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Dolna 17, Warsaw,
Poland 00-773
+48 226 0 227 03
editorial_office@rsglobal.pl

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VULVAR LICHEN SCLEROSUS IN WOMEN - THE IMPACT ON QUALITY OF LIFE, SEXUAL AND MENTAL HEALTH

Agata Nowacka *(Corresponding Author, Email: agata.nowacka5@wp.pl)*
Józef Struś Multi-Specialist Municipal Hospital, Szwajcarska 3, 61-285, Poznań, Poland
ORCID ID: 0009-0007-8623-1406

Marika Gutowska
Józef Struś Multi-Specialist Municipal Hospital, Szwajcarska 3, 61-285, Poznań, Poland
ORCID ID: 0009-0004-8297-5465

Zuzanna Tomaszewska
Praski Hospital in Warsaw, 67 Solidarności Avenue, 03-401 Warsaw, Poland
ORCID ID: 0009-0002-1697-0514

Anna Zielińska
Czerniakowski Hospital, Stępińska 19/25, 00-739 Warsaw, Poland
ORCID ID: 0009-0007-6761-388X

Julia Ciechanowicz
University Clinical Hospital in Poznan, 1/2 Dluga Street, 61-848 Poznan, Poland
ORCID ID: 0009-0002-9100-7867

Aleksandra Przybylska
Józef Struś Multi-Specialist Municipal Hospital, Szwajcarska 3, 61-285, Poznań, Poland
ORCID ID: 0000-0002-5210-3277

Stanisław Ciechanowicz
University Clinical Hospital in Poznan, 1/2 Dluga Street, 61-848 Poznan, Poland
ORCID ID: 0000-0003-0191-1618

Piotr Kupidłowski
Poznan University of Medical Sciences, 70 Bukowska Street, 60-812 Poznan, Poland
ORCID ID: 0000-0003-1642-6236

Adrianna Perzanowska
Praski Hospital in Warsaw, 67 Solidarności Avenue, 03-401 Warsaw, Poland
ORCID ID: 0009-0001-3621-6482

Julia Dura
The Provincial Hospital in Poznan, Juraszów 7/19, 60-479 Poznań, Poland
ORCID ID: 0009-0004-6972-1540

ABSTRACT

Objective: Vulvar Lichen Sclerosus (VLS) is a chronic, inflammatory dermatosis that affects women. Physical symptoms and their treatment are well-documented, while the psychological impact requires further research. This review aims to summarize the current state of knowledge about quality of life, sexual health, and mental health amongst women with VLS.
Methods: PubMed and ScienceDirect were systematically searched for studies published between 2014 and 2024. Inclusion criteria focused on original research assessing quality of life, sexual function, depression, or anxiety in women diagnosed with VLS. Studies not in English or Polish, lacking full-text availability, or without original data were excluded. Data was extracted and synthesized narratively.
Key Findings: Vulvar lichen sclerosus (VLS) significantly affects women's quality of life, particularly in domains related to sexual and psychological well-being. Common challenges include diminished self-worth, decreased relationship satisfaction, and a higher presence of depressive symptoms. Anxiety is also frequently reported. In the most advanced cases, patients declared suicidal ideation. Women with VLS experience feelings of isolation and shame, often turning to online forums for information and emotional support.
Conclusion: VLS has an impact on psychological and sexual function, mental health, and quality of life. This review emphasizes the importance of recognizing and addressing psychological impairments in conjunction with physical symptoms and the need for a multidisciplinary strategy in the management of VLS. Further research needs to focus on the psychological and sexual aspects of lichen sclerosus in women.

KEYWORDS

Vulvar Lichen Sclerosus, Quality of Life, Mental Health, Sexual Health, Sexual Dysfunctions, Psychological

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Introduction.

Vulvar Lichen Sclerosus (VLS) is a chronic inflammatory dermatosis affecting the superficial dermis of the female anogenital region (De Luca et al., 2023). The etiology of VLS remains unknown; however, three main theories have been proposed: infectious, autoimmune, and chronic irritation (Fergus et al., 2020). The first symptoms may present as well-demarcated, erythematous thin plaques and sometimes erosions. The disease then evolves into dry, hypopigmented sclerotic lesions (De Luca et al., 2023). In the late stages, we can observe obliteration of the labia minora and periclitoral structures, which can cause narrowing of the vaginal introitus. VLS in females favours the vulva and perianal regions. Purpura and perineal fissures are common findings and sometimes mistaken for sexual abuse (Focardi et al., 2024; Priestley & Bleehen, 1987).

The most common symptoms are severe pruritus, soreness, dysuria, dyspareunia, pain upon defecation, and, in advanced cases, anatomical changes and functional impairments of the vulva (Conte et al., 2025). There is an association between lichen sclerosus and autoimmune diseases, including alopecia areata, ulcerative colitis, Crohn's disease, type 1 diabetes mellitus, and vitiligo (Gulin et al., 2023). Moreover, female patients with VLS have an increased risk for squamous cell carcinoma (SCC), cervical cancer, endometrial cancer and several urogynecological and gastrointestinal disorders (Gulin et al., 2023; Söderlund et al., 2023; Zweizig et al., 2014). Skin biopsy is necessary for managing more difficult cases, especially when cancer is suspected or prescribed treatment is not working properly (Zweizig et al., 2014). Although gynecologists and dermatologists primarily diagnose and treat VLS, this disease can have a profound impact on women's psychological well-being, sexual function, and overall quality of life (Melnick et al., 2020; Vittrup, Mørup, et al., 2022).

However, the exact prevalence of VLS is unknown; studies estimate that it ranges from 0.1% to 3%, particularly among children (8-13 years of age) and older women (in the 6th-7th decade) (Kirtschig et al., 2015). Pediatric vulvar lichen sclerosus may resolve, but more commonly persists after menarche (Boero et al., 2023). That highlights the need for long-term follow-ups. The diagnosis of VLS is probably underestimated primarily because up to one-third of cases can be asymptomatic (Kirtschig et al., 2015). Moreover, the proper diagnosis is often delayed due to social stigma and lack of awareness among healthcare providers (Bentham et al., 2021).

The standard treatment involves ultrapotent topical corticosteroids, which are highly effective for physical symptoms and also help prevent disease progression (Chi et al., 2011; Melnick et al., 2020). Another possible treatment includes CO2 laser and photodynamic therapy (Krause et al., 2023; Qu et al., 2024; Sirotkina et al., 2024). However, in more advanced cases, the surgical approach may benefit patients (Flynn et al., 2015). Accurate therapy can have a positive impact on the quality of life in women (Cao et al., 2024). Treatment approaches often overlook the psychological dimensions of the condition. Recent studies suggest that women suffering from vulvar lichen sclerosus (VLS) experience a heightened risk of sexual dysfunction, anxiety, distress, and challenges in their daily lives (Brar et al., 2022; Gordon et al., 2016; Vittrup, Mørup, et al., 2022).

Other factors that may contribute to worsening psychological function in patients with VLS include feelings of shame, isolation, relationship issues, and reduced self-worth (Rees & Arnold, 2025). Psychological factors may contribute to the burden and risk of treatment burnout, resulting in poor control of the condition (O'Grady et al., 2022). Despite these serious consequences, the psychological and social aspects of VLS are still rarely addressed.

In this review, the term "lichen sclerosus" (LS) will be referred to as its vulvar manifestation in women, unless stated otherwise. The goal of this systematic review is to combine existing research on how vulvar lichen sclerosus influences women's mental health, sexual functioning, and daily activities. By emphasizing the broader implications of this condition, beyond its physical symptoms, this review intends to promote more integrated clinical care and guide future research that incorporates psychological and sexual health aspects into the management of VLS.

Methodology.

Literature Search Strategy

A systematic literature search was conducted using the electronic databases: PubMed and ScienceDirect. The search strategy was made to properly assess the psychological impact of vulvar lichen sclerosus (VLS) on women. Specific search terms were adjusted to each database. The Boolean operators (AND, OR, NOT) and Medical Subject Headings (MeSH) were used. The research focused on original articles published from January 2014 to December 2024, because before 2014, studies were largely repetitive and did not provide new information regarding lichen sclerosus and its impact on quality of life, sexual health, and mental health, while the end date was set to exclude the possibility of including preprints. Only studies in English or Polish and with full-text access were considered.

Inclusion and Exclusion Criteria

Inclusion Criteria:

Population: Women diagnosed with vulvar lichen sclerosus

Scope: Articles evaluating one or more of the following: quality of life, sexual health, sexual dysfunction, mental health, depression, anxiety, suicidal ideation.

Study type: Original articles, including case-control studies, qualitative research, cohort studies and cross-sectional studies.

Language: English, Polish

Publication date: January 2014 - December 2024

Access: Only full-text articles

Exclusion Criteria:

Population: Studies not referring to women with vulvar lichen sclerosus

Scope: Studies unrelated to subjects mentioned in the inclusion criteria

Study type: systematic reviews, meta-analyses, case reports, experts' opinions, letters, editorials and conference abstracts.

Data: Articles that do not contain original data or consist solely of anecdotal evidence.

Access: Articles that do not have full-text access.

Study Selection

The first selection was based on abstracts and titles. Articles that met the inclusion criteria were thoroughly reviewed during the second screening phase. When there was uncertainty or disagreement about inclusion, discussions continued until a consensus was achieved.

Search Terms

Search strategies were implemented for each database:

PubMed

((lichen sclerosus et atrophicus OR lichen sclerosus OR Vulvar Lichen Sclerosus) AND (Quality of Life OR Psychological Well-Being OR Mental Health OR sexual dysfunctions, psychological OR sexual dysfunction, physiological OR depressive disorder OR Depression OR Anxiety OR sexual health OR suicidal ideation)) NOT (systematic review OR review OR case report)

ScienceDirect

(('lichen sclerosus et atrophicus' OR'lichen sclerosus') AND ('Quality of Life' OR'Mental Health' OR Depression OR Anxiety OR'sexual health' OR'suicidal ideation'))

Results

Quality of life and sexual health

Vulval Quality of Life Index VQLI is a valuable tool that can be used for tracking down symptom burden and treatment response in vulval conditions. In one study analyzing VQLI in patients with VLS, the baseline score had a median of 14.00 (IQR: 7.00-26.00), with the highest score in “Future Health Concerns” and the lowest in “Relationships”. The median age at presentation was 60.5 years (IQR: 49.75–68.00), and the median age at symptom onset was 56.5 years (IQR: 46.00–64.00). Patients with VLS received topical corticosteroids as treatment and after a median follow-up duration of 77.0 weeks (IQR: 17.00–124.30), there was a significant improvement in VQLI scores, with a median final score of 5.00 (IQR: 2.00–10.00) ($p < 0.0001$). Patients with VLS presented a slower improvement of VQLI compared to the vulval lichen planus (VLP) and chronic vulvovaginal candidiasis (CVVC), analyzed in the study, with a regression slope of 0.3312. Among VLS patients, 67.74% reported good adherence to treatment. Those with good adherence had higher baseline VQLI scores (median: 16.5 vs. 9.5), but no significant difference in final scores was observed between adherent and non-adherent groups. The presence of anxiety and/or depression had no significant impact on either baseline or final VQLI scores in the VLS cohort (Wu et al., 2022).

In another study of 255 women with vulval lichen sclerosus (VLS), quality of life (QOL) assessed via the Vulval Quality of Life Index (VQLI) was significantly better in treated patients than in those untreated. Among pre-treatment patients, 50.7% had good QOL (gQOL) and 49.3% poor QOL (pQOL), while in the treatment group, 93.1% had gQOL and only 6.9% pQOL. Treated patients with pQOL had higher rates of urinary incontinence (38.5% vs 15.4%, $p = 0.049$), older age, sexual abstinence, and greater symptom burden. Median total VQLI scores improved significantly with treatment (gQOL: 2.0 vs pQOL: 15.0, $p < 0.001$), with the greatest differences observed in sexuality and anxiety domains. Poor QOL was associated with partial treatment adherence, suboptimal disease control, and scarring progression. Adherent patients had significantly better outcomes, including higher rates of disease control and less scarring. Side effects were infrequent and mild (Wijaya et al., 2022).

In a long-term follow-up study of juvenile-onset vulvar lichen sclerosus (VLS), 81 adult women (median age 29 years) with confirmed VLS in childhood were assessed for quality of life (QoL), sexual function, and clinical outcomes. The median age at biopsy was 9 years, and the median follow-up time was 19.5 years. More than half of respondents (56.2%) reported VLS symptoms within the past year, with 45% undergoing regular follow-ups. The presence of recent symptoms was associated with poorer scores across QoL and sexual health measures (DLQI, Skindex-29, FSFI, FSDS-R; all $p < 0.01$). In adulthood, 51.9% of patients had QoL impairment on the DLQI, and 30.9% had reduced QoL on the Skindex-29. Sexual dysfunction was present in 51.9% of women (FSFI <26.55), while 53.7% reported sexual distress (FSDS-R ≥11). These findings highlight the long-term burden of juvenile-onset VLS on physical, sexual, and psychosocial well-being, emphasizing the need for early diagnosis, consistent follow-up throughout adolescence and adulthood (Morrel et al., 2023). Women with LS consistently report reduced sexual activity, likely due to a combination of pain (e.g., dyspareunia), physical discomfort, and psychological distress related to genital changes (García-Souto et al., 2022).

Sexual health was notably impaired in women with LS. In another research, 23,7% of women with LS reported that their sexual activity was “rarely or never satisfactory”, compared to 0% of healthy controls ($p < 0.0001$) and 6,5% of women with Candida infection ($p = 0.03$). Moreover, women with LS were much less likely to engage in vaginal intercourse (71,6%) compared to healthy women (89,0%; $p = 0.003$) and those with Candida albicans infections (100%; $p = 0.0003$). Despite the importance of vaginal intercourse across all groups, LS was associated with a more negative impact on sexual engagement and satisfaction (Haefner et al., 2014).

Another study used the Sexual Quality of Life-Female (SQoL-F) questionnaire and confirmed a remarkable decline in sexual well-being. Among 51 patients with LS, the median AQoL-F score was 47 (IQR = 13), compared to a median of 79 (IQR = 13) in 45 healthy controls ($p < 0.0001$). The most affected areas included psychosexual feelings, self-worth, sexual repression, and relationship satisfaction (Jabłonowska et al., 2023).

Mental health

Women diagnosed with lichen sclerosus (LS) showed a remarkably higher presence of depressive symptoms when compared to healthy individuals. In one study, researchers used the Patient Health Questionnaire-9 (PHQ-9) to observe signs of depression among LS patients. The results reveal that the LS group had a median score of 10 on the Patient Health Questionnaire-9 (PHQ-9), indicating moderate depression, while the control group had a median score of 6 ($p = 0.0006$). More than half (53%) of women with LS achieved PHQ-9 scores of 10 or higher, in contrast to 16% in the control group ($p = 0.0001$). Moreover, 29% of women with LS met the criteria for Major Depressive Syndrome (MDS), while only 4% of controls did so ($p = 0.0034$). Overall, 47% of patients with LS fulfilled diagnostic criteria for a depressive disorder, compared to just 13% of women without LS ($p = 0.0004$) (Jabłonowska et al., 2023).

In another matched case-control study, the frequency of depression and anxiety was significantly higher in women with LS. 42,5% of LS patients were diagnosed with depression, compared to 24,4% of controls ($p<0.001$). The diagnosis of anxiety was in 42,6% of LS patients versus 22,6% of controls (Fan et al., 2022). An important component of evolving anxiety is fear of possible malignant transformation in the anorectal area. One study reported that 53% of women with VLS were experiencing fear of developing vulvar cancer (Meyer-Wilmes et al., 2024). Patients with VLS, especially those with juvenile onset of lichen sclerosus, may express persistent worry about future sexual and reproductive health (Morrel et al., 2023).

In another study, psychological impairments were observed regardless of the physical symptoms. Several factors, like chronic pain, pruritus, sexual dysfunction, and persistent discomfort, were associated with a negative impact on mental health. 1,4% of patients reported active suicidal ideation related to vulvar lichen sclerosus. Despite having mostly mild disease severity, these patients experienced psychological distress (Chang et al., 2024).

As the impact of LS extends into daily functioning. In professional life, work productivity is noticeably impaired, with increased rates of absenteeism, presenteeism, and use of personal leave due to outbursts of symptoms. In one study, 45% of participants required a leave from work due to symptoms, with an average of 18.8 hours taken. Work productivity losses were reported at 31.35%, and overall productivity impairment reached 36.67%. A total of 64% of women with LS experienced work-related challenges, and 41% described a moderate to severe impact on daily functioning (Jabłonowska et al., 2023).

Discussion

This review highlights the complex impact of vulvar lichen sclerosus (VLS) on women’s quality of life, mental health, and sexual health. Women with VLS consistently report reduced sexual activity, likely due to a combination of pain (e.g., dyspareunia), physical discomfort, and psychological distress related to genital changes (García-Souto et al., 2022). The Sexual Quality of Life–Female (SQoL-F) scores in women with LS are significantly lower than in healthy controls, reflecting impairments across multiple domains, including psychosexual well-being, relationship satisfaction, self-worth, and sexual repression (Jabłonowska et al., 2023).

Across the analyzed studies, patients experienced increased prevalence of mental health disorders, such as depression, anxiety, and suicidal ideation (Fan et al., 2022; Chang et al., 2024). Women with VLS are nearly twice as likely to experience mood disorders compared to those without lichen sclerosus. Studies using validated tools such as the PHQ-9 show that almost half of women with VLS meet the criteria for depression, often with moderate to severe symptoms (Jabłonowska et al., 2023).

Moreover, the patients may experience negative interactions with healthcare providers (Morrel et al., 2023). Before receiving a proper diagnosis of LS, patients may be misdiagnosed or dismissed by healthcare professionals (HCPs). The delay in identifying the LS can lead to feelings of isolation, permanent anatomical changes, and functional impairments. The vulvar symptoms have a stigmatizing nature and women with VLS often seek help and gather information independently from online forums or internet websites, trying to understand the treatment or receive support from others experiencing similar symptoms. Moreover, patients may experience feelings of shame and not talk to others about their health condition (Arnold et al., 2022). This highlights the importance of early diagnosis and an empathetic approach that validates patients' feelings and serves an educational purpose, encouraging an open dialogue. The clinical implications of this research are profound. The diagnosis of lichen sclerosus or other vulvovaginal skin diseases is often nuanced. It can be a diagnostic challenge, so additional education for healthcare providers in this area would be beneficial (Comstock et al., 2020).

The chronic character of VLS impacts daily life functioning. This highlights the need for flexible sick leave policies and additional support to help individuals maintain employment and stability (Fan et al., 2022). Even patients with mild disease symptoms may experience psychological distress, including suicidal ideation (Chang et al., 2024). Healthcare providers should take an active role in routine screening for mental health and suicide risk. Proper education for healthcare providers is crucial for the early diagnosis of lichen sclerosus, which can help prevent the complications of this disease. These findings emphasize the role of sexual health counseling and psychosexual interventions (Jabłonowska et al., 2023). Regular mental health check-ups and easy access to professional psychological support should be fundamental to clinical management.

The clinical implications of these findings are far-reaching. Comprehensive VLS care should involve dermatologists, gynecologists, mental health professionals, surgeons, and ideally, psychodermatology specialists who narrow the gap between somatic and psychological care. Patient education, through individualized counseling that includes visual aids and demonstration of proper treatment application, has been shown to significantly improve understanding, satisfaction, and adherence to therapy (Vittrup, Westmark, et al., 2022).

Conclusions

In conclusion, vulvar lichen sclerosus has an impact on sexual and mental health, and also correlates with overall quality of life. This review emphasizes the importance of recognising and addressing psychological impairments alongside physical symptoms. For patients with VLS, comprehensive care that includes psychological support, individualized education, and open dialogue about sexual health should be a part of standard care.

A multidisciplinary management strategy should involve specialists from various fields, including gynecology, dermatology, surgery, and mental health professionals. Moreover, other vulvar conditions, such as vulvovaginal candidiasis and vulvar lichen planus, similarly impact sexual function, psychological well-being and intrapersonal relationships, further supporting the need for accurate diagnosis and proper treatment in vulvar dermatoses (Gordon et al., 2016). Further research is necessary to evaluate the psychotherapeutic options and holistic approaches for not only vulvar lichen sclerosus, but also for other vulvar dermatoses.

Disclosures

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Authors' contributions:

Conceptualization: Agata Nowacka, Zuzanna Tomaszewska
Methodology: Julia Ciechanowicz, Anna Zielińska, Stanisław Ciechanowicz
Software: Zuzanna Tomaszewska, Marika Gutowska
Check: Aleksandra Przybylska, Julia Dura,
Formal analysis: Adrianna Perzanowska, Aleksandra Przybylska, Agata Nowacka
Investigation: Anna Zielińska, Agata Nowacka, Julia Dura
Resources: Stanisław Ciechanowicz, Adrianna Perzanowska, Piotr Kupidłowski
Data curation: Julia Dura, Zuzanna Tomaszewska, Marika Gutowska
Writing - rough preparation: Marika Gutowska, Piotr Kupidłowski
Writing - review and editing: Piotr Kupidłowski, Julia Ciechanowicz,
Visualization: Julia Ciechanowicz, Aleksandra Przybylska
Supervision: Adrianna Perzanowska, Anna Zielińska
Project administration: Agata Nowacka, Stanisław Ciechanowicz

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