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Assess The Lived Experiences, Overall Stigma And Quality Of Life Among People Affected With Leprosy Of Selected District East Champaran, Bihar

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Abstract

Introduction: Leprosy is a curable disease but stigma associated with it destroys lives. However people adopt with the situation but, it has significant impact on quality of life.

Objectives: The aim of the study was to assess the lived experiences, overall stigma and quality of life among leprosy affected people.

Method: A mixed method (concurrent triangulation) research design was used. 45 participants were selected by using purposive sampling techniques to assess overall stigma and QOL by using SARI stigma scale & WHO BREIF-QOL scale respectively. Lived experiences were assessed using semi-structured open-ended questionnaire. Sample size for qualitative data was depending on data saturation which was achieved after data collection from 15 participants. Data was collected from participants at leprosy welfare associations of selected district “East Champaran” by using interview method. Data of quantitative part was analysed using descriptive (frequency, percentage, mean and standard deviation) and inferential (Karl Pearsson, ANOVA and chi square) statistics and of qualitative part was analysed using Colaizzi method.

Results: Study result revealed 41.82±5.22 mean score of overall stigmas 72.46±9.16 of quality of life. In different aspects of stigma participant had experienced stigma with mean score 17.48±2.60, disclosure concerns with mean score 7.73±1.49, internalized stigma with mean score 5.73±2.48 and anticipated stigma with mean score 10.86±0.78. In QOL overall finding showed 23(51.1%) participants with moderate QOL followed by 21 (46.7%) with low QOL and then 1 (2.2%) with high QOL. According to share lived experiences five themes were identified that are initial attitude towards illness, signs and symptoms, challenges faced, supports and reintegration. Significant correlation between overall stigma and quality of life with “r” value 0.36 and “p” value is 0.01 was found.

Conclusion: It was concluded that participant faced significant stigma which affects their quality of life.

Keywords: lived experiences, overall stigma, quality of life, leprosy affected people.

1. INTRODUCTION

Hansen's disease (HD), also known as leprosy, is a chronic bacterial infection that has been present for a very long period. Despite being treatable, it remains a serious health concern in many parts of the world. Mycobacterium leprae, the bacteria that causes leprosy, mainly affects human skin and peripheral nerves, although it can also damage the eyes, mucous membranes, bones, and testes. The condition was named "Hansen's disease" because the bacterium was found in 1874 by Dr. Gerhard Armauer Hansen, a Norwegian physician who was looking for an unknown-bacteria in the skin nodules of lepers.

The World Health Organization (WHO) defines leprosy as a chronic infectious disease that primarily affects the skin, peripheral nerves, upper respiratory tract mucosa, and eyes and is brought on by the bacterium Mycobacterium leprae. Skin lesions and nerve damage are its hallmarks, and if left untreated, it can result in impairments.

The bacillus known as Mycobacterium Leprae, which causes leprosy, is rod-shaped and rapidly acidic. It cannot be cultivated in cell cultures or bacteriological media. Both intra- and extracellularly, it forms distinctive aggregates known as Globi. With a preference for colder tissues, Mycobacterium Leprae invades the dermal (cutaneous) nerves or the main peripheral nerve trunks that are superficially located in the comparatively cooler parts of the face and limbs. Leprosy is a disease that is common in hot, humid regions, poor developing countries, and poor tropical countries.

Disease-transmitting droplets come from the mouth and nose. Leprosy must be contracted through months of close, prolonged contact with an untreated case. Casual contact with an infected individual, such as handshakes, hugs, meal sharing, or sitting close to each other, does not transmit the disease.

Clinical diagnostics are used to diagnose leprosy. Hard-to-diagnose conditions could necessitate laboratory-based services. Peripheral nerve involvement and skin lesions are typical disease manifestations. Finding at least one of the following cardinal indications will help diagnose leprosy: One of three conditions may occur: (1) a distinct loss of sensation in a pale (hypopigmented) or reddish skin patch; (2) an enlarged or thicker peripheral nerve accompanied by weakening in the muscles it supplies; or (3) microscopic identification of bacilli in a slit-skin smear.

Transmission interruption has not been achieved with case discovery and treatment using MDT alone. In order to increase leprosy prevention, the World Health Organization advises, with the index case's permission, tracking down each patient's household contacts as well as their neighbours and social contacts. Additionally, a single dosage of rifampicin is recommended as preventive chemotherapy. The disease leprosy is treatable. Three medications are included in the current suggested treatment regimen: clofazimine, rifampicin, and dapsone. We call this combination "multi-drug therapy" (MDT). For PB patients, the treatment lasts six months, and for MB cases, it lasts twelve months. If left untreated, leprosy causes disability and severe physical, psychological, and social impairments.

Leprosy differs from the majority of other infectious diseases in that it causes terror and disgust in addition to fear of infection, which can result in aversion and social exclusion. This particular response, known as the stigma of leprosy, entails social rejection, job loss, and inability to find suitable housing. The sufferer no longer knows who he really is. Because illness irreversibly alters a person and diminishes the utility of specific physical components, those who suffer from it are essentially noticeable and may experience increased social unhappiness and self-consciousness. Even though there has been a treatment for leprosy since 1940, civilizations all over the world have long put those who are afflicted into facilities known as "leper colonies," forcing them to live in misery. Furthermore, negative body image issues can lead to social disengagement, isolation, depression, and in extreme situations, thoughts of self-destruction. WHO offers Member States technical assistance in the prevention and control of leprosy.

2. STATEMENT OF PROBLEM

A mixed method study to assess the lived experiences, overall stigma and quality of life among people affected with leprosy of selected district East Champaran, Bihar.

3. OBJECTIVES

- To assess the overall stigma and quality of life among people affected with leprosy.
- To assess lived experience of stigmatized people affected with leprosy.
- To find out the correlation between overall stigma and quality of life among people affected with leprosy.
- To find out the association of overall stigma and quality of life with their selected demographic variables.

4. REVIEW OF LITERATURE

B. Nasrullah (2023) conducted research entitled “A study on "Lived experiences of stigma among elderly former leper patients in Kashmir, India”. The purpose of this study was to find the lived experiences of those elderly people affected with leprosy within the framework of sociocultural viewpoints. Following their consent, the subjects were purposefully chosen to participate in the study. Ten people in all took part in the research. In order to examine the lived realities of living with stigma, this study used interpretative phenomenology. Two themes emerged from the data analysis, 1) living among untouchables, and 2) the outcast children, which illustrate the stigma that persists even after being treated. The themes that arose from the data demonstrate how deeply ingrained stigma is in society and how institutional discrimination contributes to the persistence of stigma among former patients.

N. Kavana Krishna and C. Namratha (2023) carried out a cross-sectional study titled "A study on the quality of life of patients with leprosy." The Dermatology Department and Leprosarium Hospital served as the study's sites. The Dermatology Life Quality Index (DLQI) questionnaire was used to evaluate the quality of life (QoL) of 164 leprosy patients. Of the 164 patients, 14 (8.54%) had no effect of leprosy on their quality of life, 34 (20.73%) had a small effect, 47 (28.66%) had a moderate effect, 64 (39.02%) had a large effect, and 5 (3.05%) had an extremely large effect upon their quality of life. Age, occupation, and socioeconomic level were among the demographic factors that affected leprosy patients' quality of life. Because of the deformities and the social shame attached to it, leprosy, an old disease, remains the most feared. The QoL of leprosy patients is significantly impacted by the disease's clinical range, responses, deformities, and handicap.

5. RESEACH METHODOLOGY

A mixed method research approach was used with concurrent triangulation research design. 45 people affected with leprosy were selected by using purposive sampling techniques to assess overall stigma and QOL by using SARI stigma scale & WHO BREIF-QOL scale respectively. On the basis of data saturation, from 15 participants data was collected to assess lived experiences by using semi-structured open-ended questionnaire through interview method at leprosy welfare associations of selected district "East Champaran". Ethical approval taken from ethical committee of Eternal University, Baru Sahib. To assess the feasibility of the study pilot study was conducted on 5 participants and reliability of the tool obtained using split half method which was r=0.90. Data was collected from participants. Data of quantitative part was analysed using descriptive (frequency, percentage, mean and standard deviation) and inferential (Karl Pearsson, ANOVA and chi square) statistics and of qualitative part was analysed using Colaizzi method.

6. RESULTS

Objective 1: To assess the overall stigma and quality of life among people affected with leprosy

Table 6.1 Findings related to mean score of overall stigma & quality of life of people affected with Leprosy n=45

	f	Mean	SD
Overall Stigma	45	41.82	5.22
Quality Of Life	45	72.46	9.16

n = 45

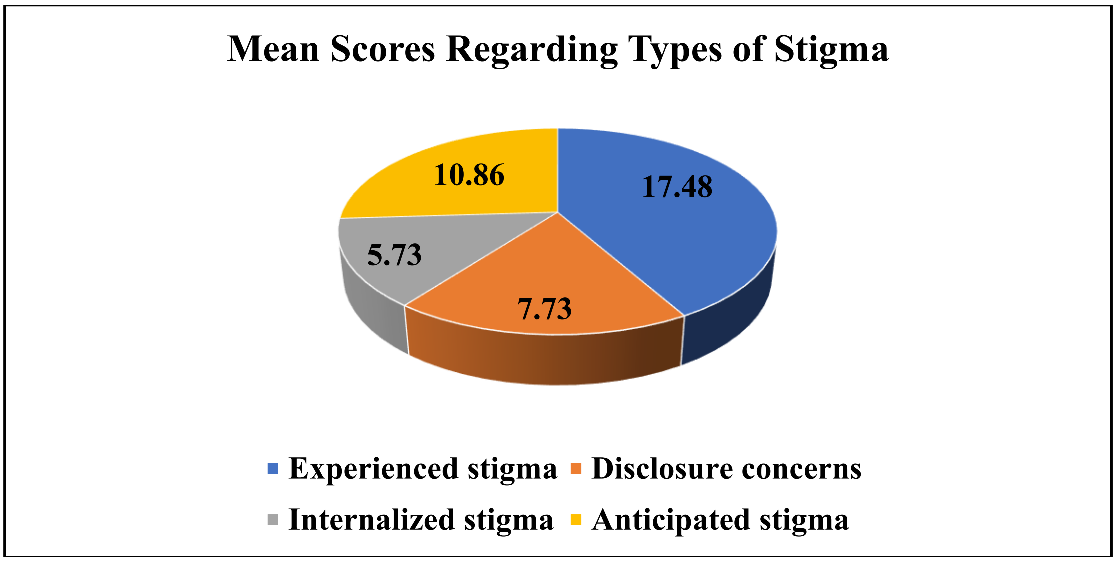

Figure 6.1: Findings related to mean scores regarding types of stigmas among people affected with Leprosy. n= 45

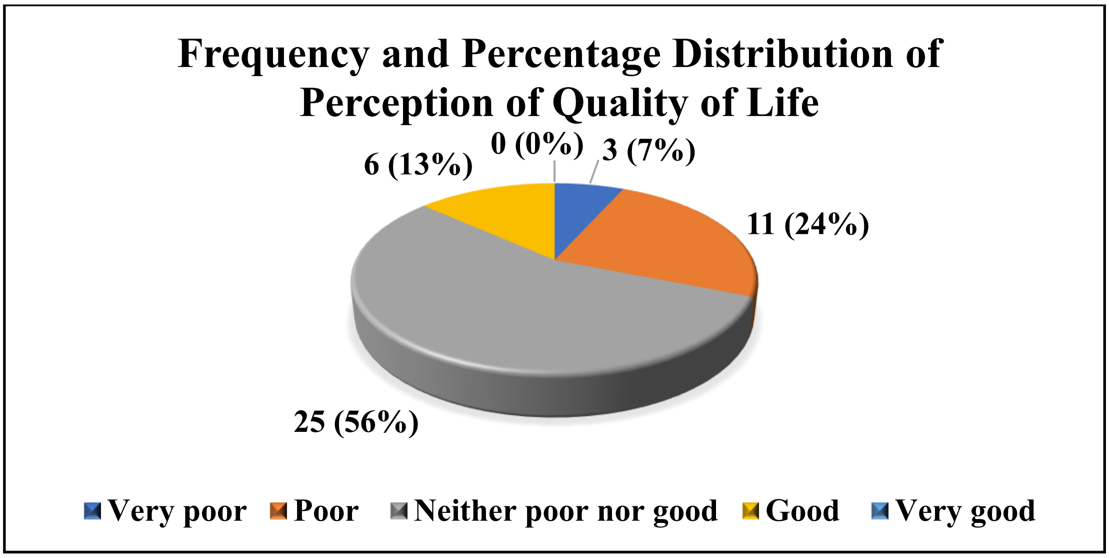

Figure 6.2. Findings related to frequency and percentage distribution of perception of quality of life of people affected with leprosy. n=45

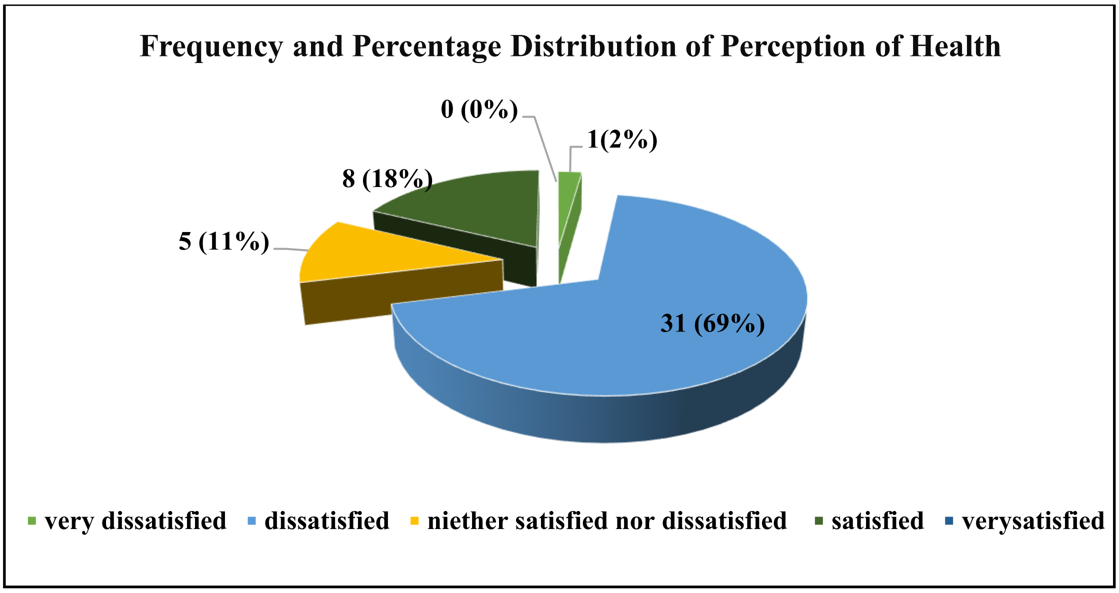

Figure 6.3 Findings related to frequency and percentage distribution of perception of health of people affected with leprosy.

Table 6.2: Findings related to frequency and percentage distribution of domains related to quality of life of people affected with leprosy n-45

Criterion measure	Domains of quality of life									
	Physical		Psychological		Social		Environmental		Overall QOL	
	f	%	f	%	f	%	f	%	f	%
Low QOL	36	80.0	28	62.2	19	42.2	3	6.7	21	46.7
Moderate QOL	9	20.0	16	35.6	15	33.3	41	91.1	23	51.1
High QOL	0	0	1	2.2	11	24.4	1	2.2	1	2.2

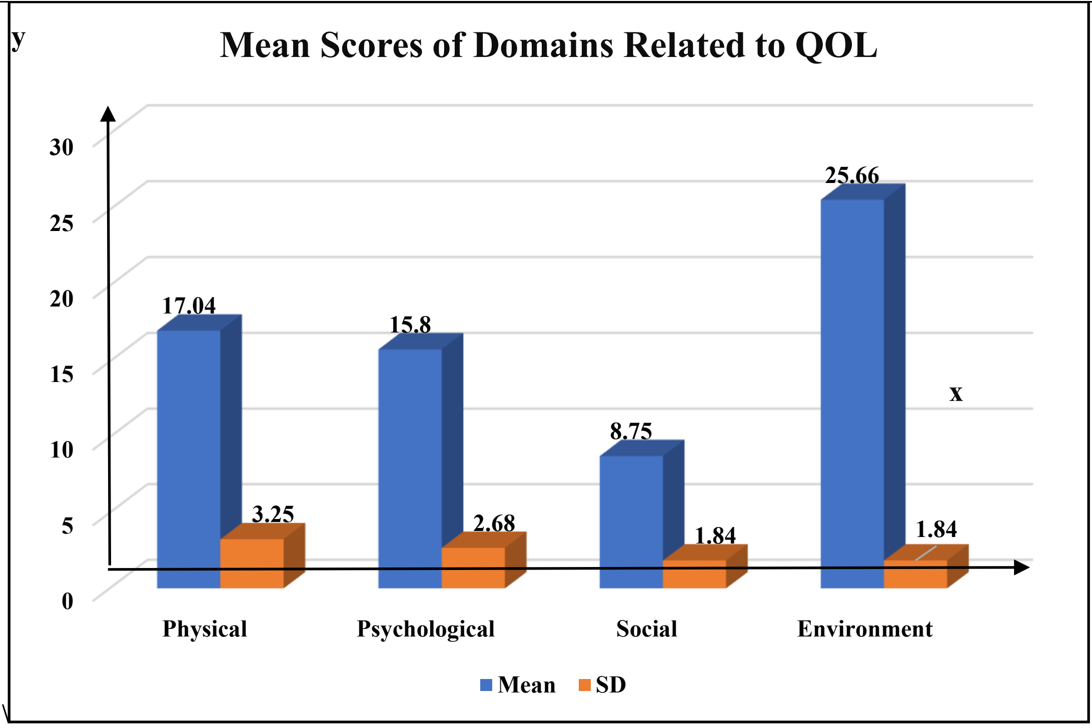

Figure 6.4 Findings related to mean score of domains related to quality of life of people affected with leprosy n-45

Objective 2: To assess lived experience of stigmatized people affected with leprosy.

Table 6.3: Findings thematic analysis of lived experiences of people affected with leprosy. n=15

S.N.	THEMES	SUBTHEMES
1.	Initial attitude towards illness	1.1 Facts
		1.2 Misconceptions
2.	Signs and symptoms	2.1 Sensory impairment
		2.2 Motor impairment & Physical disfigurement
3.	Challenges faced	3.1 Physical challenges
		3.2 Psychosocial challenges
		3.3 Economic challenges
4.	Support	4.1Support from family
		4.2 Support from leprosy welfare association
5.	Reintegration	5.1 Medical reintegration
		5.2 Psychosocial reintegration
		5.3 Economical reintegration

Objective 3: To find out the correlation between overall stigma and quality of life among people affected with leprosy.

Table 6.4: Findings Related to Correlation Between Overall Stigma and Quality of Life Among People Affected with Leprosy n=45

	f	Mean	SD	r	p
Overall Stigma	45	41.82	5.22	0.36	**0.01****
Quality Of Life	45	72.46	9.16		

7. DISCUSSION

Discussion Based On Study Objectives

Objective 1: To Assess the Overall Stigma and Quality of Life among People Affected with Leprosy.

The study reveals mean value 41.82±5.22 of overall stigma and mean value 72.46±9.16 of quality of life hence, it indicates there is stigma but their quality of life is better than earlier.

On observation of different aspects of stigma participant had experienced stigma with mean score 17.48±2.60, disclosure concerns with mean score 7.73±1.49, internalized stigma with mean score 5.73±2.48 and anticipated stigma with mean score 10.86±0.78 hence it was concluded that there is maximum experienced stigma and minimum internalised stigma.

On assessment of QOL among the participants 3 (7%) perceived QOL as very poor, 11(24%) as poor, 25 (56%) as neither poor nor good, 6 (13%) as good and 0 (0%) perceived QOL as very good hence it concluded that most of the participant has neither poor nor good QOL and no one has very good QOL.

On determination of perception of health in1 (2%) of participants are very dissatisfied with his/her health, 31 (69%) were dissatisfied, 5 (11%) were neither satisfied nor dissatisfied and 8 (18%) were satisfied whereas no one were very satisfied hence it concluded that most of the participants were dissatisfied and no one was very satisfied with their health.

On evaluation of various domains levels of QOL, findings reveals that in physical domain 36 (80.0%) participant were those who had low QOL followed by 9 (20.0%) with moderate QOL whereas no one were with high QOL. In psychological domain 28 (62.2%) participant were with low QOL followed by 16 (35.6%) with moderate QOL and then 1 (2.2%) with high QOL. In social domain 19 (42.2%) participant were with low QOL followed by 15 (33.3%) with moderate QOL and then 11 (24.4%) with high QOL. In environmental domain 41 (91.1%) participant were with moderate QOL followed by 3 (6.7%) with low QOL and then 1 (2.2%) with high QOL hence, it concluded that in physical, psychological, and social domain maximum participant had poor QOL while very few had high QOL whereas, in environmental domain maximum had moderate QOL while only one had high QOL. In overall finding 23(51.1%) participant were with moderate QOL followed by 21 (46.7%) with low QOL and then 1 (2.2%) with high QOL hence, it concluded that in overall maximum participants had moderate QOL, followed by low QOL and only one had high QOL.

Findings of different domains shows that environmental domain had maximum mean score that is 25.66±1.84 followed by physical domain 17.04±3.25 and then psychological domain 15.8±2.68 whereas social domain had minimum mean score that is 8.75±1.84. Therefore, it concluded that participant's environmental domain was more favourable as compare to all other domains whereas social domain was least favourable.

Objective 2: To Assess Lived Experience of Stigmatized People Affected with Leprosy.

In order to clarify the lived experiences of people affected with leprosy, thematic analysis (Colaizzi method) was used. The interview transcripts were carefully examined, and five themes and related twelve subthemes were developed that are initial attitude towards illness (facts and misconceptions), signs and symptoms (sensory impairment and motor impairment), challenges faced (physical challenges, psychological challenges and economical challenges), supports (support from family and support from leprosy welfare associations) and reintegration (medical, psychological and economical).

Objective 3: To find out the correlation between overall stigma and quality of life among people affected with leprosy.
Findings showed correlation between overall stigma and quality of life with “r” value 0.36 and “p” value is 0.01 which is significant. Hence it concluded that there is highly significant correlation between stigma and quality of life at $p<0.05$ level of significant. **Therefore, H_1 is accepted.**

Objective 4: To find out the association of overall stigma and quality of life with their selected demographic variables.
ANOVA & Chi square was used to find out the association between overall stigma & quality of life with their selected demographic variables at $p<0.05$ level significant.
There was significant association between overall stigma with education status, extent of disability, social participation and quality of life with gender, marital status, educational status, employment, family income, extent of disability, currently living with, social participation, current disease status. **Thus, H_2 is accepted.**

8. CONCLUSION

The current study involved assessment of lived experiences, overall stigma and quality of life among people affected with leprosy of selected district East Champaran. Data was collected from people affected with leprosy to assess overall stigma and quality of life. Among the participants those were volunteer to give data related to lived experiences from them data was collected to assess the lived experiences of the leprosy affected people. It explored in depth feelings of people affected with leprosy. Correlation between overall stigma and QOL was also determined. The findings showed that there was significant relation between overall stigma and QOL. At the end study outcome revealed that stigma has affected their life significantly. The study emphasizes the significance of providing continuing assistance, education, and policy advocacy in order to reduce overall stigma and enhance the quality of life for leprosy patients in the society.

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