

#corticophobia: a review on online misinformation related to topical steroids

Paula Finnegan¹,¹ Michelle Murphy^{1,2} and Cathal O'Connor^{1,2}

¹Department of Dermatology, South Infirmary Victoria University Hospital, Cork, Ireland

²Department of Medicine, University College Cork, Cork, Ireland

Correspondence: Cathal O'Connor, Department of Dermatology, South Infirmary Victoria University Hospital, Old Blackrock Road, Ballintemple, Cork, T12 X23H, Ireland. Email: cathal.oconnor@ucc.ie

Abstract

Misinformation in healthcare is at crisis level worldwide, with the internet as primary source of prevarication. Topical corticosteroids (TCS) are a safe and effective treatment used in multiple dermatological conditions. Nonadherence to prescribed TCS can be due to phobia secondary to misinformation. TCS phobia is a complex multifaceted phenomenon that exploits patients with skin disease, creates cognitive dissonance and can obstruct successful treatment. This study aimed to examine the content of TCS-related misinformation available online. A formal review of PubMed was performed using the terms 'topical corticosteroids' AND 'misinformation' OR 'disinformation' OR 'conspiracy theory', along with an informal Google search using combinations of these terms and further targeted searches on social media applications including Facebook™, Twitter™, Instagram™ and TikTok™. 'Topical steroid withdrawal', 'red skin syndrome' or 'TCS addiction' is a particularly prevalent myth currently being propagated on social media, with most content suggesting that eczema is due to a 'leaky gut' or food intolerance and not to skin inflammation. The risks of potential adverse effects such as skin thinning and stunted growth/development are often exaggerated. Multiple websites promoting misinformation were frequently endorsed by companies advertising consultations or testing to identify 'underlying causes', or 'natural' products as alternative treatments, including 'herbal' remedies, which can contain significant quantities of corticosteroids or other potent ingredients. The dermatology community should be vigilant of the type of TCS-related misinformation online and be active in attempts to counteract it with evidence-based advice.

'Tógfaidh dath dubh ach ní thógfaidh dubh dath' ('Colour will take black, but black won't take colour', Irish proverb meaning that once spoken, a lie is permanent).

Health misinformation refers to health-related claims of fact that are false and scientifically unfounded. Phobia of topical corticosteroids (TCS), also known as corticophobia, involves vague negative feelings and/or erroneous beliefs about TCS held by patients and caregivers, which can be promoted by misinformation.¹ TCS have been used as a safe and effective treatment for many inflammatory dermatological diseases since their introduction over 70 years ago.² When used properly, they can prevent the need for systemic immunosuppressive agents with more severe adverse effect (AE) profiles.^{2,3} Poor compliance is a common obstacle to successful disease control and nonadherence to prescribed TCS can be due to TCS phobia.^{2,3} This study aimed to examine the content of TCS-related misinformation available online.

Report

A PubMed literature search was performed using the terms 'topical corticosteroids' AND 'misinformation' OR 'disinformation' OR 'conspiracy theory'. This yielded 1164 results, which were reviewed by two of the authors (PF and COC) for suitability, with eight papers deemed appropriate for inclusion, as they contained content specific to TCS-related

misinformation (Table 1). An informal Google search was also carried out using combinations of the terms 'topical corticosteroids' and 'misinformation', 'disinformation', 'conspiracy theory', 'phobia' and 'corticophobia'. Information was collected from the first 10 pages of each Google search. Further targeted searches were also conducted on social media applications including Twitter™, Facebook™, Instagram™ and TikTok™ (Figure 1). Relevant hashtags included #steroidphobia, #corticophobia, #topicalsteroid-withdrawal, #topicalsteroidaddiction, #tswwarrior, #itsan, #redskinsyndrome, #redskinsyndromejourney and #redskinsyndromewarrior. On TikTok, there were 323 million views of #topicalsteroidwithdrawal, 510.3 million views of #tsw and 41.4 million views of #topicalsteroidaddiction.

Key areas of misinformation identified included 'topical steroid addiction' or 'withdrawal', exaggeration of potential AEs, focusing on alternative 'underlying' causes and recommending alternative 'natural' treatments.

'Red skin syndrome', also known as 'topical steroid withdrawal' (TSW) or 'addiction', has been frequently covered in tabloid newspapers and social media. Content creators have highlighted their 'journey' with #TSW, explaining that they initially had mild eczema, then required increasingly potent TCS. They then withdraw TCS abruptly and unsurprisingly, have a flare of their underlying atopic dermatitis (AD), which is explained as a benign withdrawal reaction that will resolve spontaneously if TCS are avoided. Implausible underlying causes are usually reported for their AD, typically a 'leaky

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Table 1 Studies identified following PubMed search as containing data on content of misinformation related to topical corticosteroids

Findings	Reference
TCS phobia is a multidimensional phenomenon and its complexity contributes to the challenges associated with developing effective methods of allaying patients' fears of TCS. Many seemingly viable approaches, such as presenting data, are ineffective at improving adherence; even interventions that improve patients' knowledge of TCS fail to mitigate their fear. Those who are more susceptible to pseudo-profound information may be at higher risk of experiencing TCS phobia	Hrin <i>et al.</i> , 2022 ³
High rates of messages about TCS 'risk' from family/friends and the internet may affect patient/parent understanding about TCS safety, and this may contribute to treatment nonadherence	Smith <i>et al.</i> , 2017 ¹¹
Key areas of misinformation related to TCS include red skin syndrome; alternative causes such as diet, chemicals, dust and vaccines; alternative 'cures' and alternative 'natural' therapies. Some of these theories can be dangerous, especially relating to severe dietary restriction or to potentially deadly treatments. Patients with AD and their families are susceptible to misinformation given their desire for effective treatment	O'Connor and Murphy, 2021 ¹²
The high prevalence of steroid phobia does not differ based on dermatological condition or severity. Educational videos and demonstrations of topical steroid application are the most effective interventions to lower steroid phobia. Reasons for steroid phobia include misinformation, lack of education, fear of AEs, polypharmacy, negative experience with topical steroids and frequent changing of clinics	Contento <i>et al.</i> , 2021 ²
Parents of children with AD confirmed significant concerns and demonstrated poor knowledge regarding TCS use. Steroid phobia and confusing steroid packaging compound poor treatment adherence. This study emphasizes the need for solutions to improve misinformation, hesitancy and steroid phobia, including clear labelling of potency on TCS packaging	Wilson <i>et al.</i> , 2021 ¹³
Friends, family and the Internet are key sources of misinformation about TCS. Patients received conflicting advice from dermatologists, general practitioners and pharmacists regarding TCS application and AEs	Johnson Girard <i>et al.</i> , 2020 ¹
An interprofessional practice gap exists between dermatologists and pharmacists regarding TCS beliefs and counselling strategies. Collaborative education and improved communication between the two groups may be needed to ensure that patients receive a clear message about TCS	Millard and Stratman, 2019 ¹⁴
The most prevalent misinformation sources leading to steroid phobia are the internet and TV or other broadcasting media	Lee <i>et al.</i> , 2015 ¹⁵

AD, atopic dermatitis; AE, adverse effect; TCS, topical corticosteroids.

gut', with no further explanation as to what this means. Food allergies or intolerances are also frequently mentioned as a cause of their AD, which is well-recognized as being untrue.⁴ The National Eczema Society has produced a helpful statement on TSW, clarifying that symptomatology can be explained by uncontrolled severe AD, the consequences of abruptly stopping TCS, rare TCS contact allergic dermatitis, or uncommon AEs of TCS such as atrophy, rosacea, acne or perioral dermatitis.⁵ Extremely, some TSW proponents have proposed total water deprivation (both topical and oral) as a method to manage TSW (by 'recalibrating the body's ability to retain moisture'), with potentially deadly effects. Unstopped, this vicious cycle of misinformation could result in uncontrolled disease and dangerous health effects for patients.

Conversely, some websites suggest that TCS are not needed if enough emollient is applied instead, and highlight the need to avoid TCS application on skin that is 'broken or weepy'. Other misinformed posts include suggestions that TCS have antimicrobial effects and that they are absorbed into the circulatory system. While TCS may reduce the risk of infection by reducing inflammation and enhancing barrier function, they are not directly antimicrobial. Moreover, modern TCS have low percutaneous absorption and are unlikely to have systemic effects.²

The main fears expressed by patients regarding TCS included AEs such as skin thinning and potential effects on growth and development for children. Skin atrophy is an uncommon localized AE of TCS, which only occurs with persistent repeated use of potent TCS at the same anatomical site over a prolonged period⁶ and is reversible with cessation of steroid use.⁷ A systematic review examining TCS safety found no evidence of skin thinning when TCS were used intermittently to treat acute AD flares, or as 'weekend therapy' (i.e. twice weekly) to prevent AD flares, and also found no evidence of growth restriction or adrenal

suppression.⁸ A review of 16 clinical trials assessing the impact of TCS on the hypothalamic–pituitary–adrenal axis (HPAA) found that TCS are not associated with HPAA suppression and are extremely safe when used in line with current guidelines.⁹

Other points of disinformation recommended seeking an 'underlying' cause for skin problems, such as food allergies in AD or stress in psoriasis. Advocates of this were frequently affiliated with expensive pseudoscientific consultations or 'testing'. 'Natural' products (Manuka honey), alternative devices (hazelwood jewellery) or herbal supplements (*Calendula*) were often promoted at inflated prices, usually with a promise to 'cure' the skin disease, with no proven scientific evidence.

TCS-related misinformation and corticophobia are complex, multifaceted phenomena.¹ Risk factors for corticophobia include misinformation, lack of TCS education, fear of potential AEs, urban residency, higher education, higher income, higher number of general practitioner visits prior to dermatology review and lack of dermatology clinic continuity.² The psychosocial and visual impact that dermatological disease can have on patients leaves them desperate to find a quick fix for their cutaneous ailments and vulnerable to misinformation. This desperation, combined with the overwhelming amount of misinformation about the efficacy and safety of TCS, can lead to patients (and parents) opting for nonadherence to prescribed TCS regimens, or for use of nonconventional treatment options that have not undergone rigorous testing or research. Patients may also psychologically protect their sense of self by blaming external factors (e.g. TCS) for their skin disease. Our previous research has shown that mixed messaging from healthcare professionals (HCPs) regarding TCS leads to tension and conflict for families with skin disease.¹⁰

This study was limited to accessible online media and therefore may have missed some content. The dermatology

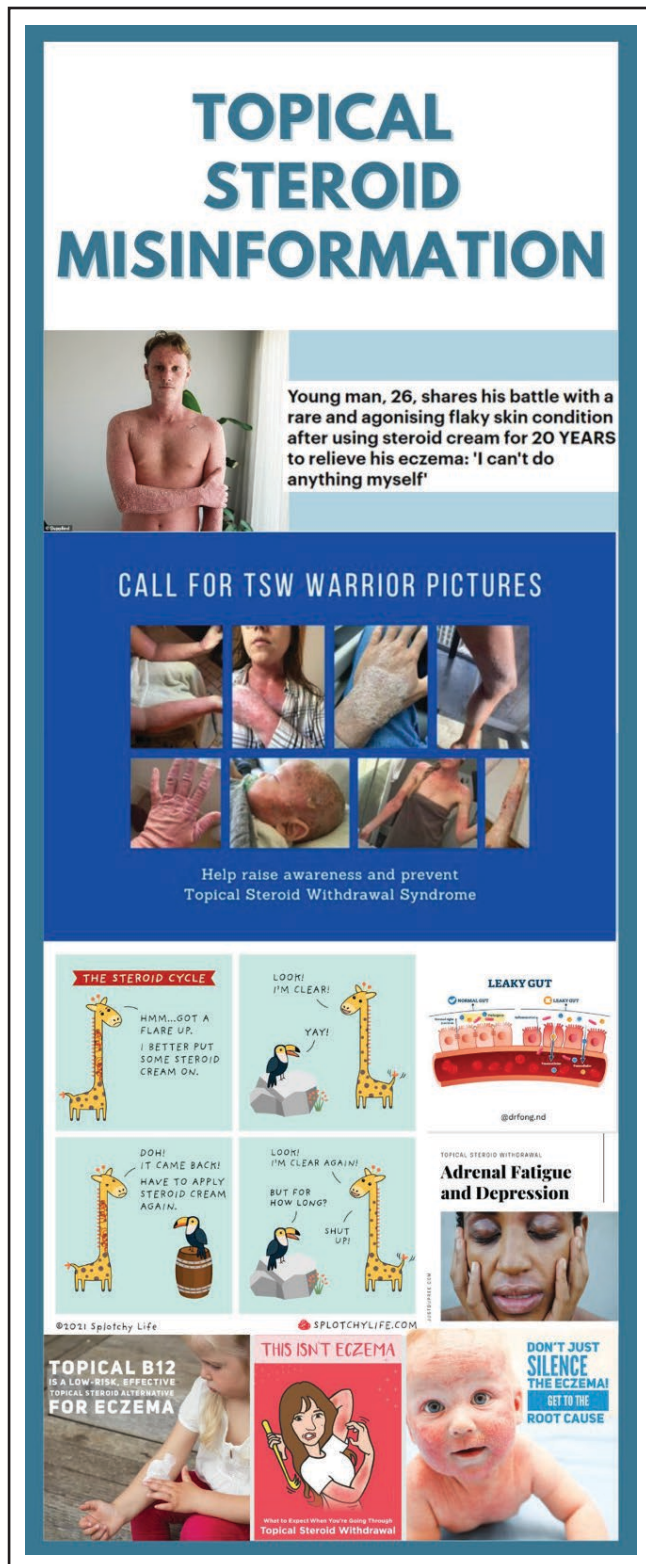


Figure 1 Various posts related to topical steroid misinformation from (top) [dailymail.co.uk](https://www.dailymail.co.uk), [itsan.org](https://www.itsan.org), [spotchylife](https://www.spotchylife.com), [facebook.com](https://www.facebook.com), [justdupree.com](https://www.justdupree.com) and [amazon.co.uk](https://www.amazon.co.uk).

community should be vigilant of the content of TCS-related misinformation online and actively pre-empt and counteract it with evidence-based research and guidelines.

Learning points

- TCS-related misinformation has fuelled the global development of corticophobia, a complex problem defined as vague negative feelings and/or erroneous beliefs about TCS held by patients and carers.
- Risk factors for corticophobia include misinformation, lack of TCS education and fear of potential AEs, while common fears held by patients and carers about TCS application include skin thinning and potential impact on growth and development.
- Key themes of TCS-related misinformation identified in this study included TCS withdrawal or red skin syndrome, exaggeration of potential AEs, and alternative 'underlying' causes or 'natural' therapies.
- Dermatologists and other HCPs should be aware of the impact of healthcare misinformation on adherence to TCS treatment and of the tension and conflict that mixed messaging can inflict on patients and their carers.

Conflict of interest

The authors declare that they have no conflict of interest.

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Ethics statement

Ethics approval: not applicable. Informed consent: not applicable.

Data availability

Data are available on request from the corresponding author.

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