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Sexual Distress and Quality of Life in Women With Genital Erosive Lichen Planus—A Cross-sectional Study

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Objective: The study aimed to assess sexual distress and quality of life in women with moderate-to-severe genital erosive lichen planus (GELP).

Materials and Methods: Thirty-six women with GELP were recruited at the Oslo University Hospital in Norway. The diagnosis was confirmed by a dermatologist with experience in vulvovaginal disease and based on characteristic clinical changes in the vulva and/or vagina, and biopsy results if available. Clinical severity was measured using the GELP score with a score ≥5 required for inclusion. Sexual distress was measured using the revised Female Sexual Distress Scale (FSDS-R), and quality of life was measured using the Dermatology Life Quality Index (DLQI). Topical steroid treatment was allowed.

Results: The mean FSDS-R score was 22.7 (range 0–45) with 27 women reporting high scores for sexual distress (FSDS-R score >15). The mean DLQI score was 8.8 (range 1–19) with 15 women reporting a moderate impact (DLQI score 6–10), and 12 women reporting a very large impact (DLQI score 11–20) of GELP on their quality of life. No clear correlations were found between disease severity assessed by GELP scores and FSDS-R or DLQI scores. Age was not correlated with FSDS-R or DLQI scores.

Conclusions: These results demonstrate that a substantial number of women with GELP experience sexual distress and a reduced quality of life.

Key Words: vulva, vagina, lichen planus, sexual health, quality of life

(*J Low Genit Tract Dis* 2025;29: 72–75)

Lichen planus is an inflammatory cutaneous and mucosal disease. Genital involvement in women is often chronic and presents in adult women, with the erosive form being the most common subtype. Genital erosive lichen planus (GELP) is characterized by vulvar and vaginal inflammation, erosions, scarring, and synechiae, with resorption of the labia minora, narrowing of the introitus, and obliteration of the vagina as potential complications.[1] GELP causes symptoms such as pain, burning, itching, vaginal discharge, and bleeding and may lead to severely impaired sexual function.[2–6] Its general prevalence is not known, but in 2 separate studies, genital lichen planus was reported in 8.8%[7] and approximately 7%[8] of women attending vulvar clinics. Most gynecologists, dermatologists, and general practitioners have limited experience with this potentially disabling disease. The effects of present treatment options are unsatisfactory and poorly documented.[5]

Using different questionnaires, several genital inflammatory skin diseases have been described as causing sexual distress and reduced quality of life in women.[9,10] A limited number of studies have included women with GELP, and to the best of our knowledge, none have assessed sexual distress and quality of life relative to disease severity.

The objective of this study was to explore the psychosocial impact of GELP in women by assessing its impact on sexual distress and quality of life.

METHODS

Women with GELP were recruited from August 2019 to November 2022, primarily from the Vulva Clinic at Oslo University Hospital, Norway, a specialized clinic for women with vulvar disease, with referrals from gynecologists and dermatologists in southeast Norway. The study was approved by the Regional Committee for Medical and Health Research Ethics, South East Norway (#2018/1841), and was performed in accordance with national and international guidelines. Signed informed consent was obtained from all participants.

A dermatologist with special expertise in vulvovaginal disease examined all women. The diagnosis of GELP was based on characteristic clinical findings and, for some women, supported by histopathological findings. The severity of GELP was measured using the GELP score, a clinical scoring system developed for a randomized clinical trial of vulvovaginal photodynamic therapy in GELP.[11] In this scoring system, the size of the affected area, degree of erythema, number of erosions, degree of (Wickham's) striae, and degree of patient-reported pain in the vulva and vagina were scored from 0 to 3, giving a total score of up to 30.

Excluding women with mild GELP, based on a clinical assessment, women with moderate or severe GELP (total GELP score ≥5) and aged 18 years or older were invited to participate in a randomized controlled trial on the use of apremilast, a phosphodiesterase-4 inhibitor.[12] Treatment with topical corticosteroids was allowed at inclusion

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The authors have declared they have no conflicts of interest.

All authors have approved the manuscript and submission.

Sources of financial support and role of the funding source: This investigator-initiated study was sponsored by the Oslo University Hospital and the Norwegian Research Centre for Women's Health. Oslo University Hospital is responsible for the study. It was supported by funds from Celgene (from May 2020, Amgen). Celgene/Amgen provided the study medication and the funds received covered part of the expenses for data collection and monitoring, clinical visits, phone interviews, pharmacy services and immunohistochemical analyses in the AP-GELP Study.

Celgene/Amgen had no role in the study design; in the actual collection, management, analysis, or interpretation of data; in the writing of the report; or in the decision to submit the article for publication.

The corresponding author had the final authority in submitting the manuscript for submission.

Review board status: All medical and health research projects in Norway must be preapproved by the Regional committees for medical and health research ethics. Regional Committee for Medical & Health Research Ethics, Section B, South East Norway, approved the research project "THE AP-GELP Study: A randomized, placebo-controlled clinical trial on the effects of phosphodiesterase 4-inhibitor apremilast in female genital erosive lichen planus", of which this study is a part, on March 4, 2019 (#2018/1841).

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site (www.jlgtd.com).

DOI: 10.1097/LGT.0000000000000847

TABLE 1. Data on 36 Women With GELP and Their Responses to the FSDS-R and DLQI Questionnaires

Age, years, mean (median; range)	**57.4 (59; 38–75)**
No. women with extragenital lichen planus	
Oral	24
Cutaneous	4
Other[a]	4
GELP score[b,c] mean (median; range)	14.2 (14; 10–21)
Vulva subscore	8.2 (8; 2–12)
Vagina subscore[c]	6.1 (7; 0–13)
FSDS-R score, mean (range)	22.7 (0–45)
No. women with FSDS-R score	
≥15	27
DLQI score, mean (range)	8.8 (1–19)
No. women with DLQI score	
≤5	9
6–10	15
11–20	12

[a]Tear duct, scalp, ear, and/or lip.

[b]A clinical scoring system based on the size of the affected area, degree of erythema, number of erosions, degree of striae, and patient-reported pain.

[c]Excluding 1 woman with vulvar subscore only.

DLQI, Dermatology Life Quality Index; FSDS-R, Female Sexual Distress Scale-Revised; GELP, genital erosive lichen planus.

and during the study period. Women reporting a concurrent or recent history of depressive symptoms, depression, suicidal ideation, use of antidepressants, or having a score >7 on the General Health Questionnaire-28,[13] indicating possible psychological disorders, were not included out of concern for potential adverse psychiatric effects of the medication during the trial. Data in this cross-sectional substudy was collected before the intervention.

Sexual distress was measured using the Norwegian-translated Female Sexual Distress Scale-Revised (FSDS-R).[14] This validated 13-item questionnaire assesses sex-related personal distress in women. Each item is scored from 0 to 4 points, with a maximum total score of 52, and with higher scores indicating a higher level of sexual distress.[15] In a 12-item version (FSDS) of the questionnaire, a total score of 15 has been recommended as a cutoff for sexually related distress.[15] Missing data were handled by imputation based on the responses from the same respondent.

Quality of life was measured using the Dermatology Life Quality Index (DLQI),[16] translated into Norwegian.[17] The DLQI is a validated 10-item questionnaire covering different aspects of health-related quality of life in patients with dermatological diseases and is widely used in both clinical practice and research. The score for each item ranges from 0 to 3, with a maximum total score of 30. A score of 6–10 is considered to indicate a moderate impact on quality of life, 11–20 a very large impact, and 21–30 an extremely large impact on quality of life.[18] In the present study, women with extragenital lichen planus or other skin diseases were asked to complete the questionnaire based only on genital involvement. The FSDS-R and DLQI were completed electronically by the participants, using the ViedocMe (Viedoc 4) system, with an optional paper version, in conjunction with a clinical visit.

We hypothesized that sexual distress and reduced quality of life in women with GELP was associated with age and disease severity. The number of participants was based on a power calculation for the randomized controlled trial, as described in a separate article.[12] Data were analyzed using Stata/SE 17.0 for Windows (StataCorp LLC, College Station, TX). Correlations between the FSDS-R, DLQI, and GELP scores, as well as with age, were analyzed using Pearson's correlation test. The level of significance was set to $p < .05$.

RESULTS

Thirty-six women were included in this analysis. All items in the DLQI questionnaires were completed, and four patients did not answer one of the 13 FSDS-R items. The mean age was 57.4 years (range 38–75 years). The mean GELP score was 14.2 (range 10–21) (see Table 1). All women had vulvar involvement of GELP, and 33 had both vaginal and vulvar involvement. One woman declined the vaginal examination.

The mean FSDS-R score was 22.7 (range 0–45), with 27 women having an FSDS-R score of ≥15 (Table 1). Items on distress about sexual life, frustrations caused by sexual problems, feeling sexually inadequate, regrets about sexuality, and dissatisfaction with sex life, had the highest mean scores (Supplementary Table 1, http://links.lww.com/LGT/A373).

The mean DLQI score was 8.8 (range 1–19) (Table 1). Fifteen women had a DLQI score of 6–11 indicating a moderate impact of GELP on quality of life. Twelve women had DLQI scores of 11–20 indicating a very large impact of GELP on quality of life. Items on itching/soreness/pain/stinging, problems with partners/close friends/relatives, and sexual difficulties had the highest mean scores (Supplementary Table 2, http://links.lww.com/LGT/A374).

Moderately positive (r = 0.54) and significant ($p < .001$) correlations were found between the FSDS-R and DLQI scores. No significant correlations were found between GELP scores and FSDS-R and DLQI scores, except for the mean vaginal GELP subscore and mean

TABLE 2. Correlation Between FSDS-R, DLQI, GELP Score, and GELP Subscores for Vulva and Vagina in 36 Women With GELP

Measure	**FSDS-R**	**DLQI**	**GELP total**	**GELP vulva**	**GELP vagina**
FSDS-R	-				
DLQI	**r = 0.543,[a]** $p < .001$	-			
GELP total	r = −0.299, $p = .081$	r = −0.232, $p = .179$	-		
GELP vulva	r = 0.010, $p = .954$	r = 0.264, $p = .120$	r = 0.262, $p = .129$	-	
GELP vagina	r = −0.287, $p = .095$	**r = −0.405**, $p = .016$	**r = 0.750**, $p = .000$	**r = −0.442**, $p = .008$	-

[a]Correlation coefficients in bold are significant ($p < .05$).

DLQI, Dermatology Life Quality Index; FSDS-R, Female Sexual Distress Scale-Revised; GELP, genital erosive lichen planus.

DLQI score, which showed a moderate negative correlation (Table 2). Age was correlated with neither FSDS-R nor DLQI scores.

DISCUSSION

In this study of 36 Norwegian women with moderate-to-severe GELP, 27 women had scores on validated questionnaires indicating sexual distress and reduced quality of life. The results showed no clear correlation with age or severity of GELP as assessed by a physician.

Our findings add to those of a limited number of studies that included women with GELP. The study settings differ, making a true comparison difficult. In a study of 77 women attending a specialized vulva clinic in New Zealand, 17 women with GELP had a mean DLQI score of 7.18,[19] which is somewhat lower than the findings of our study. In that study, 10 women with GELP had a mean FSDS (12-item version) score of 23.6, indicating sexual distress. In a German study of 24 women with vulvar lichen planus, of whom 15 had GELP, the mean DLQI score was 8.4, which was marginally lower than our results, with no significant improvement with treatment.[20] In another German study of both men and women, those with genital lichen planus had a significantly higher mean DLQI score (8.68) than those with extragenital lichen planus alone (5.01).[21]

Several studies have been performed using the FSDS/FSDS-R and DLQI in women with other and more common genital inflammatory diseases, such as lichen sclerosus and genital psoriasis, as shown in Table 3.[19–27] The mean DLQI and FSDS-R scores in the present study were generally higher than or comparable to those in other studies, although some reports had higher scores in women with lichen sclerosus.

In the present study, in which all participants were older than 37 years, sexual distress and reduced quality of life in women with GELP were not related to age. This is in contrast to a study using the Vulvar Quality of Life Index, in which women with vulvar disease, including lichen planus, had scores indicating a moderate or large impact on their quality of life, but with lower scores, indicating less impact, in older women.[28] The authors suggest that the conditions most prevalent in younger patients may be more symptomatic and that older women may be less sexually active and more accepting of chronic disease as possible explanations for the age-related difference.[28] In addition, sexual function may be more important in younger women, and the psychological impact of chronic disease might decrease over time as women adapt to the symptoms. However, in older women concurrent genital postmenopausal symptoms, the protracted course of GELP and unsatisfactory treatment response may adversely affect quality of life.

A relatively high mean FSDS-R score does not prove a causal relationship between GELP and sexual distress, as sexual distress may be caused by factors other than genital diseases in both younger and older women.

The negative association between the mean vaginal GELP subscore and the DLQI score in our study is difficult to explain. Extensive vaginal involvement often implies that intercourse is impossible.[6] This did not seem to affect the quality of life of some women. Vaginal involvement, such as stenosis, may be definite and, for some women, lead to acceptance of the limitations of sexual practice. In contrast to vaginal involvement, vulvar lesions are visible and often cause pain during the activities of daily living. Therefore, vulvar involvement may be of more concern than vaginal involvement and its symptoms.

We assume that both the FSDS-R and DLQI scores would have been higher if patients with possible depressive symptoms were not excluded. Studies have reported depressive symptoms in women with lichen planus, including genital involvement.[21,29] The results of the current study suggest that clinicians should be aware of the psychological impact of GELP, even in women without a diagnosis or symptoms of depression.

Strengths and Limitations

The number of women with GELP in this study was low, but still higher than in most other studies on GELP. This reflects the low prevalence of the disease.[2] The GELP scoring system for disease severity includes several recognized features of GELP and has previously been used in a randomized clinical trial; however,

TABLE 3. FSDS, FSDS-R, and DLQI Scores in Studies on Sexual Distress and Quality of Life in Women With Genital Skin Disease

First author	Condition	Patients, *n*	FSDS or FSDS-R, mean (SD if available)	DLQI, mean (SD if available)
Current study	Genital erosive lichen planus	36	22.7 (12.7), FSDS-R	8.8 (4.6)
Cheng[19]	Genital erosive lichen planus	17		7.18 (6.21)
		10	23.6 (12.83), FSDS	
Boch[20]	Vulvar lichen planus	24		8.4 (5.5)
Fiocco[21]	Genital lichen planus	31.6% of 100[a]		8.68 (6.96)[b]
Cheng[19]	Genital lichen sclerosus	48		3.79 (4.98)
		24	18.17 (13.95), FSDS	
Van de Nieuwenhof[22]	Genital lichen sclerosus	212		11.92 (6.18)
		206	26.08 (11.81), FSDS	
Vittrup[23]	Genital lichen sclerosus	158		7.88
Burrows[24]	Genital lichen sclerosus	36	29 and 27, FSDS[c]	
Meeuvis[25]	Genital psoriasis	172		8.5 (6.5)[b]
		59	16.1 (12.1), FSDS	
da Silva[26]	Anogenital psoriasis	245		9.02 (7.11)
Yi[27]	Genital psoriasis	17	20.7, FSDS-R	
		115		8.8[b]

[a]Exact number of patients not given by the authors.

[b]Men and women.

[c]Baseline scores in 2 different intervention groups.

DLQI, Dermatology Life Quality Index; FSDS, Female Sexual Distress Scale; FSDS-R, Female Sexual Distress Scale-Revised.

it has not been formally validated.[11] We cannot exclude possible correlations with GELP severity and/or age if women with mild GELP and younger women had been included. Vaginal wet mount was not performed as part of this study.

We used validated questionnaires on female sexual distress and quality of life related to dermatological diseases. There were very few missing items in the FSDS-R, and none in the DLQI forms, possibly due to the use of electronic forms via smartphones. The duration of the disease was not recorded, but this may be difficult to estimate as many women have genital symptoms for years before they are diagnosed with GELP. We did not systematically record whether the participants had intimate relationships. Some women reported during the clinical interview that GELP made them reluctant to engage in intimate relationships, or that they avoided intimacy with an existing or potential partner. We did not include patients with possible depressive symptoms.

The DLQI questionnaire does not specifically address genital diseases, but many of its items are relevant to GELP, both in research and clinical practice. Interestingly, the scores on the DLQI items concerning symptoms, relationships, and sexuality were the highest. More specific quality of life questionnaires, such as the validated Vulvar Quality of Life Index, may provide more precise tools to evaluate the quality of life in women with vulvar disease.[28,30]

Ideally, our study would have included an age-matched control group of women without genital skin diseases.

CONCLUSIONS

This report demonstrates that women with GELP experience sexual distress, and that the disease has a substantial impact on their quality of life, even in women without symptoms of depression. This seems to be independent of age and not correlated to disease severity. Further research should focus on clinical interventions that may reduce sexual distress and improve quality of life in women with GELP.

ACKNOWLEDGMENTS

The authors would like to thank the women who participated in the study.

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