovered *Mycobacterium lepromatosis* (*M. lepromatosis*) (Han et al 2009, Honap et al 2018, Schilling et al 2019, Tió-Coma et al 2020). Ploemacher et al., in their extensive review of the literature between January 1945

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and July 2019, conclude that given the identified reservoirs of *M. leprae* and *M. lepromatosis*, the causative agents of leprosy, the transmission of this disease is much more complicated as transmission included human-to-human, wildlife, environment, and insects (Ploemacher et al 2020). The leprosy diagnosis is essentially based on clinical findings for which a slit-skin smear examination for bacteriologic index may or may not be required. The disease progresses very slowly, with an average incubation period and signs and symptoms of five years. The initial symptoms result in light or darker skin or nodular lesions with loss of sensation. Genetic factors and immune functions possibly determine how easily a person might get the disease. The disease is curable with early diagnosis and treatment. The affected people can continue working and leading active life during and after the treatment.

India's National Leprosy Elimination Programme (<http://nlep.nic.in/>), in partnerships with national and international- governmental and non-governmental organisations including WHO, ILEP /non-ILEP has shown tremendous progress towards controlling leprosy. However, the problem persists, and the decline in new case detection rates and prevalence has only changed marginally over the last two decades. Jammu and Kashmir – a northern region of India, have witnessed Leprosy disease and missionary works towards patient care and management since historical times (Neve 1889, Nerve 1909). Among very few recent research studies concerning Jammu and Kashmir, a recent survey of leprosy-affected persons from 2005 to 2014 in the Jammu region of Jammu and Kashmir, Mushtaq et al. have reported a rise in newly detected cases of leprosy and concluded that leprosy continues to affect children with a continuous chain of transmission (Mushtaq et al 2020). Furthermore, another recent study by a group of state administrators collaborating with some eminent doctors concluded that the

leprosy-affected persons of the leprosarium of Srinagar had extreme forms of leprosy with disfigurement and amputations and have been abandoned by their families (Saleem-Ur-Rehman et al 2017). Although facilities such as dedicated leprosy hospitals/colonies and providing free rations to leprosy-affected persons have been operational in the area, minimal efforts have been made to address secondary psychosocial disabilities because of the chronic nature of the disease and the unsightly disfigurement, which results in prejudice, and stigmatization and social exclusion of those affected. Stigmatization, depression, anxiety and social exclusion contribute to increased or sustained chronic pain conditions in leprosy patients. Exact figures for new and prevalent cases of leprosy in the area are conflicting; however, a survey conducted by the current authors estimates the number of over 700.

Quality of Life

The meaning of the term “Quality of Life” (QoL) is complex as diverse factors drive it in research and practice. Several factors have further complicated this, e.g., researchers often do not define QoL (Gill 1994); factors given importance to QoL vary substantially between studies (Gronbjerg & Liu 1977); and an overlap between the notions of life satisfaction and QOL (Landesman 1986). Aiming to address this challenge, Felce and Perry suggest QoL be thought of as 1) the sum of objectively measurable life conditions; 2) a person's satisfaction with the sum of these life conditions; (Felce & Perry 1995); 3) a combination of both objective life conditions and satisfaction with those conditions (Brown et al 1989); and 4) an objective assessment of living conditions and subjective assessment of satisfaction, weighted according to the significance of an individual place on each particular domain (Cummins 1996). Lately, QoL has been defined by the World Health Organization (WHO) as an “Individual's perception of their position in the context of

culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL 1998). Quality of life (QoL) is a highly subjective measure that incorporates multidimensional nature and perception of overall QoL but is often quoted as the impact of an illness or injury on the QoL affecting the health, comfort, and happiness of an individual. Physical and psychological conditions, degree of independence and social relationship are included in the QoL factors.

Leprosy disease can cause primary and secondary health problems, e.g., skin and peripheral nerve damage, deformity, disfigurement, stigma, anxiety, depression, social exclusion, and lower socioeconomic status. These factors, with injury mainly in the physical and psychological domains, may have compromised the QoL of leprosy-affected persons. Therefore, it is imperative to design and implement rehabilitation programs to access the QoL of those affected by the disease. Although several studies have been undertaken to assess the QoL of leprosy-affected persons across the globe, including India, there is a vast scope to conduct such studies in other populations, particularly populations where leprosy patients and their families still live-in leprosarium (Barcelos et al 2021, Hunt et al 2018, Solanki et al 2020). However, no such research has been undertaken for the selected people included in this study.

In the health field, QoL can be assessed with general instruments covering different clinical conditions or specific instruments for a particular disease; however, the use of standard and validated instruments permit accurate measurement of QoL for a population with comparisons and correlations to other analysis enabling devising of effective programs for the improvement of the QoL for that population. Therefore, several dermatology-specific and disease-specific QoL instruments with varying degrees of validation have been developed and

used in literate for studying factors affecting the QoL of leprosy-affected people.

Barcelos et al (2021) in their extensive survey of literate about QoL measurements, have reported that the World Health Organization Quality of Life-Brief – WHOQOL-BREF, a validated instrument with general questions and skin diseases instruments, notably Dermatology Life Quality Index – DLQI and the Medical Outcome Study – Short form-36 – SF-36 have been used extensively to access QoL of leprosy-affected persons. The other instruments used include World Health Organization Quality of Life-100 (WHOQoL-100), Pediatric Quality of Life Inventory™ version 4.0 (PedsQL 4.0), Short Form Health Survey (RAND-36); Short Form-20 (SF-20); Wisconsin-Quality of Life Index (W-QLI), Quality of Life in Neurological Disorders (Neuro-QoL) and Children’s Dermatology Life Quality Index (CDLQI). In addition, the dermatology life quality index (DLQI) has been used in analysing the quality of life of leprosy-affected people in many studies. (Lewis & Finlay 2004, Chernyshov et al 2017a, Chernyshov et al 2017b). Others include DN4 by Bouhassira et al (2005), WHOQoL-BREF by WHO QoL Group, WHO disability grading by Brandsma & Van Brakel (2003), and other HRQoLs by Karimi & Brazier 2016).

There are other related studies on this aspect. Bottene & Reis (2012), in their study using DLQI and Short Form-36 (SF-36) on 49 (forty-nine) leprosy-affected people adopted by Sanitary Dermatology Technical Area, found that an earlier diagnosis and treatment of leprosy has a positive impact on the QoL of leprosy affected people, as Paucibacillary Leprosy (PB) affected persons showed minimum impairment on their QoL. This study suggests that delay in the adequate treatment of even this group of leprosy-affected people can decline their QoL. Though no QoL impairment was reported for PB leprosy patients in some studies, in contrast, Hunt et al (2018), in a case-controlled study using DLQI, concluded

that the burden of leprosy on QOL does not necessarily entirely disappear once the person is cured of the disease. This study's findings also suggest a significant difference in QOL between cured leprosy-affected people, people under treatment and family and friends of the affected. The study also showed no significant difference in QOL among groups based on marital status, employment and perceived stigma. De et al (2020), in a survey on QOL using the DLQI instrument on 114 leprosy-affected people with cardinal signs of leprosy in tertiary care centres of Eastern India, concluded that while demographic variables had a minimum effect on the QOL of patients, clinical aspects such as reaction, nerve involvement, deformity and disability had significant impairments on QOL. The study suggests that preventing clinical complications of people to a more considerable extent can alone improve QOL. Ingordo et al (2014), while estimating the QOL using DLQI of 161 leprosy-affected people of nine dermatological centres, found cultural and ethical characteristics of affected people responsible for QOL impairment. The study did not find any significant association between the DLQI mean score and the progression of the disease. This is in contrast to the studies of Parsad et al (2003), Wang et al (2011) and Radtke et al (2009). Some other studies reported no significant influence of the progression of disease on QOL; these include Ongenae et al (2005), Wong & Baba (2012), Silverberg & Silverberg (2013) and Karelson et al (2013). Moderate to considerable impairment on QOL due to the dark skin condition of leprosy-affected people was shown in the studies of Parsad et al (2003), Aghaei et al (2004), Belhadjali et al (2007), and Kiprono et al (2013). Studies by Ongenae et al (2005), Belhadjali et al (2007), Radtk et al (2009) and Wang et al (2011) found high QOL impairment in female leprosy-affected people, citing the reason that women felt more embarrassed and self-conscious of the

disease, more impaired in their daily routine and are more influenced by controls. On the other hand, some other studies, e.g., Kent & Al-Abadie (1996), Parsad et al (2003), Aghaei et al (2004), Al Robace (2007), Silverberg & Silberberg (2013) and Karelson et al (2013) have reported no difference in QOL between genders. Association between the age of leprosy affected and QOL has been shown in the studies of Parsad et al (2003), Kent & Al-Abadie (1996) and Wong & Baba (2012), while studies by Ongenae et al., Aghaei et al (2004), and Belhadjali et al (2007), have shown no such association. El-Refaei et al (2018), in a study on 300 affected people attending different dermatology outpatient clinics in Egypt using DLQI, DN4 and WHOQOL-BREF, found QOL impairment in all cases, even in fully treated patients. The study also reported less QOL impairment in young leprosy-affected people than in older ones and more QOL impairments in females than males. No significant difference in QOL was found based on the type of leprosy and the site of the lesion. Govindharaj et al (2019) concluded that visible deformity causes lower QoL in leprosy-affected persons. They further suggest that the QoL of the affected can be improved by early detection and management of leprosy. A study by Solanki et al. has demonstrated that leprosy significantly impacts the quality of life of leprosy-affected persons due to associated deformities and social stigma even after the bacteriological cure of the disease. Barcelos et al (2021), in their extensive literature review of 74 QoL surveys, have concluded that the improvement in the QoL of patients was related to early diagnosis and treatment, health education, a multidisciplinary approach, prevention of physical disabilities and stigma.

It has been hypothesized that the factors responsible for impairing the quality of life of leprosy-affected persons of Jammu and Kashmir are in the physical domain, such as physical deficiencies and impairments; the psychological

domain, such as anxiety and depression; the social domain, such as participation restriction; and the environmental domain, such as dependencies in activities associated with the leprosy disease. This study attempts to test this hypothesis by surveying leprosy-affected persons residing in Kashmir.

To test the above hypothesis, this study has been conducted with the following three broader objectives: (a) To measure quality of life across different sociodemographic, dermatology, and neurological factors of leprosy-affected people; (b) To determine the correlation of quality of life with various factors across physical, psychological, social and environment domains; and (c) To identify the most critical factors in each domain of life impairing quality of life.

Materials and Methods

Sample

This study was conducted as part of the first author's doctoral research (LB) in 2020-21 after receiving approvals from the University of Kashmir and GMC Srinagar's Institutional Ethics Committee. The study area was leprosarium of Srinagar; data were collected from 71 leprosy-affected persons hailing from Kashmir (65 residing in the leprosarium and six living outside the leprosarium who visited the leprosarium during the period of the study). A socio-demographic data questionnaire and study instruments based on the WHOQOL-BREF, Dermatology Life Quality Index (DLQI), and DN4 scales were prepared following the instrument adaptation procedure. Various inclusion and exclusion criteria were adopted in selecting leprosy-affected persons for the study. The following were the criteria for inclusion: 1) males and females between the ages of 15 and 75; 2) reliable information about the case; and 3) physical fitness of the person to understand and answer the questions. The following were among the exclusion criteria: 1) unsteady medical condition; 2) previously

diagnosed as a case of leprosy and under cover of any psychiatric drugs; 3) persons taking any medication, which can produce cognitive defects leading to stigma; and 4) lack of reliable informer or refusal of the patient or relatives.

Procedure

This study was conducted after obtaining all necessary approvals/permissions. Case study used quantitative methods to assess the quality of life of leprosy-affected persons. Leprosy-affected people at the leprosarium hospital were invited for interaction through councillor (a psychologist – a physician by profession). They were educated about the objectives and benefits of the study. The study's purpose was explained in groups in multiple sittings, which initially educated them about various dimensions of the disease, including its cure, management, and success stories of leprosy-affected people. They were interviewed in a private environment without external interference and served relevant instruments discussed later in this section. Ethical aspects including beneficence, autonomy, patient confidentiality, informed consent assuring confidentiality and anonymity during the publication, and conflicts of interest in healthcare were given due consideration during the study. Forward and backward translations were carried by language experts before and after the interview process for correctness and accuracy. Validation of instruments through statistical techniques, selection of patients for the interview, and building of relationship and trust with patients were given due consideration for obtaining correct results.

Measures

To access leprosy-affected persons' quality of life, a face-to-face interview by a dermatologist using WHOQOL-BREF, the Dermatology Life Quality Index (DLQI), and DN4 questionnaires have been used to determine various aspects of the quality of life of leprosy-affected persons. The choice

of these instruments has been made because of the following reasons: these instruments are standardized; cover both medical and social dimensions of the disease; and have been used extensively in the literature to assess the QoL of leprosy-affected persons, thereby enabling the current study results to be compared with standard surveys and findings.

The WHOQOL-BREF (WHOQOL 1998) comprises 26 questions grouped into four domains: physical, psychological, social, and environmental. Each question uses a 5-point response scale. Questions 3, 4 and 26 are negatively phrased items and need to be adjusted before calculating the total score. The scores are scaled in a positive direction, with higher scores indicating a higher quality of life. The possible raw score ranges for each domain are Physical Health=28, Psychological=24, Social Relationships=12 and Environment=32.

The DLQI consists of 10 questions grouped into six domains: symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment. Each question has four response alternatives, corresponding to scores from 0 to 3. The scoring of each question is as follows: 'Very much' scored 3, 'A lot' scored 2, 'A little' scored 1, 'Not at all' scored 0, and 'Not relevant' scored 0; for Question 7, 'prevented work or studying' scored 3. The DLQI is calculated by summing the score of each question resulting in a maximum score of 30 and a minimum score of 0. The higher the score, the more quality of life is impaired. The interpretation of the DLQI is as follows: a score from 0 – 1 is interpreted as 'no effect at all on patient's life', a score from 2 – 5 is interpreted as 'small effect on patient's life', a score from 6 – 10 interpreted as 'moderate effect on patient's life' a score from 11 – 20 interpreted as 'very large effect on patient's life' and a score from 21 – 30 interpreted as 'extremely large effect on patient's life'.

The DN4 questionnaire is a 10-item diagnostic

tool to assess clinical conditions associated with neurological lesions. If the score is four or higher, the pain is likely to be neuropathic; otherwise, the pain is unlikely to be neuropathic.

WHOQOL-BREF is a standardized general instrument covering physical, psychological, social relationships and environment dimensions. DLQI and DN4 are standardized skin disease instruments permitting QoL assessments. Skevington et al (2004) note that, after testing, the WHOQOL-BREF is "a sound, cross-culturally valid assessment of QOL". In addition, the WHOQOL-BREF has shown good discriminant validity, content validity, internal consistency and test-retest reliability. DLQI covers symptoms and feelings, daily activities, leisure activities and sports practices; work and school; interpersonal relationships; and treatment. DLQI, initially written in French, has been widely used since 2005 because of its simplicity. It evaluates neuropathic pain following central and peripheral neurological lesions. It is also used for diagnostic purposes, allowing us to determine if the pain is of neuropathic origin. This questionnaire has been well-validated in many studies. Dermatology Life Quality Index (DLQI) detailed in Basra et al (2008), is a skin disease-specific HRQoL assessment questionnaire designed by Finlay & Khan (1994). DN4 covers pain, loss/reduced sensitivity, diffuse sensory-motor symptoms, and limitations of activities in daily life.

Statistical Analysis

The IBM SPSS software package was used for data analysis. Sociodemographic, dermatological, and neurological characteristics of patients, DLQI, and WHOQOL-BREF quality of life scores were summarized in terms of mean, standard deviation, and range for quantitative data and frequencies and percentages for qualitative data. Comparisons between the quality-of-life scores of the different study groups were conducted using the Chi-square and Fisher's exact tests to

compare proportions as appropriate. The student t-test (t) was used to detect the mean difference between the quality-of-life scores of males and females, and the Analysis of Variance (ANOVA) test was used to compare the quality-of-life of different age groups. Pearson correlation coefficient (r) was used to test the correlation between the sociodemographic variables, DLQI, WHOQOL-BREF domains, and DN4 quality of life scores. A P-value <0.05 was considered statistically significant, and a P-value <0.001 was considered statistically highly significant.

Results

Seventy-one (71) leprosy-affected persons living in the leprosarium of Srinagar were enrolled in the study. They originally belonged to different districts of the Kashmir region of Jammu and Kashmir, a northern part of India.

Neuropathic pain was recorded in 57 (80.25%) people based on the DN4 score (≥ 4). The DN4 score range was 1-7, and its mean score was 4.42 ± 1.411 (Table 1). This showed that most of the participants had symptoms of neuropathic pain.

The mean DLQI score was 11.10 ± 6.022 . A substantial effect on patient's quality of life was found in 6 (8.45%), a very large impact in 28 (39.44%), a moderate effect in 23 (32.39%), and 14 (19.72%) of leprosy-affected people showed small effect (Table 2). The results show that the impact of leprosy on the participants mostly ranged between moderate and mild.

The WHOQOL-BREF mean score in overall quality of life and general health facets was 2.888 ± 0.838 , 10.35 ± 5.559 in physical, 8.90 ± 4.811 in psychological, 4.46 ± 2.437 in social relationships and 11.85 ± 6.460 in environment domains (Table 3). This showed that the quality of life was low primarily due to social and psychological aspects of leprosy disease.

The Pearson correlation coefficient (r) used to test the correlation between different scales of

quality-of-life scores, and the P-value obtained for each correlation shows a very strong relationship between scores of the three scales used (Table 4). Although all relationships shown are very strong, the strongest relationship can be observed between WHOQOL- BREF (Physical Domain) and DLQ1, WHOQOL- BREF (Environmental Domain) and DLQ1 and WHOQOL-BREF (Psychological Domain) and WHOQOL-BREF (Environmental Domain). Conversely, the least relationship was observed between WHOQOL-BREF (Environmental Domain) and DN4 with a correlation coefficient (r) equal to 0.549.

The correlation between DLQ1 and various age groups is highly significant, as demonstrated by using Fisher's exact test (Table 5). Similarly, the correlation between age groups and each domain of WHOQOL-BREF is significant. The chi-square and ANOVA tests have not shown a statistically significant correlation between pain and various age groups. The significant correlation between DLQI scores and different age groups using Fisher's exact test and similar results for WHOQOL-BREF scores indicate that QoL is worst affected for the elderly in the social, environmental and psychological domains. Further, a non-significant correlation between DN4 scores and age groups shows neuropathic pain is not a significant factor for decreased QoL in elderly leprosy-affected people.

The correlation between DLQ1 and the gender measured using the chi-square test was statistically significant (Table 6). Similarly, the correlation between gender and each domain of WHOQOL-BREF is statistically significant, as demonstrated by the student's t-test. The collective results of chi-square and ANOVA tests have shown a statistically significant correlation between DN4 and gender. These results indicate that QoL for female leprosy-affected people is lower than for males. All highly significant results obtained for DLQI, all domains of WHOQOL-BREF

Table 1 : Socio-demographic, dermatological and neurological characteristics of patients.

Variable (N=71)	n	%	
Age (Years)	<50	12	16.90%
	50-60	26	36.62%
	60-70	18	25.35%
	>70	15	21.13%
	Mean \pm SD		61.48 \pm 11.293309
	Median		60
	Range		37-90
Type of Disease	Multibacillary	39	54.90%
	Paucibacillary	32	45.10%
Gender	Male	44	62.00%
	Female	27	38.00%
Education	Never Attended School	60	84.51%
	Can Read But Not Write	4	5.63%
	Can Read and Write	2	2.82%
	<3rd Standard	0	0.00%
	Up to Primary	2	2.82%
	Above Primary School	3	4.23%
Marital Status	Married	42	59.15%
	Unmarried	13	18.31%
	Cohabited	0	0.00%
	Widowed	14	19.72%
	Separated	2	2.82%
Employment	Full Time	8	11.27%
	Part Time	0	0.00%
	Homemaker	27	38.03%
	Student	0	0.00%
	Retired	0	0.00%
	Sick Leave	0	0.00%
	Disabled	16	22.54%
	Unemployed	20	28.17%
Neuropathic Pain	Present (DN4 \geq 4)	57	80.28%
	Absent (DN4<4)	14	19.72%
DN4 Score	Mean \pm SD		4.42 \pm 1.411
	Range		1-7

Table 2 : Scores of the DLQI questionnaire in the studied group.

DLQI (n=71)		n	%
DLQI Scores Categorization (higher scores indicate more impairment)	Small Effect (2-5)	14	19.72%
	Moderate Effect (6-10)	23	32.39%
	Very Large Effect (11-20)	28	39.44%
	Extremely Large Effect (21-30)	6	8.45%
Overall DLQI Score	Mean \pm SD; (Range)	11.10 \pm 6.022 (2-27)	

Table 3 : Scores of the WHOQOL-BREF questionnaire in the studied group.

WHOQOL-BREF (n=71)		Mean \pm SD	Range
WHOQOL-BREF Scores	Physical Domain	10.35 \pm 5.559	2-25
	Psychological Domain	8.90 \pm 4.811	2-22
	Social Domain	4.46 \pm 2.437	1-11
	Environment Domain	11.85 \pm 6.460	2-29
Overall DLQI Score	Overall QoL (Q1&Q2)	2.888 \pm 0.838	2-4

Table 4 : Correlation between DLQI, WHOQOL-BREF domains, and DN4 scores.

Score	DLQI		Physical Domain		Psychological Domain		Social Domain		Environmental Domain		Overall Quality		DN4	
	r	P	r	P	r	P	r	P	r	P	r	P	r	P
DLQI	1													
WHOQOL-BREF	Physical Domain	0.999	0.000	1										
	Psychological Domain	0.998	0.000	0.998	0.000	1								
	Social Domain	0.994	0.000	0.992	0.000	0.992	0.000	1						
	Environment Domain	0.999	0.000	0.995	0.000	0.999	0.000	0.993	0.000	1				
	Overall QoL (Q1&Q2)	0.892	0.000	0.892	0.000	0.891	0.000	0.894	0.000	0.889	0.000	1		
DN4	0.612	0.000	0.605	0.000	0.604	0.000	0.594	0.000	0.617	0.000	0.549	0.000	1	

and DN4 scores and gender suggest that the lower QoL of female leprosy-affected people is due to all studied factors.

The correlation between DLQ1 and the type of disease (Paucibacillary -PB and multibacillary MB as per standard programme criteria) measured

Table 5 : Correlation between age and DLQI, WHOQOL-BREF and DN4 questionnaires scores.

Variable (n=71)	Age (Years)												Test	P	
	<50 (n=12)			50-60 (n=26)			60-70 (n=18)			>70 (n=15)					
	n	%		n	%		n	%		n	%				
Small Effect (2-5)	3	25.00%	10	38.46%	0	0	1	6.70%							
Moderate Effect (6-10)	6	50.00%	8	30.77%	6	33.30%	3	20.00%							
Very Large Effect (11-20)	1	8.30%	8	30.77%	10	55.60%	9	60.00%						FET	0.002
DLQI (higher scores indicate more impairment)															
Extremely Large Effect (21-30)	2	16.70%	0	0	2	11.10%	2	13.30%							
Mean ± SD; (range)	8.92±6.459(2-22)		8.81±5.394(2-20)		13.44±4.961(8-26)		14.00±6.059(4-27)		F=4.414	0.007					
Mean ± SD; (range)	8.80±6.083(2-21)		8.31±4.970(2-19)		12.39±4.816(7-24)		12.93±5.675(4-25)		F=3.875	0.013					
Mean ± SD; (range)	7.33±5.176(2-18)		7.08±4.279(2-16)		10.72±4.056(6-21)		11.13±4.912(3-22)		F=4.083	0.010					
Physical Domain															
Psychological Domain															
Social Domain	3.50±2.541(1-9)		3.54±2.177(1-8)		5.50±4.816(7-24)		12.93±5.675(4-25)		F=4.687	0.005					
Environment Domain	9.33±6.853(2-23)		9.31±5.836(2-21)		14.50±5.113(9-28)		15.07±6.453(4-29)		F=4.900	0.004					
Overall QoL (Q1&Q2)	2.50±0.798(2-4)		2.69±0.884(2-4)		3.11±0.785(2-4)		3.27±0.704(2-4)		F=3.020	0.036					
DN4															
Absent neuropathic pain (<4)	1	8.33%	4	15.38%	4	22.22%	6	40.00%						X ² =4.913	0.178
Neuropathic pain (≥4)	11	91.67%	22	84.62%	14	77.78%	9	60.00%							
Mean ± SD; (range)	3.0±2 (1-7)		4.0±1 (3-6)		4.0±1 (3-7)		6.0±1 (4-7)		F=1.660	0.184					

Table 6 : Correlation between gender and DLQI, WHOQOL-BREF and DN4 questionnaires scores.

Variable (n=71)	Gender				Test	P
	Male (n=44)		Female (n=27)			
	n	%	n	%		
DLQI (higher scores indicate more impairment)	Small Effect (2-5)	14	31.82%	0	0	X ² =18.68 <0.000
	Moderate Effect (6-10)	14	31.82%	9	33.33%	
	Very Large Effect (11-20)	16	36.36%	12	44.45%	
	Extremely Large Effect (21-30)	0	0	6	22.22%	
	Mean ± SD; (range)	8.57±4.234(2-18)		15.22±6.284(6-27)		
WHOQOL-BREF	Physical Domain	Mean ± SD; (range) 7.98±3.806(2-17)		14.22±5.944(6-25)		t=-5.404 0.000
	Psychological Domain	Mean ± SD; (range) 6.86±3.303(2-14)		12.22±5.079(5-22)		t=-5.393 0.000
	Social Domain	Mean ± SD; (range) 3.45±1.704(1-7)		6.11±2.577(2-11)		t=-5.233 0.000
	Environment Domain	Mean ± SD; (range) 9.16±4.675(2-19)		16.22±6.641(6-29)		t=-5.254 0.000
	Overall QoL (Q1&Q2)	Mean ± SD; (range) 2.59±0.692(2-4)		3.37±0.838(2-4)		t=-4.245 0.000
DN4	Absent neuropathic pain (<4)	12	27.28%	3	11.11%	X ² =2.623 0.021
	Neuropathic pain (≥ 4)	32	72.72%	24	88.89%	
	Mean ± SD; (range)	4.07±1.301 (1-7)		5.00±2.000 (2-7)		

using the chi-square test has been found to be statistically significant (Table 7). The correlation between the type of disease and each domain of WHOQOL-BREF is statistically significant, as demonstrated by the student's t-test. The chi-square and ANOVA tests' collective results have not shown a statically significant correlation between DN4 and the type of disease. These results for DLQI and WHOQOL-BREF, DN4 scores, and type of leprosy demonstrate that QoL with MB type of leprosy has reduced QoL primarily due to psychological conditions, degree of independence and social relationship and not due to neuropathic pain.

The results of the data analysis given in tables 1-7 show the following important findings from the

study: i) neuropathic pain measured through DN4 was present in most of leprosy affected people, and females experienced more pain than males; however, no significant relationship was found between age and degree of pain; ii) quality of life of LAPs measured through DLQ1 and WHOQOL-BREF was low with most leprosy affected people having the significant effect of leprosy disease on their QoL, the highest affected domain was social relationship followed by psychological domain; iii) QoL has a strong relationship with age, gender and type of leprosy disease; with progression in age the QoL impairments increase; more QoL impairments in females than males and PB category of leprosy showed less QoL impairments.

Table 7 : Correlation between type of disease and DLQI, WHOQOL-BREF and DN4 questionnaires scores.

Variable (n=71)	Type of Disease				Test	P
	MB (n=39)		PB (n=32)			
	n	%	n	%		
DLQI (higher scores indicate more impairment)	Small Effect (2-5)	2	5.13%	6	18.75%	
	Moderate Effect (6-10)	12	30.77%	10	32.39%	X ² =16.225
	Very Large Effect (11-20)	19	48.72%	13	39.44%	
	Extremely Large Effect (21-30)	6	15.38%	3	9.34%	0.001
	Mean ± SD; (range)	13.67±5.900(4-27)		7.97±4.561(2-18)	t=4.473	0.000
Physical Domain	Mean ± SD; (range)	12.72±5.563(4-25)		7.47±4.150(2-17)	t=4.421	0.000
Psychological Domain	Mean ± SD; (range)	10.92±4.770(3-22)		6.44±3.601(2-14)	t=4.389	0.000
Social Domain	Mean ± SD; (range)	5.51±2.416(2-11)		3.19±1.786(1-7)	t=4.523	0.000
Environment Domain	Mean ± SD; (range)	14.62±6.252(4-29)		8.47±4.990(2-19)	t=4.506	0.000
Overall QoL (Q1&Q2)	Mean ± SD; (range)	3.21±0.800(2-4)		2.50,0.718(2-4)	t=3.865	0.000
DN4	Absent neuropathic pain (<4)	6	15.38%	9	28.17%	X ² = 1.712
	Neuropathic pain (≥ 4)	33	84.62%	23	71.83%	
	Mean ± SD; (range)	4.77±1.477 (1-7)		4.00±1.218 (1-7)	t=2.354	0.019

Discussion

Among other reasons that include the segregation of leprosy-affected persons from the population to avoid the spread of leprosy infection before introducing MDT therapy, the concept of leprosarium was conceived to provide a dignified quality of life and improved medical and social care to the affected persons. However, this study demonstrates that despite living in a leprosarium, the quality of life of its residents is inferior. The DLQ1 instrument, essentially unidimensional and focused on six parameters with a limited set of questions, and WHOQOL-BRIEF, which has multiple domains with broader questions and cross-cultural validity, have demonstrated an unsatisfactory quality of life for leprosy-affected people. This study's results confirm Bottene et al., which showed lower impairment on QoL for PB type compared to MB. It is in contrast to the results of the study of Ingordo et al. Still, in conformity with the study of Parsad et al (2003), Wang et al (2011) and Radtke et al (2009). While agreeing with other results of the study by El-Refaei et al (2018), this study's results show a significant difference in QoL based on the type of leprosy. Like the studies by Ongenae et al (2005), Belhadjali et al (2007), Radtke et al (2009) and Wang et al (2011), this study also found high QoL impairment in female leprosy-affected people. The results are in contrast to some other studies that include Kent & Al-Abadie (1996), Parsad et al (2003), Aghaei et al (2004), Al-Robace (2007), Silverberg & Silverberg (2013), and Karelson et al (2013). Multiple reasons, including cultural and ethical characteristics, women being more self-conscious, emotional and easily influenced by controls, could be responsible for their higher QoL impairment than men. This study shows a negative correlation between progression in age and QoL, which has also been with slight differences demonstrated in the studies by Parsad et al (2003), Kent & Al-Abadie (1996) and

Wong & Baba (2012). In contrast, Ongenae et al (2005), Aghaei et al (2004), and Belhadjali et al (2007) have found no such correlation. Ageing reduces the cognitive and other functionality of the human body. With increasing age, isolated from their original society, most of them being abandoned by their family, increased age makes them more dependent and thus reduces their QoL. The individual domain results of WHOQOL-BREF suggest that leprosy-affected people are not satisfied with their social life, such as social support from family and friends, and suffer from psychological aspects such as participation restriction, anxiety, stigma, and depression. Also, pain adversely affects physical, environmental and psychological domains. Govindharaj et al (2019), with 358 respondents from West Bengal, India, using the WHOQOL-BREF instrument, observed that physical disability, disease duration, and family income influenced QoL more. In a similar recent cross-sectional study of leprosy patients at the tertiary care centre of Ahmedabad, India, using DLQI, Solanki et al. reported a substantial effect on the quality of life. The present study results are in tune with recent studies from other populations; however, the current research using multiple instruments provided the intensity of each factor on the QoL impairment. The results of this study and literature review of 74 QoL surveys by Barcelos et al (2021) suggest that improvement in the QoL of leprosy-affected people, irrespective of their geographical area, needs a multidisciplinary approach in physical, psychological, and social domains. Given the disease and associated social, psychological and environmental complexities, a multi-front strategy for each setting may be useful to improve the QoL. This includes controlling the intensity of neuropathic pain, which otherwise emerges as a disabling condition affecting physical, psychological, environmental and social domains and contributing to the reduced QoL.

An early diagnosis and treatment of leprosy could effectively reduce the number of lesions associated with the disease, control the pain intensity, and minimize its effects on other domains responsible for QoL impairments. Active surveillance and treatment of wounds could also reduce the intensity of pain. Social and psychological impacts that reduce QoL can be addressed by lowering discrimination, counselling for diverse complexities (including stigma, depression, and anxiety), rehabilitation programs, and creating occupational opportunities. Environmental aspects can be addressed by reintegrating leprosy-affected people with society to provide opportunities without restrictions and social exclusion.

Conclusion

This study demonstrates that all domains of QoL of leprosy-affected persons living in this leprosarium at Srinagar are negatively affected due to the disease, be it neuropathic pain or social, environmental or psychological sphere. The QoL gets further reduced with the complexity of the disease and increasing age. Females experience more QoL imperilments than men as their concerns are higher concerning culture and value systems in their society. The results obtained using three different instruments of QoL, their statistical analysis, and correlations between the variables and results across instruments have confirmed the hypothesis. In the current era, individuals' perception of their position is highly influenced by other individuals' positions as the lifestyle of other individuals living in close vicinity or remote locations is not hidden. Despite knowing their limitations due to some physical imperilment, their goals, expectations, standards and concerns, irrespective of the culture and value systems in which they live, are high. Social or environmental impediments coupled with complexities in the physical domain also cause complexities in their psychological domain. Thus,

QoL gets affected adversely in all four domains of life. Though early diagnosis and treatment of the disease, effective pain management, counselling, and rehabilitation can improve the QoL, reintegration into society can bring them much closer to the QoL of the community to which they belong.

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