EDITORIAL

Topical Steroid Withdrawal: The Challenging Transition from Patient Self-Diagnosis on Social Media to Medical Science and Care

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Published Apr 3, 2025. DOI: 10.2340/actadv.v105.43455. Acta Derm Venereol 2025; 105: adv43455.

A PubMed search for «topical steroid withdrawal» (TSW) traces its earliest description to Ian Sneddon in 1969, albeit unnamed (1). He reported rebound pustular inflammatory episodes of rosacea following at least six months of potent fluorinated topical corticosteroid (TCS) use on the face. All patients exhibited telangiectasia, a hallmark of chronic TCS application. Rebound occurred within a week or less of TCS discontinuation and was controlled within one to nine months with TCS avoidance and tetracycline therapy. Despite limited pathophysiologic understanding, these observations led to improved management of rosacea and other chronic facial dermatoses.

Factors contributing to the surge in topical steroid withdrawal cases

The recent rise in self-reported TSW cases is likely multifactorial. As highlighted by Indian colleagues (2), unsupervised TCS use – deviating from established guidelines regarding quantity, frequency, and duration – along with unregulated corticosteroid-containing products, are major contributors. Many topical corticosteroids remain available over the counter in various countries, enabling their use without medical supervision. Patients often rely on recommendations from non-medical sources, such as friends and family, rather than consulting healthcare professionals. Additionally, a significant proportion of individuals use topical steroids for skin lightening, often without awareness of the associated risks (3).

In the context of atopic dermatitis (AD), limited treatment options, particularly for facial involvement, have compounded longstanding concerns about TCS safety. The rise of social media in the 2010s further amplified these fears. The dermatology community was slow to address this emerging wave of patient concerns. Today, TSW is a widely used, patient-driven term on social media encompassing TCS-related side effects and is closely linked to corticosteroid phobia (4). A turning point was the 2015 publication (5) of a systematic review supported by the National Eczema Association (US), which spurred further research into whether TSW represents a distinct clinical entity or a social media-driven phenomenon.

Topical steroid withdrawal in the context of atopic dermatitis: clinical and diagnostic challenges

The incidence of TSW in AD remains unclear. If we adhere to Sneddon's initial observations for rosacea – characterized by rapid inflammatory rebound after prolonged fluorinated TCS use – how frequently does this pattern occur in AD? Images from patient advocacy groups depict severe cutaneous manifestations suggestive of AD rebound (6). However, without thorough clinical analysis, including disease duration, typical disease course, and prior treatments, the etiology of these cases remains uncertain.

Many dermatologists encounter similarly severe presentations of AD that, upon appropriate investigation, are attributed to undertreated or uncontrolled AD requiring systemic therapy. Distinguishing true intractable eczema from the therapeutic failure of a misguided topical regimen necessitates a comprehensive, patient-centered approach. Extended consultations incorporating educational diagnosis and objective severity assessments are essential. Whenever possible, multidisciplinary care – including structured follow-up with nurses and pharmacists – enables individualized treatment strategies. Between consultations, patient-reported outcomes (7), integrated into digital platforms such as ECZEMA CARE or ECZEMA WISE (8,9), can facilitate real-time monitoring and communication with healthcare providers.

The risks of overdiagnosing topical steroid withdrawal

As previously noted by British colleagues (10), the growing gap between patient concerns and healthcare professionals' responses to TSW risks alienating patients, reducing adherence, and exacerbating TCS phobia. Many proponents of TSW advocate for abrupt TCS discontinuation, despite the increasing availability of alternative treatments (11, 12). Firsthand patient accounts of «going cold turkey» are concerning, as abrupt cessation may lead to unnecessary suffering and loss of disease control. Overdiagnosing TSW – especially in the absence of expert clinical evaluation – may further distance patients from evidence-based treatment guidelines developed by specialists (13).

Bridging this divide between patient narratives and medical expertise is critical to ensuring optimal, individualized care. The work published by Mikael Alsterholm. and colleagues (14), along with a recent scientific analysis of social media content (15), represents an important step in this direction. Their findings underscore the need to first identify the underlying disease, typically AD – before making broad generalizations about TSW. Additionally, they highlight the close association between TSW and perceived TCS addiction. However, the interpretation of addiction requires further investigation, as chronic treatment is often necessary for disease control, and some patients report that

TCS use worsens their condition. The possible overlap between TSW and allergic contact dermatitis to TCS is another crucial factor to consider (16).

Emerging research and therapeutic perspectives

A recent study (17), supported by the International Topical Steroid Awareness Network (Dacula, Georgia, USA), proposed that TSW is distinct from AD and potentially treatable with metformin or berberine. The study found that transcriptomic analysis of TSW skin biopsies showed significant upregulation of mitochondrial complex I activity and increased NAD+ oxidation. The use of metabolic imaging to compare TSW, AD, and healthy skin provided additional insights. However, the distinction between AD and TSW requires further validation. Moreover, given the widespread role of NAD+ in cellular metabolism, its viability as a therapeutic target remains uncertain.

ACKNOWLEDGEMENT

The author thanks Prof JF Stalder and Dr HR Rezvani for their helpful comments.

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