



## Invited Editorial

## Living with vulval lichen sclerosus: Unheard stories and silenced voices



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Vulval lichen sclerosus (VLS) is a chronic skin condition affecting the vulval skin and often also involves the skin around the anus. A 2020 Finnish study found VLS to be commonest in prepubertal girls and postmenopausal women [1], but it may occur at any age. VLS has a major impact on everyday activities. Women's self-identity may be profoundly threatened. VLS causes intense itching and painful tears in the vulval skin, and can result in architectural changes such as narrowing of the vaginal entrance and burying of the clitoris [2]. It is also associated with an increased risk of vulval cancer, with up to 60% of vulval cancers occurring on a background of VLS [2]. VLS is a chronic condition which cannot be cured. Evidence from a cohort study in Australia, however, indicates that long-term topical highly potent steroid treatment may be effective in preventing flare-ups and malignancy [3]. VLS is often misdiagnosed, sometimes repeatedly for many years, as recurrent thrush [4]. If a clinician suspects a patient may have VLS, they should refer them to an experienced dermatologist for diagnosis and ongoing care.

A 2015 survey from the British Association of Dermatology found that one in five women with a vulval condition had considered suicide or self-harm as a result of their condition [5]. Those affected may be embarrassed to talk about it, and thus receive no support from their social network. Yet vulval conditions continue to be a neglected area of research. Randomised controlled trials of new, expensive, treatments for VLS may be appealing, but do we really understand the experience and therefore understand how best to improve it? If topical steroids are effective and inexpensive, do we understand what it is actually like to apply a highly potent steroid ointment to the genitals potentially for the rest of one's life? Do patients consider this a good enough treatment?

We badly need evidence from the perspective of patients in order to understand how best to support them. Qualitative and mixed-methods

social research is a powerful way of understanding an illness from the perspective of those experiencing the phenomenon. Findings can be used to inform the design of supportive interventions and improve healthcare pathways. They can also help us prioritise research. For example, do those with VLS wish us to prioritise researching new treatments, improving access to swift diagnosis, or increasing patients' confidence to self-manage the condition?

Evidence on the experience of VLS is extremely limited [6]. Just two published studies exist which have used qualitative methods to explore the topic [4,7,8]. These found that affected women struggle to access diagnosis and care, and that they seek alternative and complementary treatments. We need to understand the obstacles to diagnosis and treatment, in order to identify how to improve access for all by developing better pathways to diagnosis for all affected women. Reasons for lack of satisfaction with mainstream treatment need to be further explored. Some studies have used quantitative methods to demonstrate the profound impact of VLS on sexual function [9–13], but greater depth on this and on other domains of life affected by VLS is badly needed. The experience of VLS needs to be understood in its context, including the gender norms which shape experiences of VLS and decisions to undergo vulval surgery [7], and the societal stigma around the vulva.

Any evidence base about the experience of VLS would be incomplete if it does not include the voices of minority ethnic patients. Furthermore, research should seek to include disabled patients, and also transmasculine and non-binary people. These groups may experience particular barriers to diagnosis and treatment. A poor understanding of skin conditions in people of colour is currently a topic of discussion [14]. Those seeking help for VLS symptoms must additionally contend with the lack of knowledge amongst GPs of the condition [15], plus societal stigma attached to talking about the vulva. Finding pictures online of a 'normal' vulva is made more difficult for those

with black or brown skin, and whose bodies are racialised and sexualised. Transmasculine and non-binary people will experience particular obstacles in accessing urogynaecological services, as they are forced into spaces which are less accommodating or welcoming to them.

There are many unanswered clinically-oriented questions about VLS. There are also many, many unheard stories and silenced voices. Accessing and amplifying these voices is crucial to increase research in the area, tackle the stigma attached to the condition, and improve access to swift diagnosis, optimal care, and a better quality of life for those with VLS.

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