

'A hundred paper cuts over my vulva': a patient's experience of vulval lichen sclerosus

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Patient viewpoint

Early symptoms

I began experiencing pain with sex during my early 20s. It began as mild discomfort but grew in complexity and intensity over the years. For some reason, my skin seems to tear open with almost any attempt at insertion, almost as if it lacked the elasticity required to stretch to accommodate objects such as a speculum being inserted into the vaginal opening. As such, my fourchette and perineum would often tear. Additionally, I experienced chronic vulval fissures – I recall explaining to a friend that it felt like someone made a hundred paper cuts all over my vulval skin and then poured rubbing alcohol on them. My vulva would often burn and feel irritated, regardless of what I did.

I spent over a decade seeing different healthcare providers (over 15) trying to get answers. Each time I sought help, however, I was told I was tearing because I was too stressed out. Sometimes, wine was recommended to me so that I could 'loosen up'.

I was 31 when I was finally diagnosed with vulval lichen sclerosus (VLS). Having been untreated for almost 10 years, my case was quite progressed. I had complete labial agglutination, clitoral phimosis, and significant pallor and hypopigmentation.

Quality-of-life impact

While my diagnosis was in part a relief – after being told for almost a decade that my symptoms were in my head – it also led to significant distress and my quality of life suffered. Since I received no education or guidance on my treatment plan, I felt completely on my own in navigating and managing this scary new condition. I developed severe health anxiety, and my days became riddled with panic attacks; my mental health hit an ultimate low. Unable to predict how my symptoms would be on a given day, I became reclusive, shutting down any and all invitations to social events. My

sexual health was destroyed, and I felt completely hopeless and without support.

Turning things around

Upon experiencing suicidal ideation, I recognized the necessity for assistance, particularly concerning my sexual health. Seeking help, I engaged a sex therapist and a pelvic floor physical therapist to address both psychological and physical aspects. The therapy proved pivotal in my recovery. Acknowledging my privilege in affording regular therapy, I am aware that accessibility to counselling remains a challenge for numerous individuals affected by VLS.

As my mental health eased, I began to dive into the scientific literature on VLS. I educated myself on my condition, mastering its management and care. This education underscored the vital role of scientific and health literacy in handling chronic conditions. My ability to comprehend scientific papers on VLS allowed me to develop an understanding of its pathophysiology, treatment and care. I applied these theoretical learnings into practice, ultimately achieving remission and enhancing my overall wellbeing.

Motivated by this, I became involved in knowledge translation-based education efforts and patient advocacy to improve the lives of fellow VLS patients. For example, I created an evidence-based knowledge sharing hub called The Lost Labia Chronicles¹ and enrolled in the European Patients Academy on Therapeutic Innovation (EUPATI)'s Patient Expert Training Programme. Finally, I began to engage as a patient partner in international research efforts to help foster a more dynamic and patient-oriented background upon which to do VLS research.²

Conclusion

In order to uphold the welfare and needs of individuals affected by VLS, it is imperative to establish robust

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patient advocacy initiatives, enhance the knowledge base of healthcare practitioners, provide comprehensive patient education, and foster collaborative efforts among diverse healthcare professionals and patient advocates. These collective endeavours are essential in promoting holistic care, improving outcomes, and addressing the complexities associated with VLS.

Clinician's comments

Lichen sclerosus is the most common inflammatory vulval skin condition, causing pain, itching and anatomical changes and increasing vulval cancer risk. VLS presents most frequently in the postmenopausal age group, with approximately 20% of cases presenting premenopause. The prevalence of VLS is unknown due to poor recognition and misdiagnosis, but it is thought to occur in up to 3% in women. Once diagnosed, VLS can be effectively treated using potent topical corticosteroids; these reduce symptoms, sequelae and vulval cancer risk.³ Delayed diagnosis can lead to irreversible structural change, with long-term consequences for sexual function and toileting.

This patient viewpoint exemplifies the profound impact that VLS has on women and highlights their unmet needs when seeking diagnosis and treatment. VLS is associated with higher rates of depression, decreased work productivity and poor sexual quality of life.⁴ Women report distress, anger and abandonment because of dismissal, lack of examination and poor follow-up care attributed to lack of knowledge of health professionals.⁵ There are no validated diagnostic criteria or outcome measures with which to determine the effect of treatment. The development of these is being prioritized to expedite diagnosis, guide treatment and enable standardized clinical trials.

We commend this individual's efforts in advocacy and recognize the key role representatives have in stigmatized conditions such as VLS. Patient advocacy groups and resources provide social support and accessible information and guide research. This patient author provides valuable input into research on outcome measures.² Insights into patient

journeys are crucial in helping clinicians and researchers focus on solutions to their difficulties.

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Conflicts of interest

The authors declare no conflicts of interest.

Data availability

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Ethics statement

Not applicable.

Patient consent

Written patient consent for publication was obtained.

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