



Combating Atopic Dermatitis Misinformation in the Digital Age:

A Public Health Approach to Addressing “Topical Steroid Withdrawal” (TSW) Myths

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Disclosure

- I have no conflicts of interest to disclose.

The Rise of Topical Steroid Withdrawal (TSW) Concerns

- Atopic dermatitis (AD) is *susceptible* to misinformation because it's a common skin disorder, with a complex, multifactorial etiology
- TSW is a **rare**, severe adverse reaction after prolonged use of high-potency steroids
- Social media has exaggerated **TSW fears**, leading to "*steroid phobia*"

Understanding TSW Emergence

► Br Med J. 1969 Mar 15;1(5645):670.1-673. doi: [10.1136/bmj.1.5645.670](https://doi.org/10.1136/bmj.1.5645.670) [↗](#)

Adverse Effect of Topical Fluorinated Corticosteroids in Rosacea

[Ian Sneddon](#)

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PMCID: PMC1982750 PMID: [4237682](#)

Abstract

Fourteen patients suffering from rosacea treated by prolonged topical applications of fluorinated steroids showed adverse effects. Aggravation and extension of telangiectasia occurred in all, and in most cessation of the treatment was followed by severe rebound inflammatory oedema and acute pustular eruption. The telangiectasia cleared or was much improved within three months of cessation of the use of fluorinated steroids. Hydrocortisone did not produce the same effect, and hence it was used, together with oral tetracycline, for treatment.

- The first documentation of TSW is not explicitly mentioned in the medical literature...
- However, a study published in 1969 reported an “**adverse reaction**” of rebound erythema and inflammatory edema after prolonged corticosteroid use...
- ...Could this be TSW?

Misinformation on Social Media

1. Countless viral posts spreading fear about steroids
2. Common myths:
 1. “All steroids cause withdrawal”
 2. “Natural remedies are enough to cure AD”
 3. “Doctors are hiding the dangers of steroids”

FALSE information

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Tricked into using protopic for my eczema, ended up with withdrawal #eczema #topicalsteroidwithdrawal #protopic

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Omg i used that
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I do a 3 weeks detox and took veg juice for maintenance. No more eczema
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Bông lan trứng muối
I have been using it for almost 3 months now. I was concered every time I stop it, I got red spots and blisters on my lips. I vist my dermatologist +

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Increased fears

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There are so many options for TSW treatment! Eve & I will continue to share these on @althhealth.show so you can more

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Comments (145) Creator videos

Korra Defence Attorney !!
imo i feel like dermatologists are unwilling to stray from what they've been taught. 143

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e
I went through TSW 2017-2020, The things doctors said during that time has caused serious trauma. I'm healed now bc I didn't listen to them. 1053

2022-6... Reply

ctrl.skin · **Creator**
I'm so happy for you that you're healed now! I hope you're proud of yourself, absolute legend 🥰 282

2022-6... Reply

Most stray away from any medications and choose to heal TSW "naturally"

The Consequences of Misinformation

- Increased "**steroid phobia**" → patients stop treatment too soon
- Worsening of AD, leading to **uncontrolled inflammation, infections, and hospitalization**
- Leading to unnecessary **under-treatment** of AD
- More reliance on **unproven and expensive "natural" remedies**
- Misinformation ***spreads faster*** than **corrections from medical experts**

Behavioral Health Psychology: Why People Trust Social Media Over Experts?

- **Cognitive Biases**
 - **Confirmation Bias**: More likely to trust information that aligns with their pre-existing beliefs or fears. For instance, patients already fearful of steroids are more inclined to believe stories about TSW.
 - **Availability Heuristic**: Personal stories about TSW shared on social media feel more memorable and relatable than scientific data. “A mental short-cut”
 - **Dunning-Kruger Effect**: Individuals with limited knowledge about dermatology may overestimate their understanding after seeing simplified, confident explanations on platforms like TikTok.
- **Social factors:**
 - **Peer influence**: from close friends or social media influencers
 - **Perceived authority**: More followers, more legitimacy
- **Emotional Appeal:**
 - **Fear and anxiety**: Health-related fears make people more vulnerable to misinformation
 - **Trust in the personal experience**: People's stories are more appealing

Healing with steroids: A 1-day success story



Patient consented to photos being shared

Collaboration & Engagement



BRITISH ASSOCIATION
OF DERMATOLOGISTS
HEALTHY SKIN FOR ALL



Topical Steroid Withdrawal

A joint statement by National Eczema Society, the British Dermatological Nursing Group, and the British Association of Dermatologists

Produced February 2024

Introduction

The aim of this document is to describe the various topical steroid withdrawal reactions reported by patients. Hopefully, this will make it easier for patients and healthcare professionals to discuss the condition.

Topical corticosteroids (described in this document as topical steroids) are often used to treat eczema and other skin conditions. For many people, they are a safe and effective treatment. Millions of people around the world have successfully benefitted from topical steroid treatment without any problems. Like other treatments, they can have side effects. In the UK, topical steroids are divided into four groups of increasing strength from mild to very potent (or very strong). Side effects are more common when using stronger steroids.

Most side effects of topical steroids are well-known. Often, this means that there is enough good research to understand and manage them. The group of side effects known as 'topical steroid withdrawal' (TSW) are generally less well understood. TSW is also sometimes called 'red skin syndrome' (RSS) and 'topical steroid addiction'.

Recently, there has been increased awareness of TSW, in part because people are sharing their experiences on social media. The Medicines and Healthcare products Regulatory Agency (MHRA), the UK regulator for medicines, reviewed topical steroid reactions in 2021. As a result of this review, all topical steroid products in the UK now include a warning about TSW.





A joint statement by the National Eczema Society, the British Association of Dermatologists released in 2024 on TSW

Expressed, urgent need for high-quality research into this condition.




Pathophysiology, epidemiology, creating diagnostic tools or criteria

Engagement with the Online Community


- **Comment on misinformation posts with facts**
- Use **hashtags (#EczemaAwareness, #SteroidFacts, #TSWTruth)** to reach wider audiences
- Join **Facebook groups, Reddit discussions** to counter false claims
- **Be active on social media** – don't let misinformation dominate
- **Develop shareable content** to spread accurate dermatology facts
- **Work with policymakers** to push social media accountability (e.g., requiring verified medical professionals to provide health content)


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DEBUNKING STEROID PHOBIA MYTHS


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drchloegoldman Let's talk steroid phobia 🗨️ There's a lot of fear around topical steroids, but here's the truth: when prescribed by a dermatologist for a few days or weeks, they're NOT something you'll become dependent on. The key is proper use! Overusing them can lead to side effects, but when used correctly, you'll be just FINE! Don't fear the right treatment for your skin 💡

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Original Paper

Investigating Topical Steroid Withdrawal Videos on TikTok: Cross-Sectional Analysis of the Top 100 Videos

[Firas Haddad BSc 1](#), [William Abou Shahla MD 2](#), [Dana Saade MD 2](#)

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Background

Social media platforms like TikTok are a very popular source of information, especially for skin diseases. Topical steroid withdrawal (TSW) is a condition that is yet to be fully defined and understood. This did not stop the hashtag #topicalsteroidwithdrawal from amassing more than 600 million views on TikTok. It is of utmost importance to assess the quality and content of TikTok videos on TSW to prevent the spread of misinformation.

- TikTok is a huge platform
- Current content on TSW are low-quality, >90% not correctly define TSW
- Calls for dermatologists to become more active and reduce growing steroid phobia

> Clin Exp Dermatol. 2022 Aug;47(8):1554-1557. doi: 10.1111/ced.15194. Epub 2022 May 10.

Topical steroid withdrawal through the lens of social media

Stephanie Bowe ¹, Sophie Masterson ², Gregg Murray ³, Isabel Haugh ⁴

Affiliations + expand

PMID: 35340034 DOI: [10.1111/ced.15194](https://doi.org/10.1111/ced.15194)

Abstract

The term 'topical steroid withdrawal' (TSW) describes an adverse effect that generally occurs with inappropriate prolonged use of high-potency topical corticosteroids (TCS). The presence of user-generated content relating to TSW on social media (SoMe) has not been well-defined to date. We aimed to explore content relating to topical steroid withdrawal on SoMe. Using a data analytics platform, we retrospectively analysed the hashtag #topicalsteroidwithdrawal on SoMe over a 5-year period from 8 February 2016 until 8 February 2021. We assessed interactions, performance, shares, likes, mentions, language and country of origin using descriptive statistics. Across all SoMe platforms, there was a 274% increase in mentions of the hashtag #topicalsteroidwithdrawal in the year 2020 (n = 7992) compared with the year 2016 (n = 2138). The top associated hashtags included #TSW, #eczema and #topicalsteroidaddiction. On Instagram, we found a 288% increase in number of mentions and a 592% increase in performance of #topicalsteroidwithdrawal in 2020 (n = 618 354) compared with 2016 (n = 89 390). Our results confirm an increase in the presence of user-generated content relating to TSW on SoMe and also highlight its extent. Large numbers of patients are exposed to this content, which could influence their engagement with TCS.

On Instagram:

- **288% increase** in number of mentions
- **592% increase** in performance of #topicalsteroidwithdrawal in 2020 (n = 618 354) compared with 2016 (n = 89 390).

Fighting Misinformation Together!

- “Misinformation thrives in silence—let’s be the voice of science.”
- **Call to action:** Join the conversation, educate, and empower patients!

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Thank you

