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Perspectives

Topical corticosteroid withdrawal syndrome: the patient community call for high-quality research, clear definitions and diagnostic criteria

Topical corticosteroids (TCS) are a long-established treatment for eczema (syn. atopic eczema, atopic dermatitis). Research evidence and learning from widespread clinical use suggest they have good efficacy for most people with eczema and are generally safe when used appropriately. However, the quality of evidence for safety of application over multiple years, which many patients require, is generally low.[1]

Topical corticosteroid withdrawal syndrome (TSWS), sometimes called 'steroid addiction', is of increasing interest to the eczema community. The period from 2016 to 2021 saw a 274% increase in mentions of TSWS on social media platforms.[2] It is challenging to provide a clear description of TSWS as the concept is currently ill-defined, but a UK drug safety update has recognized distinct withdrawal reactions if higher-potency TCS are stopped after prolonged or continual use, noting erythroderma/redness and burning worse than the original condition.[3] A systematic review of evidence outlined clinical characteristics of TSWS and found it is most common in adult females, predominantly with the use of moderate- or high-potency steroids.[4] However, the quality of available evidence was low, and there is a lack of shared understanding among patients and clinicians about what constitutes TSWS. It can be challenging for patients and clinicians to distinguish TSWS symptoms from eczema that has not been adequately treated by the TCS, as uncontrolled eczema and TSWS share similar characteristics (e.g. inflamed skin). Cotter *et al.* called for research to better understand the nature of TSWS.[5] We support this call to action and herein add the voice of patients living with symptoms self-reported as TSWS. Concerns from the patient community need to be fully understood and addressed.

As part of a broader programme of eczema research, the Centre of Evidence Based Dermatology, University of Nottingham hosted an online stakeholder workshop focused on TSWS. Attendees shared experiences and key concerns, pointed to areas where evidence is missing, and highlighted the potential impact of research on healthcare for TSWS. The workshop allowed exchange of ideas and relationship building, and has resulted in an ongoing dialogue between researchers, patients and patient organizations collaborating to develop this research area.

We have five take-home messages for the clinical and research community:

1. **High-quality research is needed.** Figure 1 outlines key areas of research that need attention. These are the building blocks that will form an evidence base to inform practice. They can be somewhat interrelated and may need to involve patients with different conditions using TCS and span across health specialties.
2. **Clear definitions and diagnosis criteria are a priority.** It is currently unclear how many people are living with TSWS, how well healthcare professionals are effectively diagnosing and treating the condition, and whether all reports of TSWS have the same aetiology and require the same treatment. TSWS may currently be a term that is used to cover several different conditions with different causes rather than one over-arching condition.
3. **Prevention will require understanding of the complex conditions that result in TSWS.** Patients feel blamed for their condition when it is classed as due to 'inappropriate use'. We must recognize the complex factors that contribute to long-term continuous use, and the need for better education and support from healthcare professionals for patients using TCS in the long term. Prevention of TSWS symptoms is a key goal for the research agenda.
4. **Research can raise awareness and acceptance of TSWS within the medical community.** An absence of research in the past is likely to have contributed to patients feeling unsupported when reporting TSWS. Patients want professionals to recognize the impact of symptoms experienced and feel that recognition would be an important first step to better management. As co-author Holly Broome phrased it:

   > The impact of topical steroid withdrawal is way over and above what eczema causes. It is far more severe and affects the body systemically – trouble controlling body temperature, oedema, insomnia, changes in menstrual cycle, nerve pain, et cetera. The impact of topical steroid withdrawal isn't just for the individual but their wider family and support group.

5. **Research needs to be conducted with the TSWS patient community.** Patient involvement in research has many benefits and is particularly important for underserved communities. People experiencing TSWS and key patient organizations who advocate for TSWS research [e.g. Scratch That and the National Eczema Society (NES) in the UK and the International Topical Steroid Awareness Network (ITSAN) internationally] should be consulted and involved in future research endeavours to ensure the research is meaningful to patients.

To conclude, together as patients and researchers we propose future research topics we believe are the building blocks to meet the needs of the TSWS community, starting

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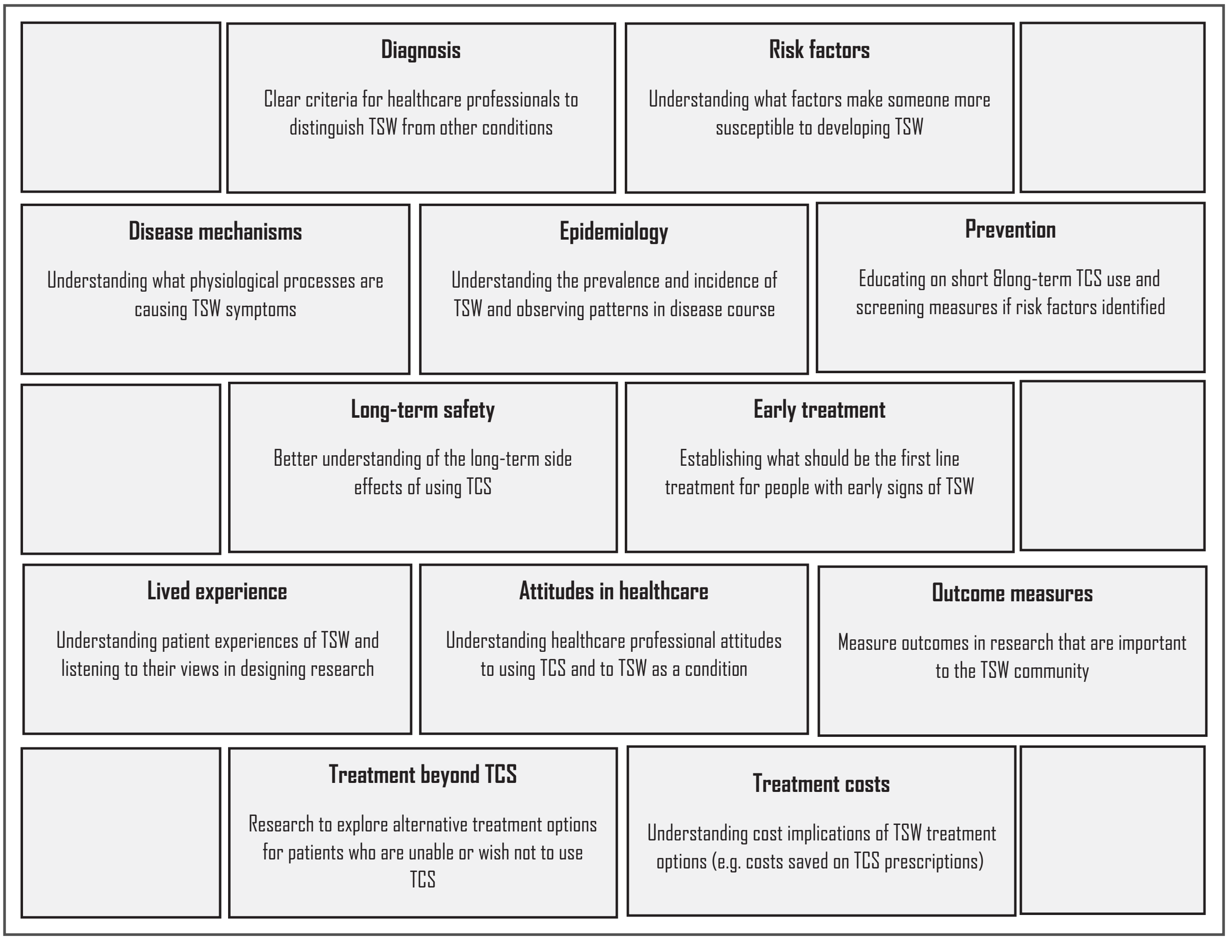

Diagnosis
Clear criteria for healthcare professionals to distinguish TSW from other conditions

Risk factors
Understanding what factors make someone more susceptible to developing TSW

Disease mechanisms
Understanding what physiological processes are causing TSW symptoms

Epidemiology
Understanding the prevalence and incidence of TSW and observing patterns in disease course

Prevention
Educating on short &long-term TCS use and screening measures if risk factors identified

Long-term safety
Better understanding of the long-term side effects of using TCS

Early treatment
Establishing what should be the first line treatment for people with early signs of TSW

Lived experience
Understanding patient experiences of TSW and listening to their views in designing research

Attitudes in healthcare
Understanding healthcare professional attitudes to using TCS and to TSW as a condition

Outcome measures
Measure outcomes in research that are important to the TSW community

Treatment beyond TCS
Research to explore alternative treatment options for patients who are unable or wish not to use TCS

Treatment costs
Understanding cost implications of TSW treatment options (e.g. costs saved on TCS prescriptions)

Figure 1 Building blocks for high-quality research into topical corticosteroid withdrawal syndrome (TSWS). TCS, topical corticosteroids.

with clear definitions of symptoms that are known as TSWS and to establish robust diagnostic criteria that can distinguish TSWS from uncontrolled eczema and other skin conditions.

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