

# What lies beneath: A qualitative review of misinformation on vulval lichen sclerosis

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## Abstract

**Background:** Lichen sclerosis (LS) is a chronic inflammatory skin condition that most commonly affects the vulva and can significantly affect quality of life. While websites and social media can offer helpful information, there is little known about the content of misinformation on LS online.

**Objectives:** This study aimed to qualitatively assess the content of misinformation surrounding vulval LS.

**Methods:** We reviewed misinformation related to LS on the internet through a search on PubMed, Google and various social media platforms.

**Results:** The key themes of misinformation included incorrect causes of LS such as gut dysbiosis and infections; fake 'cures' for LS such as elimination diets, homeopathic remedies, Borax, or unproven 'ground-breaking' procedures like lasers and plasma-rich protein injections; and criticism of topical corticosteroids and exaggeration of potential side-effects, despite corticosteroids being the gold-standard treatment.

**Conclusions:** Dermatologists, gynecologists and general practitioners should be aware of these misleading claims, be prepared to refute them, and steer patients to reliable sources of information and evidence based therapies.

## KEYWORDS

conspiracy theories, disinformation, fake news, genital dermatology, lichen sclerosis, misinformation

## BACKGROUND

“Is minic gur sia a théann an bhréag ná an fhírinne” (seanfhocail)—Lies often travel further than truth (Irish proverb).

Lichen sclerosis (LS) is a chronic inflammatory skin condition that most commonly affects the vulva, causing symptoms of itch, discomfort and dyspareunia.<sup>1</sup> Ultra-potent topical steroids remain the mainstay of treatment.<sup>2</sup> If left untreated, LS results in permanent

architectural change of the vulva and increased risk of vulval carcinoma.<sup>1</sup> Though it has a significant impact on quality of life, it continues to be an under-recognized and under-served disease.<sup>1</sup> Women with LS value the lived experiences of other women with LS and frequently seek out information about their condition online from websites and social media platforms.<sup>3</sup> While this can be helpful, it also puts them at risk of health misinformation—information that is false, inaccurate or misleading based on current scientific evidence.<sup>4</sup>

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## OBJECTIVES

This study aimed to qualitatively assess the content of misinformation surrounding vulval LS.

## METHODS

A literature search on PubMed was conducted, using search terms “lichen sclerosis” AND “misinformation” OR “disinformation” OR “conspiracy”. Combinations of these terms were also searched on Google and information was collected from the first 10 pages of each Google search. Further targeted searches were performed on YouTube, Instagram, Twitter, Facebook and TikTok. Results were qualitatively assessed separately by YG and COC for common themes of misinformation. Searches were performed in February 2024.

## RESULTS

There have been no previous publications relating to misinformation and LS. Some of the common themes of misinformation found online across all platforms included incorrect causes of LS, alternative ‘cures’ for LS, bogus treatments, and exaggerated or false effects of topical corticosteroid (TCS) use (Figure 1). Happily, much of the information available online related to LS was accurate, while most of the posts containing misinformation were on websites which were selling products of therapies to people living with LS.

The cause of LS remains a key area of misinformation. While the etiology of LS is complex, there is evidence that genetic predisposition, autoimmunity, mechanical trauma, and urine exposure are associated with disease development.<sup>1</sup> Gut dysbiosis and infections, such as candidiasis and Epstein-Barr virus (EBV), were asserted to be causes of LS. A source stated how LS is a result of EBV causing “dermatoxins to float to the surface of the skin” that “tend to stay lower in the body”. A misunderstanding of the basis of this disease could lead to inappropriate treatments being sought. Numerous online sources also claimed diet to be a mediator in LS. The ‘autoimmune protocol diet’ was the most popular online diet which claimed to treat LS. This was popularized by a wellness influencer who claims that it healed her LS. There are various infographics and lists of foods to avoid available online. Specific foods which were highlighted to avoid included sugar, gluten, dairy, oxalate-rich and histamine-rich foods. Specialized diet plans are also commonly a part of functional medicine and Ayurvedic treatment plans. Despite these claims,



**FIGURE 1** Various images of misinformation related to vulval lichen sclerosis taken (clockwise from top right) from [youtube.com](https://www.youtube.com), [stephaniehrhirschuk.com](https://www.stephaniehrhirschuk.com), [elite-aesthetics.co.uk](https://www.elite-aesthetics.co.uk), [tiktok.com](https://www.tiktok.com), [facebook.com](https://www.facebook.com), [steinbergurology.com](https://www.steinbergurology.com), [coyleinstitute.com](https://www.coyleinstitute.com), [mergemedicalcenter.com](https://www.mergemedicalcenter.com), [medicalmedium.com](https://www.medicalmedium.com), [gutsybynutrition.com](https://www.gutsybynutrition.com), [youtube.com](https://www.youtube.com) (all websites accessed 11/09/2024).

there is a lack of scientific evidence showing a link between diet and LS.

The psychosocial impact that LS can have on patients leaves them desperate to find a quick fix for their cutaneous ailments, and vulnerable to misinformation regarding ‘cures’. There are online claims of homeopathy and other alternative treatments being able to treat and cure LS, promoted by LS influencers as advertisements on social media. These include a variety of washes, creams, ointments, salves and even teas. They are advertised as products which treat LS specifically and even ‘prevent secondary malignancies’. They emphasize their use of natural ingredients such as emu oil, botanicals, vitamin E, and antioxidants. Borax, generally used as an insecticide and found in household products such as washing powder, was recommended for bathing and/or oral ingestion by several ‘natural health’ groups. One group claimed that LS is caused by boron deficiency and

that Borax can cure LS and reverse scarring. Topical exposure to Borax can lead to skin irritation, and oral administration can lead to gastrointestinal upset, anemia, seizures, renal failure and 'boiled lobster' erythroderma.<sup>5</sup> The British Association of Dermatology has issued a statement highlighting the lack of evidence of efficacy and potential for a wide range of side effects.<sup>6</sup> Many posts also emphasized that "natural" products were "steroid-free", despite TCS being the gold-standard treatment. Misinformation in this area is often associated with links to purchase products. Other unproven treatments were claimed to be "ground-breaking" and "revolutionary". These included laser treatments, plasma-rich protein injections and radiofrequency microneedling.<sup>7,8</sup> They were marketed as highly effective, or 'curative' by some service providers. This is despite limited robust research data on their efficacy and potential complications such as severe pain.<sup>8</sup>

While TCS are the gold-standard treatment for LS, steroid phobia (or corticophobia) remains a major issue online.<sup>9</sup> The main concern expressed on websites was skin atrophy. This is despite research showing that skin atrophy does not occur from intermittent long-term use of TCS when applied correctly to the mucosal surface.<sup>10</sup> Fortunately, there were also multiple websites and influencers debunking these myths and advocating for appropriate use. Good adherence to TCS in managing LS has been shown to reduce the risk of vulvar squamous neoplasia, which includes vulvar intraepithelial neoplasia and invasive squamous cell carcinoma.<sup>10,11</sup> TCS adherence also reduces symptoms of itch, pain and dyspareunia, and also reduces progression to scarring.<sup>12</sup>

## CONCLUSIONS

The advent of the internet and social media has led to a large amount of health misinformation, taking advantage of patients' uncertainty, to push alternative incorrect theories. Others make false claims to promote their own products or services. Misinformation can cause harm by delaying diagnosis, promoting inappropriate treatments and reducing uptake of proven treatments. Poor compliance to TCS is a common obstacle to successful disease control in LS and nonadherence to prescribed TCS can be due to TCS phobia secondary to misinformation.<sup>10</sup> This is the first study looking at misinformation surrounding LS online. Limitations include that only online content was reviewed, and the impossibility of reviewing all potential sources of misinformation. Dermatologists, gynecologists and general practitioners should be aware of these misleading claims, and steer patients to reliable sources of information and evidence-based therapies.

## AUTHOR CONTRIBUTIONS

Cathal O'Connor and Michelle Murphy conceived the research idea. Yixuan Goh and Cathal O'Connor performed the literature review, wrote the initial draft and created the figure. Yixuan Goh, Cathal O'Connor and Michelle Murphy reviewed and revised the manuscript.

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

## DATA AVAILABILITY STATEMENT

Data are available on request from the corresponding author.

## ETHICS STATEMENT

Not applicable.

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