

# The impact of genital lichen sclerosus and lichen planus on quality of life: A review

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## ABSTRACT

**Background:** Lichen sclerosus (LS) and lichen planus (LP) are inflammatory diseases that demonstrate genital and extra-genital manifestations. Genital involvement may result in pruritus, sexual dysfunction, pain, and irritation. It is intuitive that the severity of symptoms may result in functional impairment and emotional distress, leading to a reduction in quality of life (QoL).

**Objective:** Investigate the current literature on the impact of genital LS and LP on QoL.

**Methods:** A literature review was performed using PubMed and results were summarized. Articles published between 1994 and 2020 were screened and reviewed by both the authors.

**Results:** These diseases have been assessed with dermatological assessments, such as the Skindex-29 and the Dermatology Life Quality Index, general health surveys such as the Short Form-12 questionnaire, and mental health instruments including the Beck Depression Inventory, and others; these instruments consistently demonstrate impaired QoL. It follows that treatment may reduce these symptoms. Interventions, such as photodynamic therapy, have demonstrated improvement in the depressive symptoms that impact QoL. Although both females and males experience a reduction in QoL related to these diseases, they experience the symptomatology differently. Through interviewing, male patients were more likely to report no symptoms compared with female patients, while female patients were also more likely to report worse QoL in the work-school domain of the Dermatology Life Quality Index as compared with male patients.

**Limitations:** Few studies have addressed the effect of disease severity or treatment on QoL.

**Conclusions:** Understanding how genital LS and LP contribute to reduced QoL for patients is critical for health care providers to better prioritize treatment strategies. Future prospective studies should investigate how QoL correlates with disease severity and response to treatment.

**Keywords:** genital disease, lichen planus, lichen sclerosus, mental health, quality of life, vulvar disease

## Introduction

Lichen sclerosus (LS) is an idiopathic inflammatory disease with predilection for the anogenital skin. Erythema and edema precede the characteristic white, atrophic papules and plaques, and longstanding disease activity may result in obliteration of the vulvar architecture.<sup>1,2</sup> Mucocutaneous atrophy may lead to development of hemorrhagic bullae and erosions. Symptoms include pruritus, burning, and dyspareunia, which may have significantly detrimental effects on function and sexual health.<sup>3</sup>

Like LS, lichen planus (LP) is a chronic, idiopathic inflammatory disease that affects the skin, mucous membranes, and nails and may affect the vulva. The symptoms of LP include burning, dyspareunia, dysuria, and irritating vaginal discharge, and the chronic pain precipitated by LP may result in increased anxiety, stress, and depression.<sup>4,5</sup>

The physical symptoms associated with genital LS and LP result in reductions in quality of life (QoL) due to the manifestations of emotional, mental, and physical distress. QoL may be measured by various validated instruments; important dermatology-specific tools include the Dermatology Life Quality Index (DLQI) and the Skindex-29.<sup>6,7</sup> Such surveys allow for quantification of the effect dermatologic diseases have on QoL and assist in comparison across disease states.

The goal of this review is to gather the available data on the effects of genital LS and LP on QoL, and evaluate the differences in QoL between female and male patients. Consolidation of this information will provide a resource for providers and illuminate the knowledge gaps related to this information, with the goal of motivating future prospective studies.

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### What is known about this subject in regard to women and their families?

- Genital lichen sclerosus and lichen planus may result in diminished quality of life and associated mental health comorbidities.

### What is new from the article as messages to women and their families?

- Studies have demonstrated that there may be a difference in how females and males experience these diseases, and that these differences are multifactorial in nature.
- Further prospective studies should be conducted to address changes in quality of life as it correlates to disease severity and treatment.

## Methods

A literature review was performed using PubMed and results were summarized. The literature search was performed using the terms “vulvar lichen sclerosus,” “lichen sclerosus,” “balanitis xerotica obliterans,” “vulvar lichen planus,” “lichen planus,” “quality of life,” and “psoriasis.” Articles published between 1994 and 2020 were screened and reviewed by both authors.

## Results and discussion

### Effects of vulvar LS on QoL

Several studies have evaluated the effects of vulvar LS on QoL, using dermatology-specific and general physical and mental health metrics.

### Dermatology Life Quality Index

A study of 215 female members from the Dutch LS Foundation found the mean total score on the DLQI was 11.92 of 30 (Table 1).<sup>2</sup> This study also found that the highest individual domain mean score was sexual difficulties, scoring a 2.1 of 3.0, followed by the domain of itching, sore, painful or stinging symptoms at 1.7 of 3.0.<sup>2</sup> In comparison, a separate study found that genital psoriasis scored 13.9 and non-genital psoriasis scored 10.08 on the DLQI.<sup>16</sup> These data suggest that vulvar LS may result in a diminished QoL and likely correlates with sexual functioning impairment. Sexual dysfunction may be attributed to the physical symptoms of LS such as burning, pruritus, and pain, in addition to feelings of embarrassment and self-consciousness that these symptoms may precipitate. Vulvar LS compares closely to genital psoriasis on the DLQI and scored higher than non-genital psoriasis, demonstrating that vulvar LS has a similar impact on QoL.

### Skindex-29

The Skindex-29 questionnaire was employed in a study of 262 patients with LS and demonstrated a total score of 38.4, with

domain scores of 46.8, 38.2, and 33.6, in symptoms, emotions, and functioning, respectively.<sup>3</sup> In comparison, patients with psoriasis scored 42.1, 38.9, and 22.8 on the same domains, respectively.<sup>3</sup> Another study of 303 patients noted 18% reported mild impairment, 25% experienced moderate impairment, and 26% had severe impairment, while only 29% had little to no impairment in the overall score for all domains (Table 1).<sup>10</sup> This spectrum of impairment may indicate that vulvar LS has variable effects on QoL. Most notably, more patients report impaired QoL versus patients with little to no impairment. According to the Skindex-29, patients with vulvar LS may also have greater impairment compared with patients with psoriasis in the domains of symptoms, emotions, and functioning.

### Physical and mental health

The 12-item Short Form survey is a questionnaire that consists of 12 items measuring both physical and mental health; scores are separated into physical health (PCS-12) and mental health (MCS-12); higher scores indicate better health.<sup>3</sup> This survey was utilized to compare females with LS to age-matched females from the general population of the Netherlands.<sup>3</sup> Females with low or mild self-reported LS burden compared similarly to females from the general population. Scores were reported as LS versus the general population. PCS-12 scores (51.6 vs 49.6, low; 49.6 vs 49.5, mild) and MCS-12 scores (49.2 vs 52.1, low; 51.4 vs 52.2, mild). However, women with moderate, severe, or very severe LS had lower average PCS-12 scores compared with the general population (45.9 vs 49.2, moderate; 45.8 vs 49.1, severe; 42.0 vs 48.6, very severe) (Table 1).<sup>3</sup> Similar, but more pronounced results were observed with MCS-12 scores (47.6 vs 52.3, moderate; 45.5 vs 52.4, severe; 45.6 vs 52.7, very severe) (Table 1).<sup>3</sup> Statistical significance was not calculated in this study since control data were reported only as mean scores without sample size information. Despite this limitation, there are notable differences in the physical and mental health of patients with moderate to very severe LS as compared with healthy controls

**Table 1.**  
**Comparison of QoL metrics in vulvar LS and vulvar LP**

Metric	Vulvar LS	Vulvar LP
DLQI mean total score <sup>2,7,8</sup> (0–30; higher score indicates greater impairment)	11.92 (SD 6.18, N = 215)	7.18 (SD 6.21, n = 17/77)
Skindex-29 mean total score <sup>3,9</sup> (0–100; higher score indicates greater impairment)	38.4 (SD 17.2, N = 262)	NA
Skindex-29 level of impairment <sup>9–11</sup>		
>25-mild impairment	18%	25.6%
>32-moderate impairment	25%	20.5%
>44-severe impairment	26%	25.6%
N	303	39
PSC-12 score by level of disease activity (24–72; lower score indicates greater impairment) <sup>3</sup>		
Low (n = 40)	51.6	NA
Mild (n = 68)	49.6	
Moderate (n = 98)	45.9	
Severe (n = 40)	45.8	
Very severe (n = 4)	42.0	
MSC-12 score by level of disease activity (24–72; lower score indicates greater impairment) <sup>3</sup>		
Low (n = 40)	49.2	NA
Mild (n = 68)	51.4	
Moderate (n = 98)	47.6	
Severe (n = 40)	45.5	
Very severe (n = 4)	45.6	
PASS20 score >30 <sup>12</sup> (indicates diagnosis of anxiety)	26% (N = 54)	NA
PHQ-8 score >10 <sup>12</sup> (indicates diagnosis of depression)	2% (N = 54)	NA
BDI mean score <sup>13,14</sup> (0–11, minimal; 12–26, mild; 27–49, moderate; 50–63, severe)	12 (pre-treatment); 9 (post-treatment) (N = 37)	6.65 (SD 6.72) (N = 49)
STASI-S mean score <sup>15</sup> (20–80; higher score indicates greater stress)	NA	32.94 (SD 8.71) (N = 49)
PSQ mean score <sup>15</sup> (0.34–0.46; higher score indicates increased stress)	NA	0.25 (SD 0.16) (N = 49)

BDI, Beck's Depression Inventory; DLQI, Dermatology Life Quality Index; PHQ-8, Patient Health Questionnaire; LP, lichen planus; LS, lichen sclerosus; MSC-12, Mental health component of SF-12; NA, not applicable; PASS20, Patient Anxiety Symptom Scale questionnaire; PSC-12, physical component of SF-12; PSQ, General Perceived Stress Questionnaire; QoL, Quality of life; SD, standard deviation; SF-12, 12-Item Short Form; STASI, State-Trait Anxiety Inventory Questionnaire.

or those with mild disease. This illustrates that vulvar LS diminishes QoL as measured by both dermatology-specific as well as on general health metrics; thus vulvar LS has demonstrable negative effects on patients' overall health.

### Anxiety and depression

The Patient Anxiety Symptom Scale questionnaire and the Patient Health Questionnaire (PHQ8) were used to assess anxiety and depression, respectively, in patients with LS.<sup>12</sup> Cut off scores for diagnosis were set at greater than 30 for the Patient Anxiety Symptom Scale questionnaire and greater than 10 for the PHQ8.<sup>12</sup> Patients with LS were not stratified based on severity of disease. Of 54 patients within this study, 26% were found to have anxiety, 2% had depression, and 4% had both anxiety and depression (Table 1).<sup>12</sup> Anxiety and depression may result from the physical symptoms of the disease, the effect of the disease on functional activity, and shame or embarrassment of the symptoms associated with vulvar LS. Understanding that anxiety and depression may be associated with vulvar LS may stimulate further research and is an opportunity for health care providers to address and treat these comorbidities.

### Beck's Depression Inventory

Beck's Depression Inventory second edition (BDI) was used to measure depression levels in an uncontrolled study for patients with vulvar LS before and after treatment with photodynamic therapy (635 nm, 5-aminolevulinic acid 5%).<sup>13</sup> Items on the BDI are ranked from 0 to 3, and total scores range from 0 to 63. In this study, 0 to 11 was considered minimal range, 12 to 26 as mild, 27 to 49 as moderate, and 50 to 63 as severe.<sup>13</sup> Before starting treatment, patients with vulvar LS reported a median BDI score of 12.00 (interquartile range, IQR, 8.00–21.00), and after completing therapy, the median BDI score was 9.00 (IQR, 8.00–16.50; Tables 1 and 2).<sup>13</sup> The improvement in median BDI score after treatment was significant ( $p = .003$ ); however, there was no noted decrease in the prevalence of depression.<sup>13</sup> This study also found that depressive symptoms were observed in 18 subjects (48.65%). Of the 18 subjects with depressive symptoms, 12 subjects had mild symptoms and 6 subjects had moderate symptoms; no severe symptoms were noted.<sup>13</sup> These data illustrate that depression may be associated with vulvar LS

and that treatment may improve symptoms of depression as measured by the BDI. However, no significant difference in sexual functioning before versus after photodynamic therapy was found. Similar to anxiety and functional impairment, patients with vulvar LS may experience a spectrum of depressive symptoms. Furthermore, photodynamic therapy may be a viable treatment option for reducing symptoms, thereby leading to an improvement in depressive symptoms.

### Treatment satisfaction

QoL in patients with vulvar LS may also be examined by satisfaction with treatment. One study of 264 patients with LS measured global satisfaction ratings with current treatment and found that 3.0% were very dissatisfied, 7.6% were dissatisfied, 25% were neutral, 47% were satisfied, and 18% were very satisfied with their treatment plan (Table 2).<sup>17</sup> This study also demonstrated that 5.3% were very dissatisfied, 17% were dissatisfied, 22% were neutral, 43% were satisfied, and 13% were very satisfied with the effectiveness of their LS treatment (Table 2).<sup>17</sup> Based on multiple linear regression analysis, both higher HRQoL emotion scores based on the Skindex-29 and higher disease severity correlated significantly with lower treatment satisfaction ( $p < .001$ ).<sup>17</sup> It is intuitive that patients who are dissatisfied with their treatment plan and feel that their treatment plan may not be effective have lower QoL. Treatment plan dissatisfaction may be linked to side effects, ease of following the treatment plan, and treatment plan cost. Dissatisfaction with effectiveness may be based on lack of symptom improvement, absence of symptom remission, or worsening of disease state. Based on Skindex-29 data, more severe disease states were associated with lower treatment satisfaction, which may indicate that as vulvar LS progresses it becomes increasingly difficult to manage, resulting in a decreased QoL. Additionally, while based on these data we cannot grade patients in terms of clinical response, other studies have demonstrated improvement in DLQI and PRISM scores from baseline as compared to after a 12-week treatment course of topical corticosteroids.<sup>18</sup>

### Female and male comparison

One study collected a detailed medical history from 44 females and 32 males to evaluate sex differences in genital LS.<sup>1</sup> They found 56% of both females and males experienced pain during sexual intercourse (Table 3).<sup>1</sup> In contrast, 22% of males reported no complaints regarding their LS, while no females in this study were found to be symptom free (Table 3).<sup>1</sup> Another study using similar methods found that 38% (209/549) of female patients without LS "sometimes" had dyspareunia and 56% (310/549) "never" experienced dyspareunia.<sup>19</sup> These data demonstrate that female patients with LS have reported increased dyspareunia compared with patients without LS. Similarly to the above-stated studies, other studies focused on LS in male patients found that 55% (180/329) experienced dyspareunia.<sup>20</sup> However, circumcision led to disease remission in 22 of the 32 male patients.<sup>1</sup> This finding highlights a limitation in assessing differences in how male and female patients experience LS, since the circumcision status of male patients may markedly impact severity of symptoms, disease activity, and QoL. Further investigation into these sex differences may improve symptom management and related sexual dysfunction.

### Effects of vulvar LP on QoL

Like vulvar LS, vulvar LP may have detrimental effects on QoL, and has been assessed using dermatology-specific and general physical and mental health metrics.

**Table 2.**  
Treatment satisfaction and BDI scores in patients with LS

Lichen sclerosus	
Treatment global satisfaction <sup>17</sup>	
Very dissatisfied	3.0%
Dissatisfied	7.6%
Neutral	25%
Satisfied	47%
Very satisfied	18%
N	264
Treatment effectiveness <sup>17</sup>	
Very dissatisfied	5.3%
Dissatisfied	17%
Neutral	22%
Satisfied	43%
Very satisfied	13%
N	264
BDI-median score <sup>13</sup>	
Before treatment [IQR]	12.00 [13]
After treatment [IQR]	9.00 [8.5]
N	37

BDI, Beck's Depression Inventory; IQR, interquartile range; LS, lichen sclerosus; N, sample size.

**Table 3.****Comparison of females and males with LS and LP by QoL metric**

Metric	Females	Males
Lichen sclerosis <sup>1</sup>		
Medical interviewing		
Pain during intercourse	25 (56%)	18 (56%)
No symptoms reported	0 (0%)	7 (22%)
n	44	32
Lichen planus <sup>14</sup>		
DLQI, work and school domain score, total score: 0–3	1.467 (SD 1.506, n = 15)	0.1500 (SD 0.6708, n = 20)
BDI, depression present (score ≥17)	46.67% (n = 7/15)	10% (n = 2/20)
Borderline depression (score 17–20)	14.28% (n = 1/7)	0% (n = 0/2)
Moderate depression (score 21–30)	42.86% (n = 3/7)	50% (n = 1/2)
Severe or extreme depression (score >30)	42.86% (n = 3/7)	50% (n = 1/2)

BDI, Beck's Depression Inventory; DLQI, Dermatology Life Quality Index; LP, lichen planus; LS, lichen sclerosis; n, subgroup sample size; SD, standard deviation.

### Dermatology Life Quality Index

A study examined QoL changes in patients with erosive vulvovaginal LP, vulvar LS, and other vulvar dermatitides, and found that of the 77 patients surveyed, the mean DLQI score was 5.3.<sup>8</sup> Subgroup analysis showed the mean DLQI score for erosive vulvovaginal LP was 7.18 (17/77) compared with 3.79 for patients with vulvar LS (48/77), and 8.67 for patients with vulvar dermatitides (12/77;  $p = .009$ , 1-way analysis of variance; Table 1).<sup>8</sup>

### Skindex-29

In a small study of 39 female LP patients utilizing the Skindex-29, 72% of patients experienced impaired QoL.<sup>11</sup> This was separated into mild impairment (25.6%), moderate impairment (20.5%), or severe impairment (25.6%) in the overall score for all of the Skindex-29 domains (Table 1).<sup>9,11</sup> While the specific factors leading to diminished QoL were not evaluated in this study, like vulvar LS, impairment may be attributable directly to disease symptoms or a decrease in function.

### Depression and anxiety

Prior studies have investigated mental health conditions such as depression, anxiety, and perceived stress in patients with genital LP. The impact of erosive genital LP on mental health was evaluated with the Swedish version of the revised 21-item BDI, with scores ranging from 0 to 63.<sup>14</sup> Patients with erosive genital LP had a mean score 6.65 on the BDI, compared with the mean score of 4.03 in the control group ( $p < 0.001$ ; Table 1).<sup>14</sup> The State-Trait Anxiety Inventory questionnaire (STAI-S) was used to evaluate state anxiety, which is defined as transient in nature pertaining to feelings of apprehension and worry around a specific occurrence or event.<sup>15</sup> The STAI-S is a 20-item questionnaire scored on a 4-point scale.<sup>15</sup> Mean scores on the STAI-S for patients with erosive LP were higher than controls (32.94 vs 29.60, respectively;  $p = .002$ ; Table 1).<sup>15</sup> Finally, the study employed the General Perceived Stress Questionnaire (PSQ) to analyze perceived stress levels. The PSQ is a 30-item questionnaire with scores ranging from 1 to 4 for each item, with higher scores indicating higher levels of perceived stress.<sup>15</sup> Mean PSQ scores for patients with erosive LP were reported as 0.25, whereas the control group had a mean score of 0.19 ( $p = 0.001$ ; Table 1).<sup>15</sup> Patients with erosive genital LP reported statistically significant higher scores on the BDI than the general population, indicating greater depression experienced by patients with genital LP. Comparably, patients with genital LP also scored higher on the STAI-S than the general population, which were statistically significant also indicating that state anxiety levels may be higher in patients with genital LP. Perceived stress was also

statistically significant compared with the control group. The chronic pain, shame or embarrassment, and disruption in daily activities may lead to the increase in depression, state anxiety, and perceived stress in patients with genital LP.

### Female and male comparison

The BDI was also employed to evaluate differences in depression symptoms and severity between females and males.<sup>14</sup> This study included 15 female and 20 male participants with 28 out of 35 having extra-genital lesions and 7 of 35 having genital lesions.<sup>14</sup> They found that depression was present in 7 females (46.67%) and 2 males (10%;  $p = .0216$ ; Table 3).<sup>14</sup> When stratified into borderline, moderate, and severe to extreme depression, females were reported at higher percentages in all three categories than males. Regarding severity of depression, moderate depression was reported in 1 male (50%) and 3 females (42.86%), and severe to extreme depression was noted in 1 male (50%) and 3 females (42.86%; Table 3).<sup>14</sup> When comparing how females and males experience vulvar LP through the DLQI, females were found to have significantly higher scores in the domain of work and school (1.467 vs 0.15 in males,  $p = .0156$ ), indicating more impairment (Table 3).<sup>14</sup> This indicates that, similarly to LS, females and males report differences in how they experience LP, and investigation of these differences is an important topic for future research.

### Conclusion

It is evident that vulvar LS and vulvar LP are associated with a reduced QoL, as demonstrated by multiple validated instruments. There are a wide range of potential causes to patient's diminished QoL, which the astute clinician should recognize and address. These include physical symptoms, shame and embarrassment, diminished ability to perform daily activities of living, and sexual dysfunction related to both diseases. While clinicians should understand and employ treatment options that have demonstrated the ability to improve QoL, high-quality data are limited. An additional important limitation to existing studies is the impact of disease severity on QoL; because many studies evaluated patients based on diagnosis alone, rather than disease severity, it is difficult to establish endpoints for QoL-related goals of treatment. These endpoints are critical for patient-centered care and evaluating response to novel treatments. Furthermore, females and males may experience genital LS and genital LP differently, which may be due to differences in disease presentation, treatment (including circumcision in male patients), and effects on QoL; thus, a patient-centered approach is necessary. These topics require further studies to improve our understanding of patients' experiences, as well as specific factors that may contribute to reduced QoL.

## Funding

None.

## Conflicts of interest

D.R.P. is a consultant for Biogen Inc. and clinical trials principal/sub investigator for Corbus Pharmaceuticals, Elorac, Inc., Eli Lilly and Company, Emerald Health Pharmaceuticals, Kadmon, Inc., Pfizer, Inc., and Soligenix, Inc.

## Study Approval

N/A.

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