Section: DVL

Original Research Article

QUALITY OF LIFE AND SOCIAL STIGMA IN PATIENTS WITH HANSEN'S DISEASE: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Hansen's disease is associated with stigma arising from disease-related deformities and societal misconceptions. This adversely affects quality of life. The study aimed to evaluate the quality of life and assess the type of stigma in patients with Hansen's disease at a tertiary care centre.
Materials and Methods: The study was an observational cross-sectional study conducted in the Department of Dermatology, Venereology and Leprosy, Gandhi Medical College and Hamidia Hospital, Bhopal, over a period of 18 months (August 2022 to January 2024). Quality of life (QoL) was assessed using the Dermatology Life Quality Index (DLQI), and social stigma was assessed using the Stigma Assessment and Reduction of Impact (SARI) scale.
Results: We included 100 cases with a mean age of 38.55±12.24 years. Mean DLQI score was 18.08±6.65. Hansen's disease had an extremely large effect on quality of life in almost half of the cases (49%). Mean internalised stigma was 8.85±4.25, whereas stigma related to disclosure concern was 8.02±2.82. Mean experienced stigma was 13.77±4.59, whereas anticipated stigma/ perceived stigma was 7.30±3.32.
Conclusions: Hansen's disease continues to pose an important public health challenge, with those affected facing reduced quality of life along with considerable social stigma. These findings point to the importance of strengthening patient support and increasing community awareness to enhance overall well-being.
Keywords: Leprosy, Social Stigma, Quality of Life, Dermatology Life Quality Index.

INTRODUCTION

Leprosy is a neglected tropical disease (NTD) and is considered a social and public health issue of global concern. Leprosy has been eliminated as a public health problem by the World Health Organization; however, it remains prevalent in more than 122 countries [1-3]. In 1980, the burden of leprosy was very high, more than 5 million cases, which has now reduced to a much lower level (approximately 129,192 cases) in 2020, and such a reduction in the burden of leprosy has been attributed to national and international leprosy control programmes. [4] The top five countries contributing to the highest burden of leprosy are India, followed by Brazil, Indonesia, the Democratic Republic of the Congo and Bangladesh in 2020.[5]

As leprosy causes significant visible deformities in the form of nodules, skin thickening, nerve thickening, bony resorption, etc., it is associated with disability and social limitations, including social isolation.[6] In certain cultures, the disease is linked to misconceptions. Hence, leprosy is considered an epitome of stigmatisation, and once this stigma is established, it may take several different forms of stigma-related processes such as stereotype, prejudice and discrimination.[7] Leprosy-related stigma significantly impacts personal, professional, and social aspects of an individual's life. It has a major effect on marital relationships, interpersonal relationships, social interactions, as well as employment. As these patients often belong to low socioeconomic status and are deprived of basic neighbouring social amenities, their quality of life is impacted. These patients may experience social exclusion and marginalisation within their communities, adversely affecting their quality of life. In some settings, patients may face severe social and economic challenges, including loss of livelihood and social support.[8]

The term "quality of life" is a broad term encompassing one's degree of freedom, social interactions, physical health, and psychological well-being.[9] According to the World Health Organization, quality of life is defined as "Perception of an individual regarding their position in the culture in which they live and in context of value systems in relation to their expectations, goals, concerns and standards".[10] Analysis of quality of life with the help of specific and validated instruments allows assessment of the impact of the condition on daily life. The Dermatology Life Quality Index (DLQI) is a specific indicator of quality of life for patients with dermatological conditions.[11] It is one of the most commonly used instruments for the assessment of quality of life in patients presenting with various dermatological conditions. This instrument was created by Finlay and Khan in 1994.[12]

For measurement of health-related stigma, a reliable, comprehensive and valid tool is available called the Stigma Assessment and Reduction of Impact (SARI) scale, and this tool was developed by van Brakel et al. [13]. This scale helps in identifying areas of high levels of stigma and to determine the domains of stigma. This tool can help in the assessment of various dimensions of stigma quantitatively in leprosy patients. It measures stigma across four domains: experienced, internalised, perceived and disclosure by analysing 21 questions on a Likert scale.[13]

Leprosy has always been seen as a societal disease, and little information exists about how it affects patients' quality of life. This study was therefore conducted at a tertiary care centre to evaluate the quality of life and assess the domains of stigma in patients with Hansen's disease.

Aims and Objectives

Aim: To evaluate the quality of life and assess the domains of stigma in patients with Hansen's Disease at a tertiary care centre.

Objective: To assess the quality of life and social stigma in patients with Hansen’s disease.

MATERIALS AND METHODS

This was an observational cross-sectional study conducted in the Department of Dermatology, Venereology and Leprosy, Gandhi Medical College and Hamidia Hospital, Bhopal, over a period of 18 months (August 2022 to January 2024) after approval from the Institutional Ethics Committee.

Inclusion Criteria: All leprosy-diagnosed adult patients of age 18 years or more, of either sex, attending the dermatology outdoor patient department and providing informed consent were included in the study.

Exclusion Criteria: Patients who were unable to respond to the questionnaire or had coexisting chronic health conditions were excluded.

The Sample Size was estimated using the formula-
$n = Z^2 (pq) / d^2$, where Z = 1.96, p is the prevalence (0.0083), q is the 1-p (99.9917), and d is the allowable error, drop out 20%. The sample size was estimated to be 100.

Patients fulfilling the inclusion criteria were enrolled in the study. Sociodemographic data, including age, sex, education, occupation, marital status, and address, were obtained using a proforma.

Social stigma was assessed using the SARI scale.[14]

The impact on QoL was assessed using the Dermatology Life Quality Index (DLQI). Validated English and Hindi versions of the questionnaire were used with appropriate permissions. The DLQI includes 10 questions, which analyse six domains, namely symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment. Each item is scored from 0 to 3, with a total score ranging from 0 to 30 [12].

Scores were interpreted as follows:

- 0-1: no effect at all on the patient’s life
- 2-5: small effect
- 6-10: moderate effect
- 11-20: very large effect
- 21-30: extremely large effect

Statistical Analysis: Data were entered in MS Excel and analysed with the help of IBM SPSS Software version 20. Categorical data were presented as frequency and percentage. Numerical data were presented as mean and standard deviation.

RESULTS

We included a total of 100 cases with a mean age of 38.55±12.24 years

Table 1: Distribution of cases according to baseline variables

Baseline variables		Frequency (n=100)	Percentage
Age (years)	≤30	33	33.0
	31-40	27	27.0
	41-50	21	21.0
	51-60	14	14.0
	>60	5	5.0
Sex	Male	67	67.0
	Female	33	33.0
Education	Illiterate	26	26.0
	Primary school	21	21.0
	Middle school	23	23.0
	High school	12	12.0
	Intermediate/ diploma	5	5.0
	Graduate	13	13.0
Residence	Rural	50	50.0
	Urban	50	50.0
Occupation	Unemployed	49	49.0
	Elementary occupation	17	17.0
	Machine operator	8	8.0
	Skilled agricultural worker	11	11.0
	Skilled shop sales worker	9	9.0
	Skilled (market sales worker)	1	1.0
	Clerk	5	5.0
Marital status	Married	68	68.0
	Unmarried	21	21.0
	Separated	8	8.0
	Widowed	3	3.0
Socioeconomic class	Lower middle	12	12.0
	Upper lower	61	61.0
	Lower	27	27.0

The majority of cases of Hansen's disease belonged to individuals less than or equal to 30 years of age (33%), and we reported male predominance for Hansen's disease with a male: female ratio of 2.03:1. The majority, i.e. 26% of the cases, were illiterate, whereas 23% of the cases were educated up to middle school. About 50% of the cases of Hansen's disease were from urban areas. Approximately half of the cases (49%) with Hansen's disease were unemployed. The majority, i.e. 68% cases, were married, and 61% cases with Hanssen's disease belonged to the upper lower socioeconomic class. [Table 1].

Mean DLQI score was 18.08±6.65 (ranging from 3 to 28). Hansen's disease had an extremely large effect on quality of life in almost half of the cases (49%). [Figure 1]

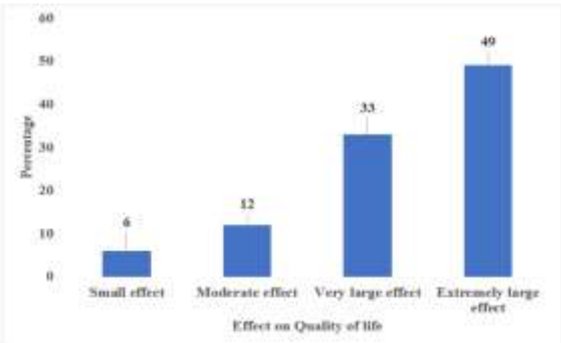

Figure 1: Effect of Hansen's disease on Quality of life

Stigma was assessed using the SARI scale, which measures stigma across 4 major domains. Mean internalised stigma was 8.85±4.25, whereas stigma related to disclosure concern was 8.02±2.82. Mean experienced stigma was 13.77±4.59, whereas anticipated stigma/ perceived stigma was 7.30±3.32. The overall stigma score was 38.02±11.57. [Figure 2]

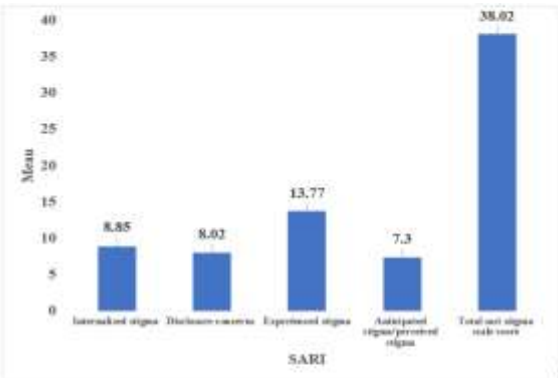

Figure 2: Distribution of cases according to type of stigma

DISCUSSION

Quality of Life

It has been observed that leprosy impacts quality of life, and very few studies have been conducted exploring this issue among patients.[16] In the present study, Hansen's disease was found to have a substantial impact on quality of life. Mean DLQI score among was 18.08±6.65. Nearly half of the patients (49%) experienced an extremely large impact on quality of life, followed by a very large effect in 33% of cases and a moderate to small effect in the remaining cases. These findings are comparable to those reported by Chaudhary et al., who observed an extremely large impact in 43% of patients and a very large impact in 37.3%, moderate impact on 14.1% and small impact on 5.6%.[15] Similarly, Solanki et al. reported a predominantly very large effect on quality of life in 54.02% of patients.[17] However, Das et al. reported relatively lower DLQI scores (mean 8.48±5.48), with no cases showing an extremely large impact.[16] This variation may be attributed to differences in disease severity, presence of deformities, and sociocultural factors across study populations. Overall, the findings of the present study highlight the considerable burden of Hansen's disease on quality of life.

Social Stigma

The present study demonstrated a significant level of stigma across all domains of the SARI scale, with a mean total score of 38.02±11.57. The highest score was noted in experienced stigma (13.77±4.59), followed by internalised stigma (8.85±4.25), disclosure concern (8.02±2.82) and anticipated stigma/ perceived stigma (7.30±3.32). The predominance of experienced stigma in our study may be attributed to visible deformities and prevailing societal misconceptions, which often lead to discrimination and social exclusion. Stigma may also contribute to delayed healthcare-seeking behaviour, resulting in disease progression and increased disability.

However, Chaudhary et al also documented a significant level of social stigma in patients with Hansen's disease using the SARI scale, but the Internalized Stigma was maximum (3.86±3.28), followed by disclosure concerns (2.49±3.10), experienced stigma (1.26±2.63) and least was Anticipated Stigma (0.66±1.69).[15] This difference may be explained by variations in disease characteristics, awareness levels, and sociocultural context. Lufianti et al documented medium stigma related to the disease in 72% cases, followed by moderate stigma (22%), and it was attributed to signs of alienation, support from stereotypes, and presence of disability.[18] Similarly, Agarwal et al. demonstrated a reduction in stigma following peer-support intervention, highlighting the role of psychosocial interventions in mitigating stigma.[19]

The present study has certain limitations. The sample size was relatively small, and no control group was included. A comparative analysis with a control population could have provided better insight into the extent of impairment in quality of life and stigma among patients with Hansen's disease. Additionally, the study was a facility-based study, which affects the generalisability of the findings. No interventional component was included to evaluate strategies for reducing stigma or improving quality of life. Although both quality of life and stigma were assessed, the study did not explore their interrelationship in detail, which may be considered in future research.

CONCLUSION

Hansen's disease continues to be a major public health concern, with afflicted people suffering from considerable impairment in quality of life and a substantial burden of stigma. Findings of the current study emphasise the necessity of all-encompassing approaches that emphasise early detection, patient support and community awareness in mitigating these challenges.

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