

## The effect of vulvar lichen sclerosus on quality of life and sexual functioning

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### Abstract

Lichen sclerosus (LS) is a chronic skin disorder mostly seen on the female anogenital skin. The aim of this study was to evaluate the quality of life (QoL) and sexuality in female patients with LS and to compare their scores with healthy controls. In addition, we wanted to find factors associated with impaired sexual functioning in patients with LS.

Members of the Dutch LS foundation and support group were asked to fill in three questionnaires: the Dermatology Quality of Life Index, Female Sexual Function Index (FSFI) and Female Sexual Distress Scale (FSDS). 215 of 368 patients returned their questionnaire (58.4%). Their scores were compared to a control group which consisted of 61 women of similar age ( $p = 0.472$ ) without a skin disorder.

Of all domains of QoL, LS interfered most with sexual functioning. Patients significantly scored lower on all subscales of the FSFI (desire ( $p = 0.016$ ), arousal ( $p < 0.001$ ), lubrication ( $p < 0.001$ ), orgasm ( $p < 0.001$ ), satisfaction ( $p < 0.001$ ) and pain ( $p < 0.001$ ), indicating worse sexual functioning. These problems with sexual functioning brought about significant sexual distress ( $p < 0.001$ ). Patients who experienced more influence on their QoL had more sexual difficulties, leading to more sexual distress independent of their age.

**Keywords:** Female health, psychosomatic gynaecology, sexual dysfunction (biological), sexology

### Introduction

Lichen sclerosus (LS) is a chronic skin disorder that affects patients of all age groups, particularly women. It is most commonly seen on the female anogenital skin, but it may occur on extragenital areas as well. LS is a tissue destructive disease that may lead to anatomical changes; resorption of the labia minora, hooding and burial of the clitoris, labial fusion and introital stenosis may occur (Figure 1). The origin of LS is unknown, and in patients with LS there is an increased incidence of vulvar squamous cell carcinomas with a life-time risk of about 5%, which is a relative risk of 300 compared to women in the general population [1,2]. Most patients complain of itching, but a burning sensation, dyspareunia, dysuria and painful defecation are also reported [3]. The current

standard treatment of LS is the use of superpotent corticosteroid ointment [4–6]. Although this treatment is effective in the majority of patients with LS, most experience exacerbations at times.

Limited data that focus on the effect of LS on quality of life (QoL) and sexual functioning are available. Probably, many patients with LS feel embarrassed and do have sexual problems [7,8]. Patients may be uncomfortable by the disfiguring changes that may occur and may therefore avoid sexual intimacy. In a study on the QoL in 43 chronic patients with LS, it was found that patients who are seeking care for LS have considerable QoL impairment: the majority of patients reported both an impact on sexual functioning and frustration and a significant impact on general happiness. Their self-esteem and confidence were also affected. Data in that study showed that all major



Figure 1. LS with narrowing of the introitus by anterior labial fusion.

QoL domains were affected except for work/school functioning [9]. Dalziel [10] reported that LS had a detrimental effect on sexual functioning, but only a small number of patients (45) were questioned. Furthermore, she did not use a validated questionnaire, and the results were not compared with a control group [10].

QoL and sexuality may be assessed in various ways; in our study on QoL and sexual functioning in female patients with LS, we choose to use the Dermatology Life Quality Index (DLQI), the Female Sexual Function Index (FSFI) and Female Sexual Distress Scale (FSDS).

Few studies have addressed QoL and sexuality in patients with LS, and these studies included a limited number of patients and/or lack a control group. In addition, they did not use validated questionnaires. Therefore, it is still largely unknown what the exact effect of LS on the QoL and sexuality is. The aim of this study was to evaluate the QoL and sexuality with validated questionnaires in detail in a large group of female patients with LS and to compare their scores with healthy controls. In addition, we wanted to find factors associated with impaired sexual functioning in patients with LS.

## Methods

### Patients

The Dutch LS foundation and support group was initiated in 2006. At the beginning of our study, 430

patients with LS (32 male, 398 female) were member of this foundation. Patients are only allowed to become a member of the foundation after they declare that they have a diagnosis of LS, preferably by taking a biopsy. Since LS is a chronic skin disease, all patients are under follow up by a gynaecologist, dermatologist or family doctor. Unfortunately, we did not know whether they all used some form of treatment at the time of the study. All female members were invited to participate in our study by an e-mail message. Thirty e-mail messages could not be delivered. As a result, a total number of 368 female patients with LS were asked to participate in the study. In the e-mail message, a link to a website was included where the questionnaires could be filled in electronically and anonymously. In addition, patients were asked for several sociodemographic patient characteristics (age and marital status) and medical data (duration of LS).

### Control group

Within the Radboud University Nijmegen Medical Centre, there is collaboration between the Department of Obstetrics & Gynaecology and the Department of Dermatology. These two departments designed a QoL study for patients with psoriasis using the same questionnaires as used in this study on patients with LS. Both patients with LS and psoriasis were asked to invite female friends of about the same age to fill in the questionnaires to form a control group for both studies. They could participate in the study when they did not have psoriasis, LS or another dermatological condition.

### Questionnaires

The DLQI is the first dermatology-specific QoL instrument, and to date it is the most commonly used [11,12]. It consists of 10 questions concerning patients' perception of the impact of their skin disease on different aspects of their QoL and has been validated for dermatology patients [9]. (Some examples of questions: 'Over the last week, how much has your skin influenced the clothes you wear?' and 'Over the last week, how much has your skin made it difficult for you to do any sport?') The questionnaire is structured with each question having four alternative responses: 'not at all', 'a little', 'a lot' or 'very much', with corresponding scores of 0, 1, 2 and 3, respectively. The answer 'not relevant' is scored as '0'. The DLQI is calculated by summing the score of each question, resulting in a minimum of 0 and a maximum of 30. The higher the score, the greater the impairment of QoL [12].

The FSFI is a 19-item questionnaire that has been developed as a brief, multidimensional self-report instrument for assessing the key dimensions of sexual

functioning in women. The FSFI has six subscales: desire, arousal, lubrication, orgasm, satisfaction and pain. The questionnaire was designed and validated for the assessment of female sexual functioning and QoL in clinical trials and epidemiological studies [13]. Individual domain scores are obtained by adding the scores of the individual items that comprise the domain and subsequently multiplying the sum by the domain factor. The full scale score is obtained by adding the six domain scores [13]. Higher scores indicate better sexual functioning. A FSFI total score of 26.55 or less is the cut-off point for differentiating women with and without sexual dysfunction [14].

The FSDS is a 12-item self-rating instrument for assessing sexually related personal distress and has been extensively used. The scale showed a high degree of discriminative ability in distinguishing between sexually dysfunctional and sexually functional women [15,16]. Every item requires an answer that is rated as: never (0 points), rarely (1 point), occasionally (2 points), frequently (3 points) or always (4 points). The total score, ranging from 0 to 48, provides a measure of sexual distress, in which the higher the score, the higher the level of sexual distress [16]. A total score of  $\geq 15$  on the FSDS is the recommended cut-off score to establish the presence of sexually related personal distress [16]. Both the FSFI and FSDS have been validated for a Dutch population [17].

### Statistics

Data were entered in a computerised database and analysed using SPSS software (version 16.0.1 for Windows, SPSS). Differences between patients and controls were calculated using the Mann–Whitney *U*-test for independent, non-parametric distributed data. Correlations were calculated using Pearson bivariate correlations, and a linear regression model was used to calculate which factor was associated with sexual dysfunctioning. *p* values  $< 0.05$  were considered statistically significant.

### Results

Patients of the Dutch LS foundation and support group returned 215/368 (58.4%) questionnaires. The median age was 50 years (range: 20–76 years). The majority of the patients (80%) were married or living together. Only 82 patients filled in for how long they had suffered from LS. The median duration of complaints was 5.0 years (mean: 8.0, range: 1–45 years). Sixty-one healthy controls filled in the questionnaires. The median age of the control group was 50 years (range: 24–69), which did not differ significantly with the median age of the patients with LS ( $p = 0.472$ ).

### DLQI

To find out whether LS has influence on the QoL in patients with LS, they were asked to fill in the DLQI. As this is a questionnaire about the influence of dermatology disorders on QoL, only patients with LS were asked to complete this questionnaire because the control group consisted of patients without a dermatological condition. The mean total score of patients with LS was 11.92 points (SD: 6.18), which indicates a very large effect on the QoL [11]. Patients with LS had the highest mean score on the item regarding sexual difficulties. LS did not interfere much with working or studying (Figure 2).

### FSFI

Patients with LS had a mean total score of 18.79 (SD: 7.95), that of the control group was 27.43 (SD: 4.03) ( $p < 0.001$ ). With a cut off value of 26.55 [14], this indicates sexual dysfunctioning in patients with LS, not in controls. Patients ( $n = 187$ ) scored significantly lower on all the subscales for the FSFI compared to the control group ( $n = 61$ ) (Mann–Whitney *U*-test:  $p < 0.001$  for subscales arousal, lubrication, orgasm satisfaction and pain,  $p = 0.016$  for desire). The smallest difference was on the subset ‘desire’ (Figure 3).

### FSDS

Mean total score for the FSDS was 26.08 (SD: 11.81) for patients and 9.97 (SD: 8.26) for controls ( $p < 0.001$ ). Using a cut off score of  $\geq 15$  [16], this indicates sexual distress in patients with LS, not in controls. Patients with LS ( $n = 206$ ) had significantly higher mean scores on all 12 items of the FSDS in comparison with healthy controls ( $n = 61$ ) (Mann–Whitney *U*-test  $p < 0.001$  for all items) (Figure 4).

With the aim to find out what factors are associated with sexual dysfunctioning, a regression analysis was performed. Of the factors age, marital status, duration of LS (years) and the total DLQI scores, the total DLQI score predicted sexual dysfunctioning significantly ( $p = 0.003$ ,  $B = -0.363$ ), indicating that patients who experience that their LS has a large effect on their QoL, have more sexual problems.

The amount of itch and/or pain (DLQI question 1) correlated significantly with the mean scores of the FSDS ( $r = 0.442$ ;  $p < 0.001$ ). Patients who experienced more itch and/or pain had more sexual distress. Moreover, they had more problems regarding arousal ( $r = -0.239$ ;  $p < 0.001$ ), lubrication ( $r = -0.221$ ;  $p = 0.002$ ), orgasm ( $r = -0.172$ ;  $p = 0.001$ ), satisfaction ( $r = 0.239$ ;  $p = 0.001$ ) and pain ( $r = -0.151$ ;  $p = 0.032$ ).

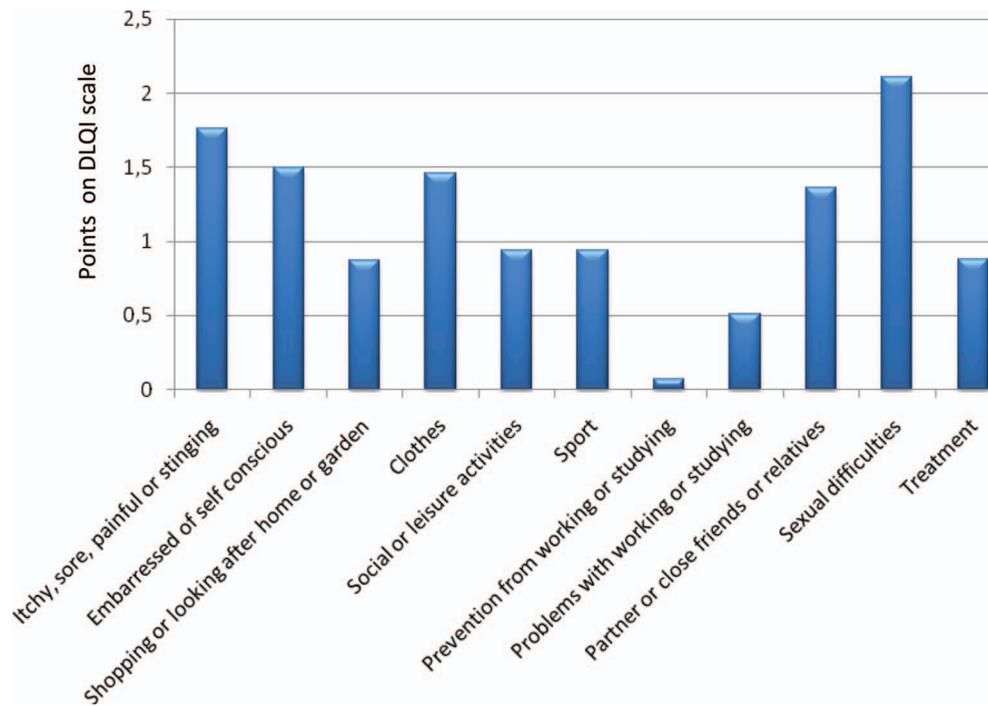


Figure 2. Mean DLQI scores. In total, 212 patients filled in all questions of the DLQI questionnaire.

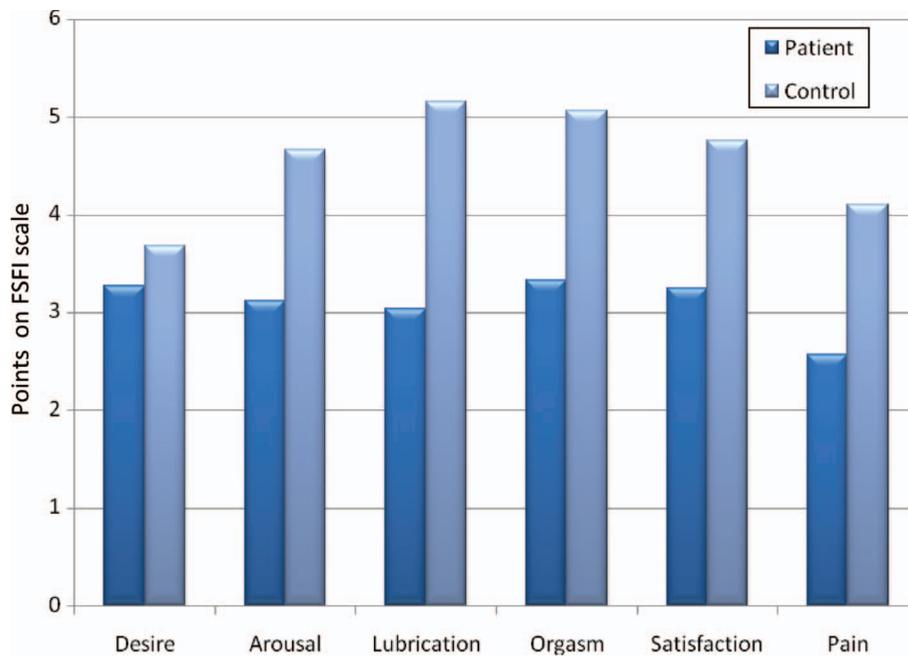


Figure 3. Mean FSFI scores. In total, 187 patients filled in all questions of the FSFI questionnaire. These scores were significantly different from controls on all domains (independent samples Mann-Whitney U test).

Older patients had lower mean scores on the subscales desire ( $r = -0.151$ ;  $p = 0.034$ ), arousal ( $r = -0.241$ ;  $p = 0.001$ ), lubrication ( $r = -0.251$ ;  $p < 0.001$ ), pain ( $r = -0.317$ ;  $p < 0.001$ ) and total score ( $r = -0.246$ ;  $p < 0.001$ ) of the FSFI questionnaire, indicating worse sexual functioning. The age of patients did not correlate with the FSFI scores ( $r = -0.50$ ;  $p = 0.485$ ).

There was no correlation between the amount of itch/pain and desire ( $r = -0.111$ ;  $p = 0.117$ ). Patients who reported to have sexual problems (DLQI question 9) had more sexual distress (total score FSFI) ( $r = 0.624$ ;  $p < 0.001$ ). In patients with LS, the marital status was not associated with sexual functioning (Chi square  $p = 0.596$ ).

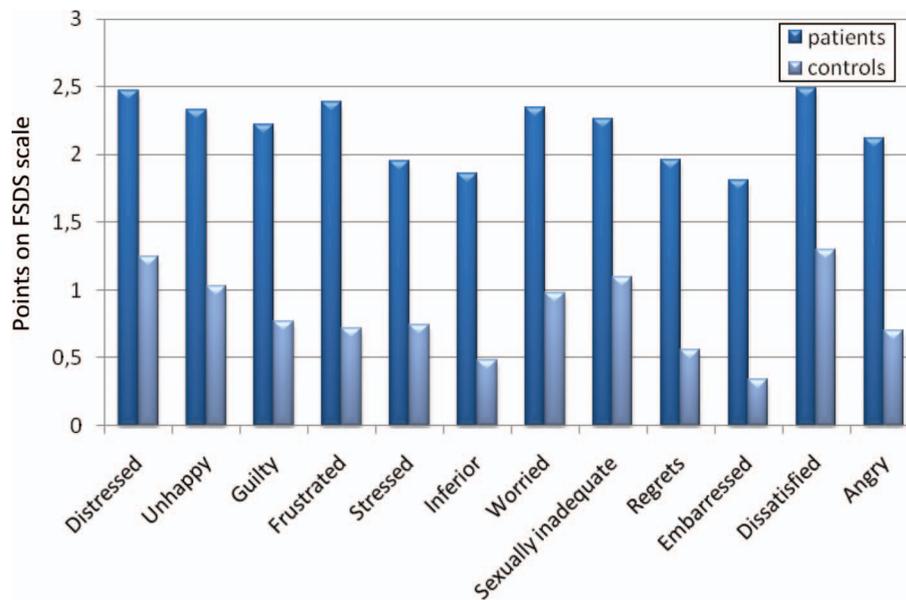


Figure 4. Mean FSDS scores. In total, 206 patients filled in all questions of the FSDS questionnaire. These scores were significantly different from controls on all domains (independent samples Mann-Whitney U test).

## Discussion

In this study, we show that LS has a considerable influence on the QoL and sexual functioning. This influence on sexual functioning causes significant sexual distress. Patients who experience a great impact on their QoL have worse sexual functioning.

Sexual difficulties in patients with LS may be attributed to three main causes for dyspareunia. The skin is sensitive and delicate, which easily tears and may cause superficial dyspareunia. The fear for pain lowers arousal, decreases lubrication and causes the pelvic muscles to contract, which indeed results in dyspareunia. In LS, anatomical changes may also occur, like hooding and burial of the clitoris, labial fusion and introital stenosis, which may make intercourse painful or give rise to problems with achieving orgasms.

In our study, the mean DLQI score was 11.92. Basra et al. [11] performed a review of validation data about the DLQI, which included a myriad of dermatological conditions. These data show that our mean score is comparable to the scores of atopic dermatitis, hyperhidrosis, psoriasis and dermatomyositis sine myositis.

There are several limitations about our study. We had no access to socio-demographic information that may have influenced the sexual functioning of patients. It may be hypothesised that patients suffering from LS may be more anxious or depressive than women in the control group, which may have influenced the results. In addition, only a minority of patients filled in the question: for how long have you had LS? This may be because the LS was set up gradually or that patients did not remember this anymore. Moreover, we did not have a fully matched

control group. Patients with LS and psoriasis may be embarrassed to tell their friends that they suffer of LS/psoriasis or ask them to fill in the questionnaires about sexual dysfunctioning. However, with these 61 control patients, we found highly significant differences between patients with LS and controls. Furthermore, we had a response rate of 58.4% and not all patients completely filled in the questionnaires; 28 patients did not fill in the FSFI, which might be due to the very intimate and personal questions about sexual functioning in this questionnaire. This may introduce a responder bias, because those most bothered by their symptoms are more likely to respond.

This study highlights the need for attention for sexual functioning when treating patients with LS. Treatment (topical corticosteroids) may make a difference in the ability to have intercourse [10]. Fusion of the labia may require simple perineotomy under local anaesthesia. However, in the case of introital stenosis, perineoplasty may be performed with the aim to ameliorate sexual intercourse [18]. No data are available about the use of lubricants, the role of the sexologist or other treatment options. Despite this lack, we often advise our patients to use lubricants to diminish friction with intercourse. When patients are motivated, we also refer them to a sexologist.

In conclusion, we have shown that patients with LS experience an effect on the QoL, especially with sexual functioning. In addition, we have found that sexual functioning is impaired on all the subscales. These difficulties in sexual functioning have led to significant sexual distress. In general, patients who experienced more influence on their QoL had more sexual difficulties, leading to more sexual distress.

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Ethical approval was obtained from the Central Committee on Research inv. Human Subjects.

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### Current knowledge on this subject

- Lichen sclerosis is a chronic skin disorder which mainly causes symptoms of itch and anatomical changes in the vulvar area.
- Probably many patients with LS feel embarrassed and do have sexual problems

### What this study adds

- This is the first study that uses validated questionnaires and a control group to find out what influence LS has on quality of life and sexual functioning.
- Patients with LS experience an effect on the quality of life, especially with sexual functioning. Sexual functioning is impaired on all the subscales, which leads to significant sexual distress.
- Patients who experience more itch and/or pain have more sexual difficulties and more sexual distress.