

Quality of life and sexuality in women with lichen sclerosis

a cross-sectional study

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The Quality of Life and Sexuality in Women with Lichen Sclerosus – A Cross Sectional Study

Running head: The Quality of Life and Sexuality in Women with Lichen Sclerosus – A Cross Sectional Study

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What's already known about this topic

- Few studies describe how lichen sclerosis impacts sexuality.
- Few studies document a potential connection between lichen sclerosis and depression.
- The incidence of lichen sclerosis has increased during recent years, indicating the need for an increased focus on assessment and treatment of this group of patients.

What does this study add?

- This study documents and confirms that women with lichen sclerosis have a high prevalence of sexual difficulties.
- Women with lichen sclerosis experience moderate effect on their general quality of life (QoL).
- 40% of women with lichen sclerosis experience signs of depression.

Summary

Background: Lichen sclerosis (LS) affects the female anogenital area, causing anatomical changes. Reported symptoms include itching, soreness and dyspareunia.

Objective: This cross-sectional study intends to evaluate the quality of life and sexual functioning in women with LS.

Methods: 158 women aged over 18, diagnosed with LS, and referred to North Denmark Regional Hospital from January 2018 to November 2019 were included. The questionnaires 'Female Sexual Function Index (FSFI)', 'Dermatology Life Quality Index (DLQI)', and the 'WHO-5 Well-Being Index' were completed.

Results. The women (mean age 47 years (18–76)) presented a low score on all FSFI scales, with a mean score of 13.83 (95% CI: 12.46;15.20), indicating reduced sexual functioning. The sub-group evaluation scored as follows: Desire 2.32; arousal 2.23; lubrication 2.39; orgasm 2.28; satisfaction 3.02; pain 1.59. The results from DLQI revealed a mean score of 7.88 (95% CI: 7.02;8.74), indicating a moderate effect on the women's everyday life. The mean sub-scores were: Treatment 0.32; sexual difficulties 1.56; relations 1.02; work/study 0.34; sport 0.45; social activities 0.54; clothing 0.89; shopping 0.22; embarrassment 0.99 and itching, soreness and, pain 1.55. The mean score for the WHO-5 Well-Being Index was 56.66 (95% CI: 53.48;59.84) indicating that 40% of the women had signs of depression.

Conclusions. This study concludes that LS has a considerable influence on the sexual functioning and quality of life of women. Health care professionals must not only consider the biological aspects but also the psychological and social aspects.

Introduction

Lichen sclerosus (LS) is a benign chronic progressive dermatologic skin condition characterized by marked inflammation, which primarily affects the anogenital skin.¹⁻⁴ The condition may occur in women of all ages but is predominantly seen in prepubertal girls and in peri- and postmenopausal women.^{1,2} Studies reported an incidence of 22 per 100,000 woman-years, and of 14.6 per 100,000 woman-years.^{5,6} LS often results in significant anatomical changes in the women's vulva, with resorption of the labia minora, hooding and burial of the clitoris.^{4,7} The vulvar skin often becomes thin and tends to crack, and most women complain of itching or burning sensation, irritation, dysuria, and painful defecation or constipation.^{4,7} In women with advanced LS, narrowing of the vaginal introitus may result in painful vaginal penetration, and intercourse can be impossible.^{1,7} All mentioned symptoms may have a negative impact on the women's everyday life, both physically and mentally, and on their quality of life (QoL) in general.^{2,4,7-9} The aim of this study is to evaluate the sexuality, QoL, and signs of depression in women with LS.

Methods

This cross-sectional study was approved by The National Committee on Health Research Ethics (N-20170082) and The Danish Data Protection Agency. The study was applied from January 2018 to November 2019 and included 158 women diagnosed with LS. A specialized nurse informed the women about the project and ensured written informed consent prior to participation.

Participants

Women diagnosed with LS in the outpatient vulvar unit at the Department of Gynecology, Pregnancy, and Childbirth, North Denmark Regional Hospital, were informed about the study. Inclusion criteria involved being over 18 years of age and newly diagnosed with LS. Exclusion criteria were women who could not speak and understand Danish and women with an untreated psychiatric disorder. A gynecologist specializing in vulvar diseases diagnosed the women based on their history and on clinical findings. If the clinical diagnosis was uncertain or dysplasia/carcinoma suspected, biopsies were taken.³

Measures

To describe the women's experience in relation to sexuality, dermatology, and QoL in general, the following three standardized and validated questionnaires were fulfilled by the women; Female Sexual Function Index (FSFI),¹⁰ Dermatology Life Quality Index (DLQI),¹¹ and the WHO-5 Well-Being Index (WHO-5).¹² The women completed the questionnaires electronically using Research Electronic Data Capture (REDCap) tools hosted in the North Denmark Region.¹³

Female Sexual Functioning Index (FSFI)

The FSFI is a self-reporting measure of sexual function that has been validated through a clinically-diagnosed sample of women with female sexual arousal disorder and women with vulvodynia.^{14,15} The questionnaire consists of 19 questions allocated to six domains; sexual desire, sexual arousal, lubrication, orgasm, satisfaction, and pain. The total score ranged from 2–36; a higher score indicates better sexual function. Scores were calculated according to the standards.¹⁶ If a woman reports zero in a score for a particular area, this indicates that the woman had no sexual activity during the past month.¹⁶ A Danish translation of the FSFI questionnaire confirming the original structure of factors was used in this study.¹⁰ The questionnaire had an excellent internal consistency. A study documents that a cut-off score below 26.55 shows the woman has a need for sexual treatment.¹⁷

Dermatology Life Quality Index (DLQI)

The DLQI is a questionnaire with 10 questions used to measure the impact of skin disease on the QoL. It has been validated for dermatology patients.¹⁸ The 10 questions cover the following topics: symptoms,

embarrassment, shopping and home care, clothes, social and leisure time, sport, work or study, partners, close friends or relationships, sexual difficulties, and treatment. The DLQI is calculated by scoring each of the 10 questions with 0–3 points, with a maximum score of 30, in accordance with the guideline.¹¹

The WHO-5 Well-Being Index (WHO-5)

The WHO-5 is a short and generic global rating scale measuring subjective well-being. Each of the 5 areas is scored from 0-5, where 5 is 'all the time' and 0 is 'none of the time'. The raw scores range from 0 (no well-being) to 25 (maximal well-being). Since scales measuring health related QoL are conventionally translated to a percentage scale from 0 (none) to 100 (maximal), it is recommended that the raw score is multiplied by 4. A cut-off score of ≤ 50 on the WHO-5 indicates signs of depression.¹²

Statistical methods

In this cross-sectional study, we presented categorical variables by numbers and percentages and continuous variables with mean scores and ranges when presenting descriptive statistics. We reported population estimates with mean FSFI and DLQI scores, and, corresponding 95% confidence intervals (CI). We presented mean subscale scores using bar charts with a 95% CI. We presented answers to the WHO-5 questionnaire using a stacked histogram displaying the percentage of participants, given each possible answer to the five questions in the questionnaire.

We investigated the associations between both the FSFI score and DLQI score, as well as the demographic and clinical characteristics of the population by creating quartile groups for both scores. We compared differences in demographic and clinical characteristics across the quartile groups with Pearson's chi-square tests and one-way ANOVA. We considered a P-value of below 0.05 as statistically significant in these analyses. No participants had missing data.

All statistical analyses were performed using R version 3.5.1. 21

Results

In total, 158 women with a mean age of 47 years (18–76) were enrolled in this study. Table 1 presents the demographic and clinical characteristics.

The mean score of FSFI was 13.68 (95% CI: 12.46–15.20). As illustrated in Figure 1, the subscales scores were: Pain 1.59 (95% CI: 1.32-1.86), satisfaction 3.02 (95% CI: 2.77-3.27), orgasm 2.28 (95% CI: 1.97-2.59), lubrication 2.39 (95% CI: 2.08-2.70), arousal 2.23 (95% CI: 1.98-2.48), and desire 2.32 (95% CI: 2.14-2.50). As demonstrated, the women's lowest score was for pain, indicating that the women experienced more pain, whereas a low score on the other subscales indicated that the women also experienced lower sexual functioning.

As illustrated in Table 2, the score of FSFI was also presented across the quartile groups:

- Quartile 1: FSFI score 2.0–5.5
- Quartile 2: FSFI score 5.7–12.8
- Quartile 3: FSFI score 12.9–20.7
- Quartile 4: FSFI score 20.8–36.0.

The results document that being older ($p=0.003$), having a partner ($p=0.01$), and being a smoker ($p=0.002$) are factors strongly associated with a low FSFI score.

As described by the FSFI guidelines, women who had not been sexually active within the last four weeks scored zero on some of the questions. The FSFI mean score for the group of women who had been sexually active ($n = 95$) is 18.98 (95% CI: 17.61 – 20.35), while the mean score for the group of women who reported not being sexually active ($n = 63$) in the past four weeks is 6.06 (95% CI: 4.86 – 7.27). In the group of women who were not sexually active, 100% had a score below the cut-off score of 26.55, while in the group of sexually active women, 83% reported a score below 26.55 ($p = 0.0015$). Women with a partner had a mean FSFI score of 14.1 (SD 9.1) and for women without a partner the score was 12.3 (SD 7.0) ($p=0.3484$)

The mean score of DLQI was 7.88 (95% CI: 7.02–8.74), indicating a moderate influence on QoL; the higher the score the higher the influence on QoL.

The results of DLQI are presented in quartile groups:

- Quartile 1: DLQI score 0–3 (no or minimal influence)
- Quartile 2: DLQI score 4–7 (minimal or moderate influence)
- Quartile 3: DLQI score 8–12 (moderate or significant influence)
- Quartile 4: DLQI score 13–25 (significant or very significant influence)

The results document a younger age ($p=0.007$) and having a partner ($p=0.05$) as factors strongly associated with a significant or very significant influence on the QoL measured with DLQI. Signs of depression measured with WHO-5 ($p\leq 0.0001$) are also associated with a high DLQI score.

The mean score of WHO-5 was 56.66 (95% CI: 53.48–59.84), and 62 (39%) of the women scored ≤ 50 in the WHO-5, indicating signs of depression. Figure 3 illustrates the answers to each of the five questions in WHO-5.

Discussion

The purpose of this study was to investigate the QoL, sexuality, and signs of depression in women with LS. This study documented that women newly diagnosed with LS experienced a considerable impact on their sexual functioning, and a moderate impact on their QoL. Furthermore, 40% of the women had signs of depression.

The present study showed that women with LS revealed a FSFI mean score of 13.68. One study reports a FSFI mean score of 18.79 and another study with women diagnosed with LS or lichen planus scored 17.0 on the FSFI. None of the studies define whether sexually inactive women were included, which has a high impact on the FSFI score.^{7,9} This study demonstrates a relatively low FSFI score compared to the studies mentioned above. A possible reason for this may be the inclusion of women who had not been sexually active within the last four weeks.

In this study 83% (n=79) of sexually active women reported a FSFI score below 26.55, indicating a need for sexual treatment. In a Danish population survey including 20,526 sexually active women, 20% of the women reported a FSFI-6 ≤ 19 , indicating a need for sexual treatment.¹⁹ The FSFI measures sexual functioning in women and has been used to assess the effects of several interventions in women with Female Sexual Dysfunction, but recent studies pointed out that the FSFI may need to be corrected so that non sexually active women are excluded.^{17,20,21}

The mean score of the DLQI was 7.68, indicating a moderate effect on the QoL, but 47% (n=64) of women reported a moderate to very significant influence on their QoL. A study evaluating QoL with DLQI in women with LS reported a score of 11.92, indicating a very significant effect.⁷ This study also reports that the women in the study had the highest mean score on the area concerning sexual difficulties, which is confirmed by the present study.⁷

This study documents that 40% of the women with LS had signs of depression. The results in this study confirm those of a study including postmenopausal women with LS, documenting a 49% prevalence of depressive symptoms.²² A Danish population survey from 2017 documents that 15.5% of Danish women experience that their mental well-being is affected.²³

A strength of this study is that all the women answered all questions, including not only socio-demographic questions but also all questions relating to the FSFI, DLQI, and WHO-5. This was enabled due to the need to answer all questions in REDCap to complete the survey.

There are some limitations within this study. The number of women and their characteristics, as well as their declining participation are not reported. It is well known that women with LS often have symptoms for several years before they are diagnosed which may influence the results, but information about possible delay of diagnosis is not reported.^{1-3,24} A further limitation is that this study did not measure sexually-related personal distress. This measure is needed for a diagnosis of female sexual dysfunction; therefore, the results in this study described sexual difficulties and not sexual dysfunction.²⁵ The severity of the disease was not measured for the purposes of this study, and this may have influenced the responses of the questionnaires.

WHO-5 has not previously been used to report on women with LS. According to the results of WHO-5, as well as the results of this study, in general, using a control group of healthy women would have been a strength.

Conclusion

The results of this study highlight that women with LS have a high prevalence of sexual difficulties, moderate effect on their QoL in general, and that a relatively large group, 40%, experience signs of depression. The study confirms the recommendations in the European guideline for the management of vulvar conditions, 'Sexual dysfunction should be considered in all patients, either as the cause of the symptoms or developed secondary to the symptoms, and assessed if appropriate'.³ Knowledge is needed about the effect of offering sexual treatment of women with LS.

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Figure Legends

Figure 1. Results of Scores of Female Sexual Functioning Index subscales (FSFI) (0–6 point scales)

Figure 2. Results of Dermatology Life Quality Index (DLQI) subscale scores.

Figure 3. Percentage distribution of answers to the WHO-5 questionnaire

Table 1 Demographic and clinical characteristics.

	N=158
Age, mean (range)	47 (18–76)
Waistlines, mean (range)	87 (64–114)
Relationship status	
Having a partner	132 (84%)
Employment	
Employed	93 (59%)
Retired	35 (22%)
Student	19 (12%)
Other	11 (7%)
Education	
High school or less	38 (30%)
College or associate degree	30 (19%)
Bachelor's degree or higher	79 (50%)
Other	1 (1%)
Smokers or former smokers	62 (39%)
Alcohol	
More than 7 units	16 (10%)
FSFI	
< cut-off score at 26.55	142 (90%)

Depressive symptoms

WHO-5 < 50 62 (39%)

Comorbidity

Thyroid disease 25 (16%)

Immuno-inflammatory disease 48 (30%)

^a Data are presented as n (%) unless otherwise indicated.

Table 2 Comparison of FSFI quartile 1, 2, 3, and 4.

	Quartile 1: FSFI 2.0-5.6 (n=39)	Quartile 2: FSFI 5.7-12.8 (n=40)	Quartile 3: FSFI 12.9-20.7 (n=39)	Quartile 4 FSFI 20.8-36.0 (n=40)
Age, mean (range)	53.5 (21–73)	47.8 (19–76)	41.1 (28–76)	45.1 (18–74)**
Waistlines, mean (range)	88.9 (64–110)	87.4 (65–114)	82.8 (71–109)	87.7 (63–104) ^{NS}
Relationship status				
Having a partner	36 (92%)	27 (68%)	35 (90%)	34 (85%)**
Employment				
Employed	25 (64%)	22 (55%)	23 (59%)	23 (58%) ^{NS}
Retired	12 (31%)	11 (28%)	4 (10%)	8 (20%) ^{NS}
Student	0 (0%)	5 (13%)	7 (18%)	7 (18%) ^{NS}
Other	2 (5%)	2 (5%)	5 (13%)	2 (5%) ^{NS}
Education				

High school or less	10 (26%)	11 (28%)	15 (38%)	12 (30%) ^{NS}
Some college or associate degree	11 (28%)	11 (28%)	6 (15.4%)	2 (5%) ^{NS}
Bachelor's degree or higher	18 (46%)	18 (45%)	17 (44%)	26 (65%) ^{NS}
Other	0 (0%)	0 (0%)	1 (3%)	0 (0%) ^{NS}
Smokers or former smokers	22 (56%)	15 (38%)	10 (26%)	14 (35%) ^{**}
Alcohol				
7 units or less	34 (87%)	36 (90%)	37 (95%)	35 (88%) ^{NS}
More than 7 units	5 (13%)	4 (10%)	2 (5%)	5 (13%) ^{NS}
Depression				
WHO5 < 50	16 (41%)	16 (40%)	20 (51%)	10 (25%) ^{NS}

*= ≤ 0.05 ; **= ≤ 0.01 ; ***= ≤ 0.001 ; NS=none significant

Table 3 Comparison of patients who were not sexually active in the last 4 weeks and who were sexually active in the last four weeks (based on answers to the FSFI questionnaire)

	Sexually active (n=95)	Not sexually active (n=63)	P-value
Age, mean (range)	42.9 (18-73)	52.8 (19-76)	<0.001

Waistlines, mean (range)	84.9 (63-110)	89.5 (69-114)	0.01
Relationship status			
Having a partner	87 (92%)	45 (71%)	0.002
Employment			
Employed	57 (60%)	36 (57%)	0.049
Retired	15 (16%)	20 (32%)	
Student	16 (17%)	3 (5%)	
Other	7 (7%)	4 (6%)	
Education			
High school or less	28 (30%)	20 (32%)	0.48
College or associate degree	16 (17%)	14 (22%)	
Bachelor's degree or higher	49 (52%)	29 (46%)	
Other	1 (1%)	0 (0%)	
Smokers or former smokers	31 (33%)	30 (48%)	0.08
Alcohol			
7 units or less	88 (93%)	54 (86%)	0.25
More than 7 units	7 (7%)	9 (14%)	
FSFI			
Mean (SD)	19.0 (6.8)	6.1 (4.9)	<0.001
DLQI			
Mean (SD)	8.3 (5.6)	7.2 (5.2)	0.22

Depression

WHO5 < 50

35 (37%)

27 (43%)

0.55

Table 4. Comparison of DLQI quartile 1, 2, 3, and 4

	Quartile 1:	Quartile 2:	Quartile 3:	Quartile 4:
	DLQI 0-3 (n=45)	DLQI 4-7 (n=39)	DLQI 8-12 (n=45)	DLQI 13-25 (n=29)
Age, mean (range)	53.4 (19–76)	45.6 (20–76)	44.0 (22–69)	42.9 (18-74)**
Waistlines, mean (range)	88.2 (65–110)	86.5 (63–114)	87.5 (65–109)	83.4 (64-104) ^{NS}
Relationship status				
Having a partner	33 (73%)	36 (92%)	36 (80%)	27 (93%)*
Employment				
Employed	27 (60%)	24 (62%)	26 (58%)	16 (55%) ^{NS}
Retired	10 (22%)	6 (15%)	12 (27%)	7 (24%) ^{NS}
Student	5 (11%)	5 (13%)	4 (9%)	5 (17%) ^{NS}
Other	3 (7%)	4 (10%)	3 (7%)	1 (3%) ^{NS}
Education				
High school or less	13 (29%)	7 (18%)	18 (40%)	10 (34%) ^{NS}
Some college or associate degree	7 (16%)	7 (18%)	12 (27%)	7 (24%) ^{NS}
Bachelor's degree or higher	25 (55%)	25 (64%)	18 (40%)	11 (38%) ^{NS}
Other	0 (0%)	0 (0%)	0 (0%)	1 (3%) ^{NS}
Smokers or former smokers	21 (47%)	16 (41%)	14 (31%)	10 (34%) ^{NS}

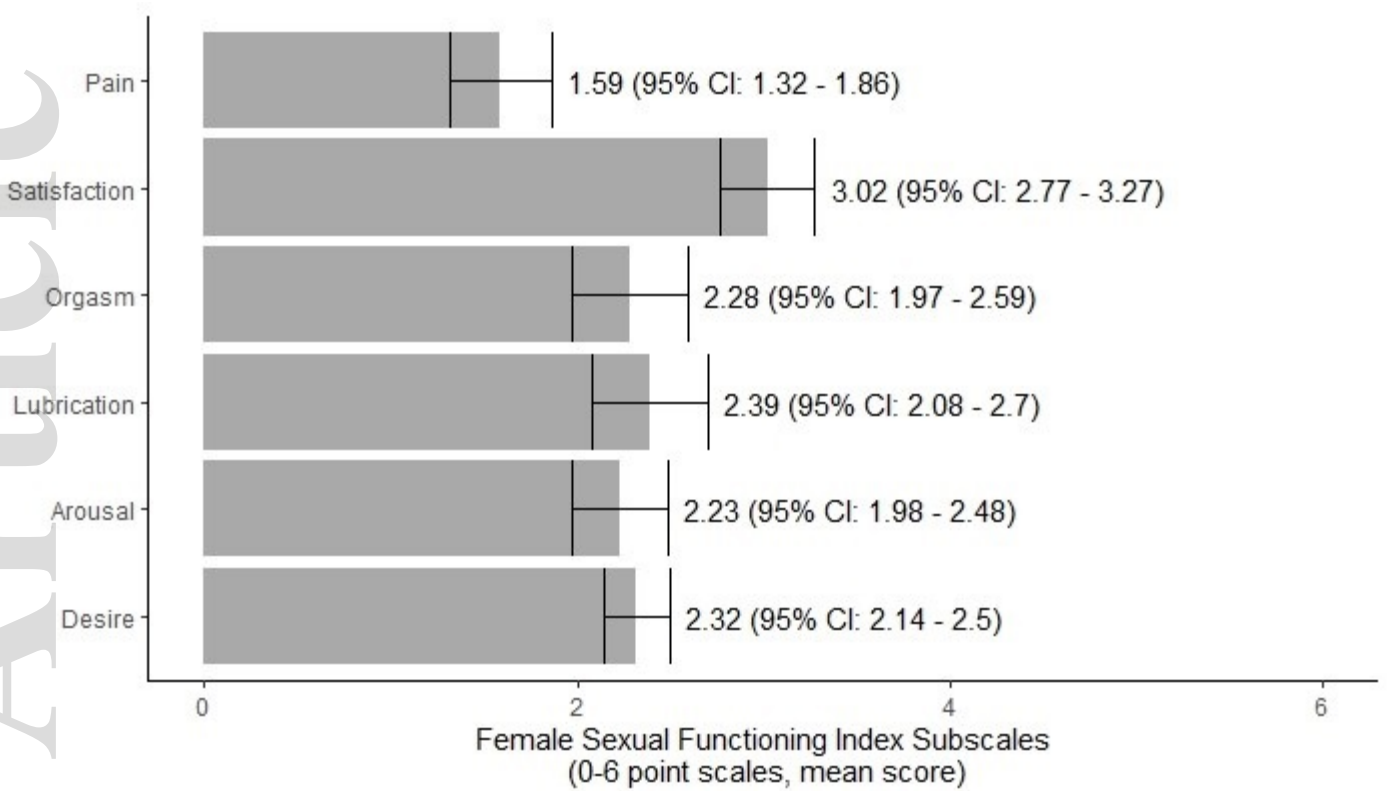
Alcohol

7 units or less	37 (82%)	35 (90%)	44 (98%)	26 (90%) ^{NS}
More than 7 units	8 (18%)	4 (10%)	1 (2%)	3 (10%) ^{NS}

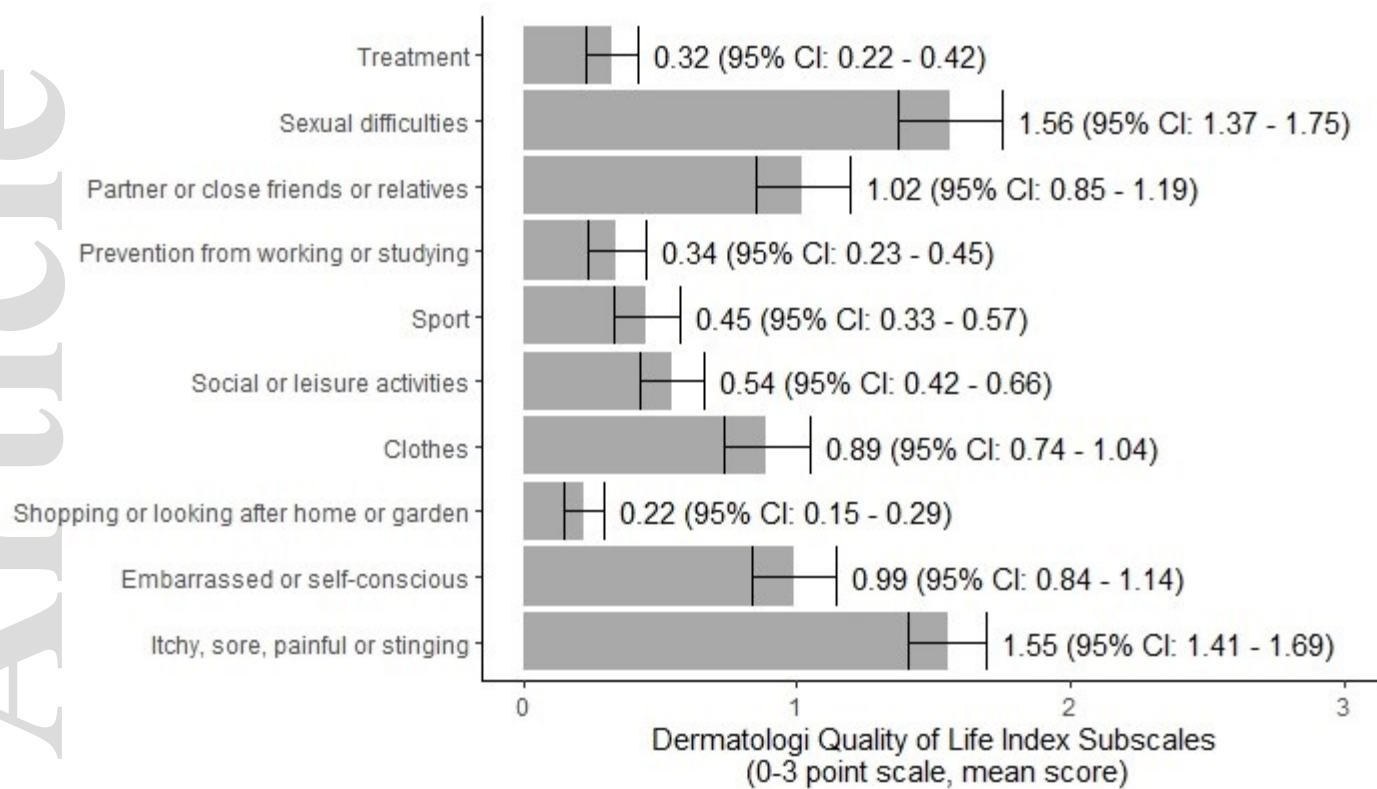
Depression

WHO5 < 50	10 (22%)	10 (26%)	21 (47%)	21 (72%) ^{***}
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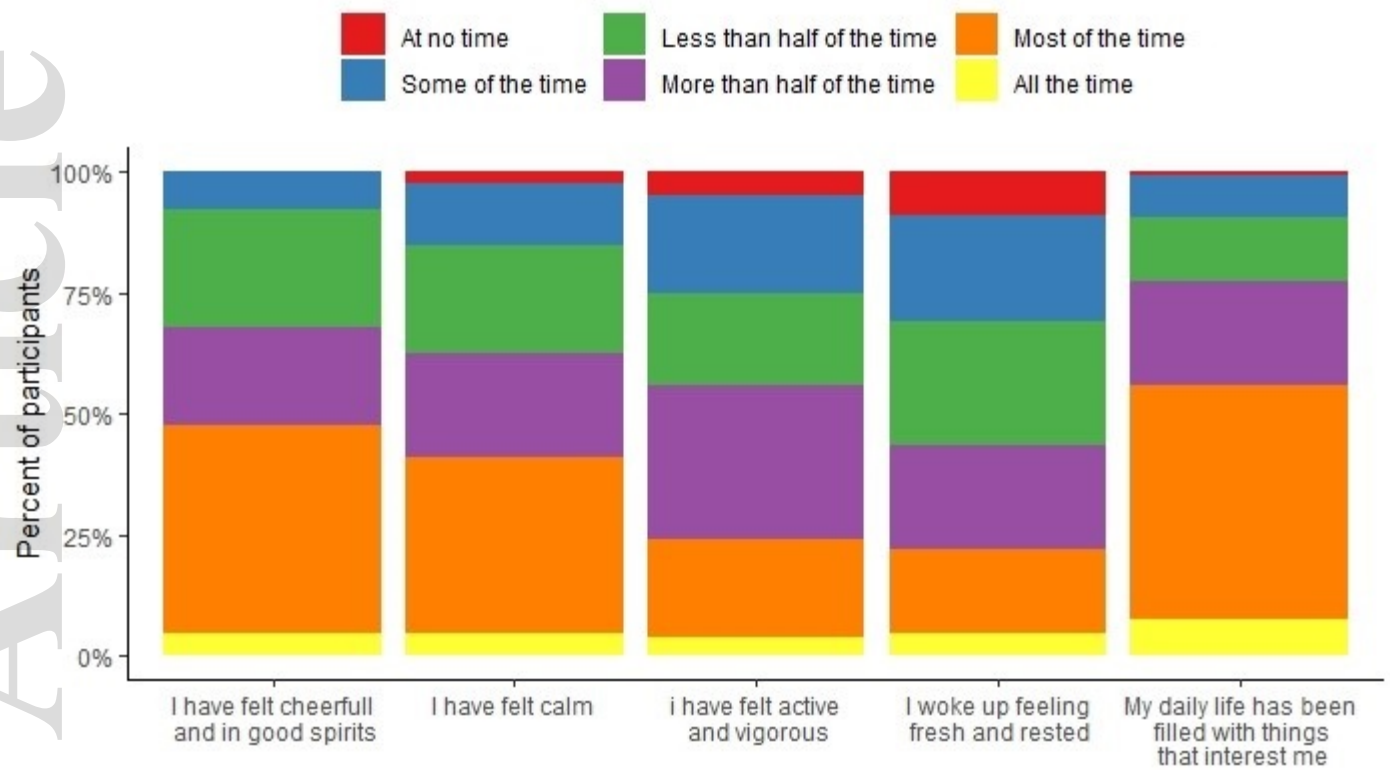
Groups are of uneven size as many participants have similar scores (ties). In this case, participants are placed in the group with the lowest DLQI score. For example, a total of 14 patients had a DLQI score of 12 and were placed in the third quartile group, making the sum of participants in the fourth quartile group smaller. *= ≤ 0.05 ; **= ≤ 0.01 ; ***= ≤ 0.001 ; NS=none significant.



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