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Quality of life in Dutch women with lichen sclerosus

C.A. Lansdorp,[1] K.E. van den Hondel,[1] I.J. Korfage,[2] M.J. van Gestel[3] and W.I. van der Meijden[1]

[1]Department of Dermatology, Havenziekenhuis, Rotterdam, the Netherlands
[2]Department of Public Health, Erasmus MC, Rotterdam, the Netherlands
[3]Dutch LS Foundation and Support Group, Sliedrecht, the Netherlands

Correspondence
Willem I. van der Meijden.
E-mail: wim.van.der.meijden@havenziekenhuis.nl

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Summary

Background Lichen sclerosus (LS) is a chronic inflammatory skin disease. Earlier studies have shown an impaired health-related quality of life (HRQoL), but more extensive research including generic questionnaires has not been reported.
Objectives To investigate, in a cross-sectional study, the HRQoL of a sample of Dutch women with LS; to compare the resulting HRQoL data with that available from other skin diseases and the general Dutch population; to explore factors that may influence the HRQoL.
Methods Female members of the Dutch LS Foundation and Support Group filled out three questionnaires electronically: the Skindex-29, the SF-12 and the EQ-5D visual analogue scale (VAS). We distinguished Skindex-29 scores into groups with 'little' (score 0–24), 'mild' (25–31), 'moderate' (32–43) and 'severe' (44–100) impact on HRQoL. We compared differences using the Mann–Whitney U-test and the Kruskal–Wallis test, and correlations using Spearman's rank correlation coefficient.
Results A total of 262 women with LS were included. The average diagnostic delay was 4·9 (SD 7·1) years. Patients had a mean total Skindex-29 score of 38·4 (0–100, SD 17·2). Domain scores for symptoms, emotions and functioning were 46·8 (SD 19·0), 38·2 (SD 20·2) and 33·6 (SD 19·3), respectively. The SF-12 showed average PCS-12 (physical component) and MCS-12 (mental component) scores of 47·7 and 48·5, respectively. For the Dutch population these scores were 49·3 and 52·3. The mean EQ-5D VAS score was 74·1 (SD 15·4).
Conclusions There is a considerable delay in diagnosis for female Dutch patients with LS. The Skindex-29 domain scores showed a moderately impaired HRQoL. Women with LS reported a lower generic HRQoL than the average female Dutch population.

Lichen sclerosus (LS) is a chronic, inflammatory skin disease. The aetiology is unknown, but there is a strong association with autoimmune disorders. Genetic factors may play a role,[1] as indicated by the association with human leucocyte antigen class II antigen DQ7.[2,3] An infectious or hormonal cause could not be established.[4]

LS can occur at any age, but there are two main peaks in incidence in both women and men. The first peak occurs before puberty, the second peak occurs in women after the menopause, and in men between 30 and 50 years of age.[5,6] Although LS affects female and male individuals, the incidence in women is much higher; some studies have shown a female/male ratio of 10 : 1, others of 6 : 1.[7,8] The prevalence is estimated to be between 1 in 30 and 1 in 1000.[9,10] In children[11] the female/male ratio appears to be reversed. The estimated prevalence in girls aged 2–16 years is estimated to be 1 in 900;[12] in boys aged 0–14 years it is estimated to be 1 in 200.[13]

LS usually affects the anogenital skin. Symptoms in women include itching, burning and superficial dyspareunia. Fissures can develop from coitus and defaecation. Scarring may lead to the destruction of anogenital architecture, such as narrowing of the vaginal introitus.[4] In addition, the vulvar skin may show whitening and atrophy, but also hyperkeratosis. In 20% of all patients there are extragenital lesions, for example on the trunk, neck, shoulders or arms.

The most serious complication of genital LS in women is the development of vulvar cancer (3–5% of patients).[14,15] Currently, a definite cure of LS is not possible. Treatment is given primarily to reduce the symptomatic burden and possibly prevent progression of the architectural changes.

The skin lesions of LS are often located on intimate places. This may cause shame, fear, embarrassment or insecurity, especially with regard to sexual relations, which can result in a worse health-related quality of life (HRQoL) in patients with

LS. The definition of HRQoL, as provided by the U.S. Centers for Disease Control and Prevention, is 'a broad multidimensional concept that usually includes self-reported measures of physical and mental health'. Although earlier research has shown an impaired sexual functioning and impaired HRQoL,[16] more extensive research on the HRQoL in women with LS using a dermatology-specific questionnaire combined with generic questionnaires has not been reported to date.

In this study we describe the HRQoL of women with LS. We compared their HRQoL data with those available from the general Dutch population. In addition, we evaluated whether the HRQoL of women with LS differs from that of individuals suffering from other skin diseases, and we investigated the factors that may influence the HRQoL of women with LS.

Materials and methods

Study population

The study population consisted of members of the Dutch LS Foundation and Support Group (http://www.lichensclerosus.nl/). This organization ensures that members have a confirmed diagnosis of LS at the moment of subscription, by asking patients about their diagnosis, the name of their current physician and the treatment they receive. All 528 registered members [459 women (87%), 42 men (8%) and 27 children (5%)] were invited by e-mail to participate in our study. By means of a link to a website (http://www.formdesk.com), the questionnaires could be filled in electronically and anonymously. The e-mail message was announced on the electronic message board of the foundation.

This study was part of a larger study conducted with the members of the Dutch LS Foundation and Support Group. For our study purpose we wanted to focus on adult women with LS, and therefore male patients and children were excluded. The Medical Ethical Committee of the Havenziekenhuis Rotterdam approved our study.

Questionnaires

To measure the HRQoL three different types of questionnaire were selected. One dermatology-specific questionnaire, Skindex-29, and a generic HRQoL questionnaire, the SF-12 (12-item Short Form Health Survey), were used to determine the HRQoL of women with LS. These questionnaires were selected based on the literature.[17,18] A second generic questionnaire [EQ-5D visual analogue scale (VAS)] was chosen to present one value for HRQoL for comparability with other diseases.

Skindex-29

The Skindex-29 is a self-administered measure developed to assess the disease-specific effects of skin conditions on patients' quality of life. The Skindex-29 questionnaire consists of 29 items, forming three domains: symptoms, emotions and functioning. An additional item addresses side-effects of medication and treatment. Each item results in a score between 0 and 100. The average of the domain-specific items combined is the domain score, and the average of all items combined is the total score. Higher scores indicate lower levels of HRQoL.[19–22] We used cut-off scores as defined by Prinsen *et al.*[19,22] for the interpretation of the Skindex-29 scores and subdivided the respondents into three groups of total Skindex-29 scores: 'mild' (25–31), 'moderate' (32–43) and 'severe' (44–100) impact on HRQoL. In addition to the groups of Prinsen *et al.*[19,22] we created a fourth group for the scores 0–24: 'little' impact on HRQoL.

The Skindex-29 has been translated into the Dutch language; research has shown a good reliability and validity.[19,22]

SF-12

The SF-12, the short version of the SF-36, was developed for the Medical Outcome Study, a multiyear study of patients with chronic conditions. The questionnaire consists of 12 items measuring both physical and mental health, and provides a solution to the problem of having to restrict survey length. Questions are answered on 2–6-point scales[23] and by using norm-based methods (a mean of 50 and an SD of 10 in the general U.S. population), scores for the physical (PCS-12) and mental (MCS-12) component summary measures are calculated. A 1-point difference can be interpreted as one-tenth of an SD.[24] The scores for the Dutch population, subdivided in 10-year age groups, are available from Statistics Netherlands (CBS; http://statline.cbs.nl/statweb/).

EQ-5D visual analogue scale

The EQ-5D VAS records the respondent's self-rated health on a VAS, with the endpoints labelled as 'worst imaginable health state' (0) and 'best imaginable health state' (100).[25,26] EQ-5D VAS scores can be compared with those of other populations with (chronic) diseases.

Independent measures

We included sociodemographic items on sex, age, weight and height, marital status, level of education, employment, menopausal status, smoking (pack-years), use of alcohol, and other diseases. Pack-years were calculated only for current smokers (not for patients who smoked in the past), by asking patients about the number of cigarettes per day and the number of years they had been smoking. The different levels of education were cut back to three categories: primary (elementary school), secondary (high school) and tertiary (higher or post-secondary education).

Clinical items on symptoms, diagnosis and treatment were also included. The symptoms we enquired about included pain, itching, skin defects (wounds/abrasions), fusion of the labia, dyspareunia, burning, painful urination and defaecation. It was also possible to add other symptoms manually.

Because LS is characterized by exacerbations and remissions, patients were asked to specify the number and kind of symptoms they experienced at the moment of filling in the questionnaire and to rate the current severity of their own disease on a 5-point scale, varying from 'low' to 'very severe'.

The diagnostic window was calculated by asking patients about their age at the start of their symptoms and their age at diagnosis. They were also asked if their diagnosis was confirmed by biopsy and if they received treatment by a specialist or their general practitioner.

Concerns about malignancy and LS in family members were determined on a 5-point scale, varying from 'no concerns at all' (0) to 'very concerned' (5).

Data analysis

Data were downloaded from the internet and entered in a computerized database, using SPSS software (version 17.0 for Windows; SPSS, Chicago, IL, U.S.A.). When filling in the questionnaires, it was not possible to skip questions, so there were no unanswered questions. Technically impossible data (e.g. a birth date in the future) were regarded as 'missing' and were excluded from analyses concerning that part of the questionnaire.

Differences between groups of Skindex-29 scores were calculated using the Mann–Whitney U-test for independent, nonparametric distributed data. Differences between groups ($n > 2$) of Skindex-29 scores were examined using the Kruskal–Wallis test; when $P < 0{\cdot}001$ we used the Mann–Whitney U-test. Correlations were calculated using Spearman. $P < 0{\cdot}05$ was considered significant.

Results

All members ($n = 528$) of the Dutch LS Foundation and Support Group were invited to participate by email; 282 responded (53%). After exclusion of children and male respondents ($n = 20$) the final study population consisted of 262 women with LS, which means a response of 57% for this subgroup.

The median age of the women with LS was 51 years (range 20–76) (Table 1). Forty-one per cent of the women were postmenopausal. The majority of the women (79%) were either married or living with a partner. Most women with LS had a secondary (35%) or tertiary education (35%). Fifty-nine per cent of the women with LS were employed and 13% stated they were retired. Fifteen per cent of the women were smokers, with a mean number of pack-years of 17·0. Sixty-five per cent of the women with LS used alcohol, on average six glasses a week. The mean body mass index was 25 kg m^{-2}. The median age when LS was diagnosed was 45 years. The average time between the first symptoms and the diagnosis of LS was 4·9 years (SD 7·1). Most women had at least two symptoms/complaints. Itching was the most prevalent complaint (65%), followed by dyspareunia (55%) and fusion of the labia (54%).

The majority of the women ($n = 229$, 87%) received treatment, mostly provided by a gynaecologist (54%). A group of 101 women (39%) classified the severity of their disease as 'moderate' and four women (1·5%) classified their disease as 'very severe'. Seventy-eight per cent of the women were concerned about the possible development of vulvar cancer. Fifty-three per cent worried about their family having LS.

Table 1 Baseline characteristics of the study population ($n = 262$)

Characteristic	
Age (years), mean (± SD) (missing $n = 12$)	50·7 (± 11·5)
Marital status, n (%)	
Not/never married	27 (10)
Married/living together	207 (79)
Widowed/divorced	28 (11)
Highest level of education, n (%)	
None/other	8 (3)
Lower	70 (27)
Secondary	92 (35)
Tertiary	92 (35)
Current smoker, n (%)	
No	224 (85)
Yes	38 (15)
Pack-years in smokers, mean (± SD)	17·0 (± 14·4)
Alcohol use, n (%)	
No	93 (36)
Yes	169 (65)
Diagnostic biopsy, n (%)	
No	97 (37)
Yes	163 (62)
Don't know	2 (0·8)
Postmenopausal, n (%)	
No	124 (47)
Not sure	31 (12)
Yes	107 (41)
Age at diagnosis (years), mean (± SD) (missing $n = 20$)	44·6 (± 12·5)
Diagnostic window (years), mean (± SD) (missing $n = 15$)	4·9 (± 7·1)
Present treatment by, n (%)	
GP	7 (2)
Dermatologist	46 (18)
Gynaecologist	141 (54)
Sexologist	1 (0·4)
Combination	17 (7)
Other	17 (7)
Not undergoing treatment	33 (13)
BMI (kg m^{-2}), mean (± SD) (missing $n = 14$)	25·3 (± 4·4)

Technically impossible data (such as a birth date in the future) are regarded as 'missing'.
GP, general practitioner; BMI, body mass index.

Skindex-29

Women with LS had a mean total score of 38·4 on a scale of 0–100 (Table 2). Domain scores for symptoms, emotions and functioning were 46·8 (SD 19·0), 38·2 (SD 20·2) and 33·6 (SD 19·3), respectively. The most frequently reported items (stratified per domain) for women with LS were soreness,

Table 2 Skindex-29 scores for different domains (n = 262)

Domains of Skindex-29	Mean (± SD)
Symptoms	46·8 (19·0)
Soreness	66·4 (27·2)
Irritation	57·7 (26·4)
Itching	55·1 (26·2)
Emotions	38·2 (20·2)
Concerns about worsening of disease	56·6 (25·8)
Annoyance	52·4 (32·4)
Frustration	43·4 (31·2)
Functioning	33·6 (19·3)
Impediment of sexual life	74·6 (30·9)
Impediment of intimacy	59·7 (36·0)
Tiredness	34·8 (32·3)
Total score	38·4 (17·2)

The domain scores and the total score are expressed on a 100-point scale, with higher scores indicating lower levels of HRQoL. For each domain, the three highest scoring items are shown.

concern about worsening of the disease and impediment of sexual life.

Table 3 shows Skindex-29 scores stratified for the level of self-reported disease burden. Skindex-29 scores of women with LS who endure a 'high' or 'very high' self-reported disease burden, were 50·8 and 55·0, respectively.

Table 4 shows Skindex-29 cut-off scores in relation to the number of symptoms patients reported. Patients with 'little impact' on HRQoL (n = 55) reported a median number of 2·2 symptoms, the 'mild impact' group (n = 41) experienced 3·3 symptoms, the 'moderate impact' group (n = 72) 3·8 symptoms and the 'severe impact' group (n = 94) reported 5·0 symptoms. The differences between groups were significant ($P < 0·001$), except for the 'mild' compared with the 'moderate' group.

Table 3 Skindex-29 scores stratified for self-reported disease burden

Self-reported severity of disease	n	Total Skindex-29 score (± SD)	P-value
Low	42	22·4 (±15·1)	
Mild	72	33·5 (±13·3)	< 0·001[a]
Moderate	101	42·5 (±15·0)	< 0·001[b]
Severe	43	50·8 (±15·3)	0·005[c]
Very severe	4	55·0 (±19·3)	0·517[d]

Higher scores indicate a lower level of HRQoL. Differences between groups were examined with the Kruskal–Wallis test ($P < 0·001$), then the Mann–Whitney U-test.
[a]Difference between the total scores of 'low' and 'mild' severity of disease; [b]difference between the total scores of 'mild' and 'moderate' severity of disease; [c]difference between the total scores of 'moderate' and 'severe' severity of disease; [d]difference between the total scores of 'severe' and 'very severe' severity of disease.

Table 4 Skindex-29 cut-off scores in relation to the number of symptoms

Impact on HRQoL	Cut-off scores Skindex-29	n	Number of symptoms (± SD)	P-value
Little	0–24	55	2·2 (±1·6)	
Mild	25–31	41	3·3 (±1·7)	< 0·001[a]
Moderate	32–43	72	3·8 (±1·8)	0·12[b]
Severe	44–100	94	5·0 (±2·0)	< 0·001[c]

Impact on health-related quality of life (HRQoL) (first column) was determined using cut-off scores by Prinsen *et al.*[19,22] (second column). Differences between groups were examined with the Kruskal–Wallis test ($P < 0·001$) and the Mann–Whitney U-test.
[a]Difference between the number of symptoms in total scores 0–24 and 25–31; [b]difference between the number of symptoms in total scores 25–31 and 32–43; [c]difference between the number of symptoms in total scores 32–43 and 44–100.

Heavy smokers (> 15 cigarettes/day) had a significantly increased score of 10·8 in the domain 'symptoms', compared with moderate smokers (< 15 cigarettes/day) and nonsmokers ($P = 0·03$). In the total Skindex-29 score they had an increased score of 9·3 ($P = 0·04$). Significant differences between different intakes of alcohol (> 10 glasses per week, < 10 glasses per week or no alcohol intake) were not found.

A correlation was found between diagnostic delay and total Skindex-29 scores [correlation coefficient (CC) = 0·13 and $P = 0·045$] and also between total Skindex-29 scores and self-reported disease burden (CC = 0·341 and $P < 0·01$).

Table 5 shows the average Skindex-29 scores of some other major dermatological diseases as reported in the literature.[27–33] Hidradenitis suppurativa, LS and psoriasis have the highest Skindex-29 scores.

Table 5 Average Skindex-29 domain scores of frequent dermatological diseases

Skin disease	Symptoms	Emotions	Functioning	n
Hidradenitis suppurativa[27]	55·6	52·6	45·9	258
Lichen sclerosus (this study)	46·8	38·2	33·6	262
Psoriasis[28]	42·1	38·9	22·8	44
Hand eczema[29]	50·5	32·0	17·2	140
Acne vulgaris[28]	29·5	39·2	14·9	57
Neurofibromatosis 1[30]	21·4	31·6	22·3	128
Hyperhidrosis[31]	12·6	30·0	30·5	70
Cutaneous T-cell lymphoma[32]	19·1	23·9	24·2	22
Nail disorders (e.g. onychomycosis)[33]	16·4	21·1	11·1	79
No skin disorder[28]	13·8	9·2	3·8	107

Scores are expressed on a 100-point scale, with higher scores indicating a lower quality of life.
n = the number of patients in the study population of each individual study.

Table 6 SF-12 scores of women with lichen sclerosus (LS) compared with the Dutch population

Self-reported severity of disease	Women with LS			Female general population[a]	
	n	PCS-12 score	MCS-12 score	PCS-12 score	MCS-12 score
Low	40	51·6	49·2	49·6	52·1
Mild	68	49·6	51·4	49·5	52·2
Moderate	98	45·9	47·6	49·2	52·3
Severe	40	45·8	45·5	49·1	52·4
Very severe	4	42·0	45·6	48·6	52·7
Average	250	47·7	48·5	49·3	52·3

SF-12 scores of women with LS are stratified for age and self-reported disease burden. Higher score means a higher health-related quality of life.
PCS, physical component summary; MCS, mental component summary.
[a]Weighted norm scores are calculated using age-matched SF-12 scores of the female Dutch population provided by Statistics Netherlands (CBS; http://statline.cbs.nl/statweb/).

SF-12 and EQ-5D visual analogue scale

The average score for the PCS-12 for women with LS was 47·7 (SD 10·5) and 48·5 (SD 12·8) for the MCS-12. The scores were compared with the scores of the Dutch population, published by Statistics Netherlands (CBS; http://statline.cbs.nl/statweb) (Table 6).

Except for women with LS with a low self-reported disease burden, this table shows that the scores in both domains were lower than the average scores of the general Dutch population, reflecting a worse HRQoL in women with LS than in the general female Dutch population.

Because Statistics Netherlands provides only average scores (and no information about sample size), it is not possible to calculate the statistical significance of the difference between our sample and the female Dutch population.

The average score of the EQ-5D VAS was 74·1 (SD 15·4), ranging from 82·1 (SD 13·9) in women with a low self-reported disease burden, to 69·0 (SD 15·4) in patients with a severe or very severe disease burden ($P < 0·01$). This reflects a worse HRQoL in patients with a higher disease burden.

Discussion

In this study, we established the HRQoL in women diagnosed with LS. To our knowledge this study is the first to examine extensively the HRQoL in women with LS, in the Netherlands or elsewhere.

Using the cut-off scores of Prinsen *et al.*,[19,22] the mean domain and total Skindex-29 scores showed a moderately impaired HRQoL in our study population. LS is characterized by exacerbations and remissions. In interpreting the results, the degree of self-reported 'disease burden' should be taken into account. We found a significant association between increased total Skindex-29 scores and a higher self-reported 'disease burden'. Women with LS who experience a high or very high self-reported disease burden, have a higher total Skindex-29 score compared with the whole group. This shows that a (very) high self-reported disease burden is associated with a severely decreased HRQoL. This is confirmed by the SF-12 and EQ-5D VAS scores. Another interesting finding is the strong correlation between the HRQoL as assessed with the Skindex-29 and the number of symptoms. The number of symptoms is significantly higher in groups with a worse HRQoL. This suggests that even though we cannot cure LS, resolving one or more symptoms may lead to a better HRQoL. It also confirms the sensitivity of the Skindex-29 for symptoms.

Lifestyle seems to be of some importance in the HRQoL of women with LS. Heavy smokers (> 15 cigarettes/day) have a lower HRQoL than moderate smokers (< 15 cigarettes/day) or nonsmokers. Heavy smokers score significantly higher in total Skindex-29 scores as well as in the domain 'symptoms'. Smoking does not correlate with a higher self-reported disease burden or with a higher number of symptoms. This might seem contradictory, as the relation between the total Skindex-29 score and the total number of symptoms (as mentioned earlier) might suggest that smokers would have a higher number of symptoms than nonsmokers, given their higher total Skindex-29 score. However, perhaps due to the relatively small number of smokers ($n = 38$), no statistical significant difference was found between the number of symptoms of smokers and nonsmokers. Also, the higher score in the domain 'symptoms' implies a higher number of symptoms, but it is possible that smokers experience a higher burden for several symptoms than nonsmokers, without necessarily having more symptoms. It is also possible that smoking has a negative association with HRQoL that is independent of LS.[34]

A minor correlation between HRQoL and the window between the start of symptoms and establishing the diagnosis (diagnostic delay) was found ($CC = 0·13$, $P = 0·045$). The longer the delay, the higher the self-reported disease burden and the lower the HRQoL. Because of delay in diagnosis, adequate treatment will also be delayed. This could be a possible explanation for the lower HRQoL and higher self-reported disease burden. This emphasizes the importance of an early diagnosis and early treatment; with an early diagnosis, patients may experience a higher HRQoL. In our study the average time until diagnosis was 4·9 years. A greater awareness among general practitioners and other medical specialists could help to achieve a proper diagnosis earlier.

Table 5 shows Skindex-29 scores from our study compared with the scores of other skin diseases.[27–33] The average self-reported disease burden of LS, compared with other skin diseases, is remarkably high. However, the studies that provided us with the scores for other skin diseases have mostly been performed in other countries, with different patient characteristics such as sex and age. It is therefore questionable if firm conclusions can be drawn.

Because sex-specific scores of the SF-12 are available for the Dutch population and because the scores were stratified for age, comparison with these scores is more accurate. The comparison shows a lower HRQoL in patients with LS than the general Dutch population.

We acknowledge several limitations. In the questionnaires we asked women with LS to assess the severity of their disease themselves. Assessment by a physician might have shown different results for this item. However, given the psychological aspect of the disease, an objective view might not have been suitable (or possible) in this case. Also, some of the symptoms we enquired about (such as fusion of the labia) can be regarded as clinical signs of LS, which ideally would have been assessed by a physician. It is also hard to conclude if one single factor really influences HRQoL, because it is possible that factors interact.

There is the risk of selection bias. It is possible that women who experience a severe impact on HRQoL might join a patient support group sooner than women who are experiencing a small impact on HRQoL. This could have resulted in a study population in this investigation with worse HRQoL levels than the total population of women with LS. On the other hand, it is also possible that women with severe LS experience emotions such as shame and/or embarrassment to a larger extent than women with less severe LS, and therefore might not want to join a patient support group. This could have resulted in a study population with a better HRQoL than the total population of women with LS. Because LS is a disease with remissions and exacerbations, the average HRQoL might be better in patients in remission and worse in patients having an exacerbation.

Strengths of this study are the use of dermatological and generic questionnaires and also the relatively large number of respondents. Furthermore, in this case, the fact that the questionnaires were filled in anonymously might have led the women with LS to fill them in more truthfully.

In conclusion, we report the HRQoL in Dutch women with LS. We found that LS has a moderate impact on HRQoL and that women with LS experience a lower HRQoL than the general Dutch population. In addition it shows that the number of symptoms is correlated with the HRQoL of women with LS. Adequate treatment might decrease the number of symptoms and by starting treatment earlier, further progression (such as extensive anatomical changes) can perhaps be prevented. Even though cure is not possible, an early diagnosis is something that can be accomplished, for example by a higher awareness among general practitioners and other specialists.

What's already known about this topic?

- Earlier research has shown impaired sexual functioning and health-related quality of life (HRQoL) in patients with lichen sclerosis (LS).

What does this study add?

- This is the first study that uses validated dermatological and generic questionnaires to investigate HRQoL in patients with LS.
- Patients with LS experience a moderately impaired HRQoL.
- Compared with the general population and other chronic diseases, the impact on HRQoL is considerable.

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