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Prospective observational study to evaluate dermatology life quality index in patients with lichen sclerosus presenting to a tertiary care centre in Nepal

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Abstract

Introduction: Lichen sclerosus (LS) is a chronic inflammatory skin disease affecting the genital area, often leading to physical discomfort, anatomical changes, and reduced quality of life (QOL). The impact on QOL remains underexplored, particularly in resource-limited.

Method: This prospective observational study on patients clinically diagnosed with LS who attended the dermatology outpatient department of Dhulikhel Hospital, Nepal, over six months from Jan to Jun 2024, after ethical approval. The QOL was assessed using validated Nepali version of Dermatology Life Quality Index (DLQI). Sociodemographic and clinical data were analysed for factors associated with higher impairment scores. A p-value <0.05 was considered statistically significant

Result: The median DLQI score was 24 (IQR 18–26). Most participants experienced very large (38.46%) or extremely large (58.97%) effects on QOL. Highest impact was observed in clothing choices (Q4: 2 [IQR 2–3]), itching or pain (Q1: 2 [IQR 2–3]), and limitation in sports (Q6: 3 [IQR 2–3]). Postmenopausal women (median DLQI 23 [IQR 20–26]), homemakers (24 [IQR 20–26]), and those from rural areas like Ramechap (24 [IQR 18–30]) and Kavre (24 [IQR 20–26]) had higher impairment scores. Bivariate analysis showed a significant association between homemaker and high DLQI scores (p=0.006), while age trended toward higher DLQI but was not statistically significant (p=0.076). Comorbidity was not significantly associated with impairment (p=0.215).

Conclusion: The LS imposes a substantial QOL burden, particularly among women from disadvantaged backgrounds. Incorporating routine QOL assessment into clinical care can improve patient-centred management and outcomes.

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Introduction

Lichen sclerosus (LS) is a chronic inflammatory skin disorder primarily affecting the anogenital skin.[1] It can affect both males and females. It can be found in women of any age, but has two peaks, the first one in pre-pubertal girls and the second in peri and post-menopausal women are mostly affected.[2,3] The etiopathogenesis of LS is poorly understood, though it is multifactorial and may include genetic, autoimmune, hormonal causes, trauma, and irritation.[2,4]

The autoantibodies against the extracellular matrix-1 protein suggest autoimmune pathogenesis.[5] The exact prevalence is not known and is likely due to misdiagnosis or women failing to present due to embarrassment or self-treatment.[5] The prevalence of vulvar LSis around 1.7-3%.[6] It is characterized by ivory white patches with areas of haemorrhage, atrophy, and scarring.[7]

The common symptoms seen in LS are intense pruritus, pain, burning sensation, clitoral hyperesthesia, dyspareunia, and constipation. It is a tissue-destructive disease, and the scarring may lead to destruction of anogenital architecture, like resorption of the labia minora, hooding and burial of the clitoris, labial fusion, and introital stenosis may occur.[2,6] This may result in painful vaginal penetration, and intercourse might be impossible.[7]

Delayed diagnosis may lead to the risk of malignancy (Squamous cell carcinoma).[8,9] All the symptoms of LS may lead to a negative impact on physical and mental well-being and their quality of life(QoL) in general.[7]

Most LS studies are focused on outcomes post-treatment. Less is known about the QoL before receiving proper diagnosis and treatment. So, our main aim is to assess QoL in patients with LS via the Dermatology Life Quality Index (DLQI).

The DLQI is used to assess QoL in a broad array of skin diseases.[10] It is a simple questionnaire technique which consists of 10 questions, each referring to the past 7 days, with 5 possible answers: very much, a lot, a little, not at all, or not relevant.[11]

Method

This was a prospective observational study conducted at the Dermatology, Venereology, and Leprosy Department of Dhulikhel Hospital, a tertiary care centre in Nepal. The study was carried out over six months from Jan to Jun 2024. All diagnosed cases were included.

Inclusion criteria were all patients aged 18 years and above with a clinical diagnosis of LS confirmed by experienced dermatologists with a typical clinical presentation of white, shiny patches of skin, itchy, crinkled, or easily damaged, like bleeding from fissures. Patients who declined consent or had other significant dermatologic or psychiatric conditions, or incomplete questionnaires. that could independently affect quality of life were excluded.

After obtaining informed written consent, participants were self-administered (the researcher helped by reading out and checking the response for those who could not read or write) the validated Nepali version of the Dermatology Life Quality Index (DLQI) questionnaire. The DLQI consists of 10 questions assessing the impact of skin disease on different aspects of a patient's life over the past seven days. Each item is scored from 0 (not at all) to 3 (very much), with total scores ranging from 0 to 30. Higher scores reflect greater impairment. Scores range from 0 to 30, with higher scores indicating a greater impact on quality of life. The categories are 0-1=no effect, 2-5=small effect, 6-10=moderate effect, 11-

20=very large effect, and 21-30=extremely large effect.

Sociodemographic and clinical variables collected included age, sex, address, occupation, menstrual history, and comorbidities (such as diabetes, hypertension, thyroid disorders, anxiety, and migraine). DLQI scores were categorized based on standard interpretation into different impact levels on quality of life.

Data were entered and analysed using IBM SPSS version 25. Descriptive statistics were presented as means, standard deviations, frequencies, and percentages. For bivariate analysis, DLQI scores were dichotomized into 'Low DLQI' (score <21) and 'High DLQI' (score 21-30) based on standard interpretation. Associations between these DLQI categories and patient variables were assessed using Fisher's exact test for categorical variables and the Mann-Whitney U test for continuous variables, as appropriate. A p-value <0.05 was considered statistically significant.

Ethical approval was obtained from the Institutional Review Committee of Kathmandu University School of Medical Sciences (IRC-KUSMS) 225/23 before study initiation.

Result

Among 39 participants with lichen sclerosus, the median age was 56[45–63] years, ranging from 29 to 82 years. The majority of participants were from Kavre 21(53.85%), followed by Bhaktapur 6(15.38%), Sindhupalchowk 5(12.82%), Ramechap 2(5.13%), Sindhuli 2(5.13%), Dolakha 2(5.13%) and Kathmandu 1(2.56%). Most participants were homemakers 27(69.23%), with others including social workers 3(7.69%), shopkeepers 3(7.69%), teachers 2(5.13%), farmers 2(5.13%), a tailor 1(2.56%) and a beautician 1(2.56%), Table 1.

The median Dermatology Life Quality Index (DLQI) score for the entire cohort was 24[20–26], with a minimum of 10 and a maximum of 30. Based on DLQI categories, 23(58.97%) participants experienced an extremely large effect on quality of life with a median DLQI of 26[24–27], 15(38.46%) experienced a very large effect with a median 16[15–19] and 1(2.56%) experienced a moderate effect with median 10[10–10]. Participants from Ramechap 2(24[18–30]), Dolakha 2(23.5[21–26]) and Kavre 21(24[20–26]) had higher median DLQI scores than those from Kathmandu 1(10[10–10]), Table 2.

Analysis of individual DLQI items showed the highest median impact for difficulty in playing sports/engaging in physical activity, with a median score of 3[2–3], followed by itchy, sore, painful, or stinging skin and influence on clothing choices, both with a median score of 2[2–3]. Sexual difficulties showed the lowest median impact with a score of 2[1–3], Table 3.

Stratification of DLQI scores revealed notable patterns. Postmenopausal participants and those with regular menstruation reported high median scores of 23 [20–26] and 25 [22–26], respectively, whereas participants with irregular cycles had a lower median score of 15 [15–15]. Geographically, participants from rural districts, including Ramechap (24 [18–30]), Kavre (24 [20–26]), and Dolakha (23.5 [21–26]), reported substantially higher impairment than the single participant from the urban center of Kathmandu (10 [10–10]). A detailed breakdown of scores by occupation showed that homemakers had a high median DLQI of 24 [20–26], Table 4.

Bivariate analysis was performed using Fisher’s exact test for categorical variables and Mann–Mann-Whitney U test for continuous variables. Fisher’s exact test was applied due to small

expected cell counts in some categories, ensuring accurate p-value estimation. Mann–Whitney U test was used for comparing age distribution between DLQI groups as the data were not normally distributed. Occupation was significantly associated with high DLQI scores (p=0.006). Age demonstrated a trend toward higher DLQI scores in older participants but did not reach statistical significance (p=0.076). Comorbidity status was not significantly associated with DLQI scores (p=0.215), although a higher proportion of participants with diabetes and hypertension were in the high DLQI category, Table 5 and Table 6.

Table 1. Sociodemographic and clinical profile of participants with lichen sclerosus (LS), n=39

Variable	Category	n	%
Age	Median (IQR)	56(45–63)	—
	Range	29–82	—
Residence	Kavre	21	53.85
	Bhaktapur	6	15.38
	Sindhupalchowk	5	12.82
	Ramechap	2	5.13
	Sindhuli	2	5.13
	Dolakha	2	5.13
	Kathmandu	1	2.56
Occupation	Homemaker	27	69.23
	Social Worker	3	7.69
	Shopkeeper	3	7.69
	Teacher	2	5.13
	Farmer	2	5.13
	Tailor	1	2.56
	Beautician	1	2.56

Table 2. Dermatology Life Quality Index (DLQI) scores and stratification among patients with LS, n=39

Variable	Category	Median(IQR)	Minimum–Maximum
Overall DLQI		24(20–26)	10–30
By DLQI Impact Category	Moderate effect (10)	10(10–10)	10–10
	Very large effect (11-20)	16(15–19)	13–20
	Extremely large effect (21-30)	26(24–27)	21–30
By Menstrual Status	Menopause	23(20–26)	16–30
	Regular	25(22–26)	10–27
	Irregular	15(15–15)	13–17
By Occupation	Homemaker	24(20–26)	15–30
	Social Worker	16(13–16)	13–16
	Shopkeeper	15(13–27)	13–27
	Teacher	20.5(17–24)	17–24
	Farmer	18(16–20)	16–20
	Tailor	25(25–25)	25–25
	Beautician	10(10–10)	10–10
By Residence	Kavre	24(20–26)	13–30
	Bhaktapur	22.5(17–25)	15–27
	Sindhupalchowk	19(16–19)	16–30
	Ramechap	24(18–30)	18–30
	Sindhuli	19.5(16–23)	16–23
	Dolakha	23.5(21–26)	21–26
	Kathmandu	10(10–10)	10–10

Table 3. The DLQI item-wise median scores among participants with LS, n=39

DLQI Item	Question Focus	Median(IQR)	Min–Max
Q1	Itchy, sore, painful, or stinging skin	2(2–3)	1–3
Q2	Embarrassment or self-consciousness	2(2–3)	1–3
Q3	Interference with shopping/home/garden	2(1–3)	1–3
Q4	Influence on clothing choices	2(2–3)	1–3
Q5	Impact on social or leisure activities	2(1–3)	1–3
Q6	Difficulty in playing sports/ engaging in physical activity	3(2–3)	1–3
Q7	Problems with work or studying	2(1–3)	0–3
Q8	Problems with partner or close relationships	2(1–3)	0–3
Q9	Sexual difficulties	2(1–3)	0–3
Q10	Treatment-related problems (time, messiness)	2(2–3)	0–3

Table 4. Association between occupation and High DLQI scores among participants with LS, n=39

Occupation	Low DLQI (Score <21)	High DLQI (Score 21-30)	Total
Homemaker	7	20	27
Social Worker	3	0	3
Shopkeeper	2	1	3
Teacher	1	1	2
Farmer	2	0	2
Tailor	0	1	1
Beautician	1	0	1

Fisher's exact p=0.006 (significant)

Table 5. Association between comorbidity status and high DLQI scores among participants with LS, n=39

Comorbidity	Low DLQI (Score <21)	High DLQI (Score 21-30)	Total
None	9	11	20
Diabetes Mellitus	0	4	4
Hypertension	1	3	4
DM/HTN	0	1	1
Thyroid	3	1	4
DM/HTN/Thyroid	0	1	1
Anxiety	1	2	3
Migraine	2	0	2

Table 6. Comparison of age distribution by DLQI category using Mann-Whitney U test among participants with LS, n=39

DLQI category	n	Rank sum	Expected rank sum	z-value	p-value
Low DLQI(Score < 21)	16	258	320	-1.772	0.0764
High DLQI(Score 21-30)	23	522	460		
Total	39	780	780		

Discussion

This prospective study demonstrates that lichen sclerosus (LS) has a profound impact on the QOL of affected individuals. Our DLQI values, nearly double those reported in high-income settings, suggest a significantly greater cumulative disease burden in our Nepalese cohort. This stark disparity likely reflects later presentation, more advanced disease at diagnosis due to limited access to specialist care, and potentially fewer resources for self-management in a

resource-limited setting. In Western cohorts, untreated LS patients generally present with much lower DLQI scores. A Swedish prospective study reported a median DLQI of 8.0 (IQR 4.5–11.5) in females before treatment and a drop to 4 after therapy, indicating only a moderate effect in most cases. Similarly, an Australian study of untreated women with vulval LS reported a median Vulval QOL Index (VQLI) score of 13.5, which corresponds to a "moderate to very large effect" category (11–20) on the VQLI scale.[1,2,9]

Although VQLI is anatomically specific and not directly equivalent to DLQI, both scales reflect symptom severity and daily life disruption. Our DLQI values, nearly double those in these studies, suggest a greater cumulative disease burden in Nepal.

South Asian studies also report lower QOL impairment compared with our findings. A Study in north India documented a mean VQLI score of 9.2 among Indian women with genital LS, indicating a mild-to-moderate impact.[13] The higher impairment in our population may reflect delayed diagnosis, limited specialist availability, and the tendency for patients to present only after prolonged disease progression. Although VQLI and DLQI are not directly comparable due to differences in scoring range and domain focus, their findings still highlight that LS has a notable impact on QOL even when assessed with a site-specific tool. Our DLQI results exceed the values reported in other South Asian studies.

In contrast, our participants, with regular menstruation, homemakers, and from rural areas, reported much higher DLQI scores, indicating more severe impairment (Tables 2 and 4). This discrepancy may be due to delayed diagnosis, limited access to dermatologic care, and cultural stigma around genital conditions in low-resource settings like Nepal.

Unlike in high-income countries, where early intervention is common, many of our patients had untreated or long-standing disease, and impacting daily functioning.[14]

Domain-specific analysis revealed that difficulty in sports or physical activities (Q6: median 3, IQR 2–3), itch or pain (Q1: median 2, IQR 2–3), and restrictions in clothing choice (Q4: median 2, IQR 2–3) were the most affected areas.[6,9]

However, unlike Australian cohorts where sexual dysfunction and anxiety were among the highest-scoring domains, our study found relatively lower median scores in sexual difficulty (Q9: median 2, IQR 1–3). This may be due to cultural underreporting, sexual inactivity in older/postmenopausal women, or avoidance of sexual activity to reduce discomfort.[9]

Sociodemographic analysis highlighted that homemakers and residents of rural districts experienced the highest DLQI scores. The physically demanding nature of household and agricultural work, combined with restricted access to dermatological care in rural Nepal, likely exacerbates symptoms and delays relief. It is important to note that these factors are closely linked (e.g., most homemakers in our study were from rural areas), and our small sample size precluded multivariate analysis to determine their independent effects. Therefore, the high impairment observed is likely due to a synergistic effect of occupation, geographic disadvantage, and delayed diagnosis.

In terms of sociodemographic condition, the highest DLQI scores were observed among homemakers (median 24, IQR 20–26, range 15–30), many of whom also resided in rural districts such as Kavre (median 24, IQR 20–26, range 13–30), Ramechap (median 24, IQR 18–30) and Dolakha (median 23.5, IQR 21–26). The physically demanding nature of household and agricultural work, common in these rural settings, likely exacerbates LS symptoms through friction, heat, and prolonged physical strain. At the same time, limited access to specialized dermatology services and delayed healthcare-seeking behaviour in these areas may prolong disease duration and severity, compounding the quality-of-life impairment.

While some participants had comorbid conditions like diabetes, hypertension,

hypotension, and anxiety, these were not significantly associated with DLQI in our study. This aligns with previous literature, which emphasized that skin disease alone can significantly affect QOL, regardless of other medical conditions.[15]

However, several limitations should be acknowledged. The small sample size restricted statistical power and precluded multivariate analysis to identify independent predictors. Being a single-centre study, the results may not be generalizable to all regions. Sample size was not calculated as this was a 6-month time-bound observation study, which may have possible selection bias and a small sample size, limiting statistical comparison. The dichotomizing DLQI scores, timing of DLQI administration (baseline, pre-treatment) could be some other limitations. Disease duration was not recorded, limiting our ability to directly link higher DLQI scores to delayed diagnosis. Finally, cultural barriers to reporting sexual health concerns may have led to underestimation in related domains.

Conclusion

Lichen sclerosus imposes a profound quality-of-life burden in Nepal, with most patients experiencing an extremely large effect on daily functioning. The impact was most severe among homemakers and rural residents, reflecting the compounded influence of physically demanding work, delayed diagnosis, and limited access to specialized dermatological care. These findings underscore the critical need for increased awareness, earlier detection programs, and improved access to dermatologic services in rural and underserved communities. Incorporating routine quality-of-life assessment with the DLQI into clinical practice can help identify those at greatest psychosocial risk and guide patient-centred management to mitigate this significant burden.

Author contribution

Conception, design: ES, AT; Data acquisition: ES, MSB, AM, KS, AT; Data analysis, interpretation: ES, MSB, AM, KS, AT; Drafting: ES, MSB, AM, KS, AT; b. Revision: ES, MSB, AM, KS, AT; Final approval of the version to be published: ES, MSB, AM, KS, AT

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Conflict of interest

None

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Supplementary material

Data and supplementary material that support the findings of this study are available from the corresponding author upon reasonable request.

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