University of Exeter

ESMI Evidence Synthesis & Modelling for Health Improvement

BRIEFING PAPER

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Reviewing the evidence base for Topical Steroid Withdrawal Syndrome in the research literature and social media platforms: An Evidence Gap Map

Within the dermatological community, Topical Steroid Withdrawal Syndrome (TSWS) is a medically contested condition with a limited research base. Published studies on TSWS indicate that it is a distinct adverse effect of prolonged use of topical corticosteroids (TCS) but there is a paucity of high-quality research evidence. Amongst the 'patient community' awareness has been increasing, with rapid growth in social media posts on TSWS[1] and the introduction of online communities such as ITSAN (International Topical Steroid Awareness Network).

This Evidence Gap Map (EGM) was developed in response to recent calls[2] for research to better understand TSWS and aims to be an important resource to guide both researchers and clinicians in the prioritisation of research topics for further research.

The Evidence Synthesis Team at the University of Exeter undertook this study which aimed to identify the range, extent and type of evidence on TSWS in the research literature and social media platforms using an EGM.

The findings highlight:

- ***research evidence is growing on TSWS but remains lacking in a number of important areas;***
- ***the lack of research evidence published across the topics of diagnosis, prevention and epidemiology*** is not surprising, given that the legitimacy of the condition is still questioned by many in the dermatological community;
- *there is a need for research to understand the* ***impact and safety of prolonged use of TCS***;
- ***the lack of qualitative research on the lived experience of TSWS*** - only two qualitative studies on TSWS published in the last fifty years;
- ***a need for more longitudinal research*** on the patient's 'TSWS journey' to healing.

In 2021, the National Eczema Society and the British Association of Dermatologists[3] published a joint statement on TSWS, and the Medicines & Healthcare products Regulatory Agency (MHRA) issued a Drug Safety Update advising patients to seek medical help if experiencing redness, burning, itching, or stinging of the skin on stopping TCS[4]

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Why did we do this Evidence Gap Map?

We wanted to identify the range, extent and type of evidence of TSWS in the research literature and compare the topics identified with the subjects of posts written by people online in blogs and on social media.

The objectives were to:

1. identify published evidence on TSWS: reviews and primary research (both quantitative and qualitative);
2. identify evidence on lived experience of TSWS in blogs and on posts in Instagram and Reddit;
3. identify gaps in evidence where further primary research is needed.

Finding the literature:

Bibliographic databases:

We searched on MEDLINE, EMBASE, CINAHL, ProQuest theses and Dissertations and looked for conference proceedings on Web of Science, We also carried out citation searching of relevant reports and included studies.

Blogs:

- Searched for 'topical steroid withdrawal' or 'topical steroid addiction' and blogs on Google
- Searched for blogposts on Medium, Blogspot and Wordpress via a targeted Google search
- Searched TSWS specific sites e.g. ITSAN for blogposts

Instagram:

- Searched in February 2023 for the 100 most recent posts featuring #topicalsteroidwithdrawal

Reddit:

- Searched in February 2023 for the 100 most recent posts under the subreddit Topical Steroid Withdrawal (r/TS_Withdrawal)

Selecting the evidence:

We included:

- Any studies investigating topical steroid withdrawal
- Letters, case reports, commentaries and opinion pieces
- Blogs and social media posts if they described any aspect of the experience of living with TSWS or caring for someone with TSWS
- The experience of TSWS could be either from complete cessation or a tapering down of TCS use

Outcomes of interest:

- Physical and psychological effects of withdrawal
- Knowledge and attitudes of people experiencing withdrawal
- Knowledge and attitudes of healthcare professionals
- Information seeking and sharing by people experiencing TSWS

All pieces of evidence were reviewed by two researchers independently.

Overview of the evidence

Academic studies	Online sources	Excluded
1284 papers screened from databases	149 records retrieved from Google	1184 academic records
	77 blogs reviewed	6 blogs
	100 Instagram posts screened	25 Instagram posts
	100 Reddit posts screened	23 Reddit posts

Included in the EGM

81 academic studies

71 blogs

152 social media posts

The Evidence Gap Map

The EGM is structured according to publication year and topic. Evidence is presented as bubbles by topic with the colour and size of the bubble indicating the type and amount of evidence found. The EGM can be found here

Research evidence

- 81 articles were included
- Dates ranged from 1968-2023
- 1 study was published in 1968, 20 studies between 2022 and 2023
- 46% of articles came from the US, 17% from the UK, 9% from Australia and 7% from Japan

Social media evidence

- 71 blogs published between 2011-2022
- 152 items from Reddit/Instagram posted between 2022-2023
- 9.4% of posts identified as from US, 8.5% from UK, 3.1% from Australia

Use of TCS

41% research articles reported people using TCS for **up to 10 years** and **16%** reported people using TCS for **>10 years**

11.2% social media posts reported people using TCS for **up to 10 years** and **17.9% of social media posts** reported people using TCS for **>10 years**

Skin symptoms

Reported in **research evidence**:

- Rash 75%
- Itching 48%
- Burning/stinging 44%
- Scalding 42%
- Pustules 41%
- Spider veins 37%
- Edema 37%
- Dryness/flaking 30%

Social media posts gave similar reports

Mental health

12% of research articles reported **depression, anxiety or stress**, 7% reported **suicidal thoughts** and 6% reported **emotional fluctuations**

Social media posts also **reported self-image** (20.2%) and **resilience** (20.2%)

Treatment

Complete cessation was the favoured strategy in ALL evidence

Tapering of TCS favoured more in research evidence (59%) than on social media (22.9%)

Research evidence focused more on **pharmaceutical treatments** such as **antibiotics** or **monoclonal antibodies**

Social media posts highlighted other treatments e.g. **bathing**, **diet** changes, **clothing** changes**, hot/cold treatments**, **psychological therapies**

Daily life

Social media posts reported:

- Disruption to **social life** (13.9%)
- Disruption to **work** (13.9%)
- Effects on **self-care** (11.2%)
- Effects on **holidays/leisure** (5.8%)
- Disruption to **education** (4.9)

Few reports of effect of TSWS on activities of daily living published in research evidence

A **TSWS diagnosis** was reported more often in research evidence (32%) than on social media posts (4%)

What are the implications of this EGM?

This EGM offers an overview of the TSWS research landscape and an insight into what people living with TSWS are discussing on social media. There are implications for:

- **Dermatological and medical communities:**
- Need for consensus on diagnostic criteria as without these, it is not possible to understand the incidence, prevalence and distribution of TSWS;
- Need to engage with patients' stories of living with TSWS from the social media rather than dismiss people living with TSWS as 'misusers' and 'misinformed', as acknowledgement of the patient experience could help bridge the 'doctor-patient gap'.
- **Researchers:**
- Research funding for longer-term studies on safety of prolonged use of TCS;
- Research on how to implement training and guidance for GPs and other health care professionals as an important part of building the evidence base on safe use of TCS.

Final thoughts:

It is crucial that future research in TSWS is underpinned by work that determines agreed diagnostic criteria for TSWS and by collaboration between researchers and clinicians **with** the TSWS patient community.

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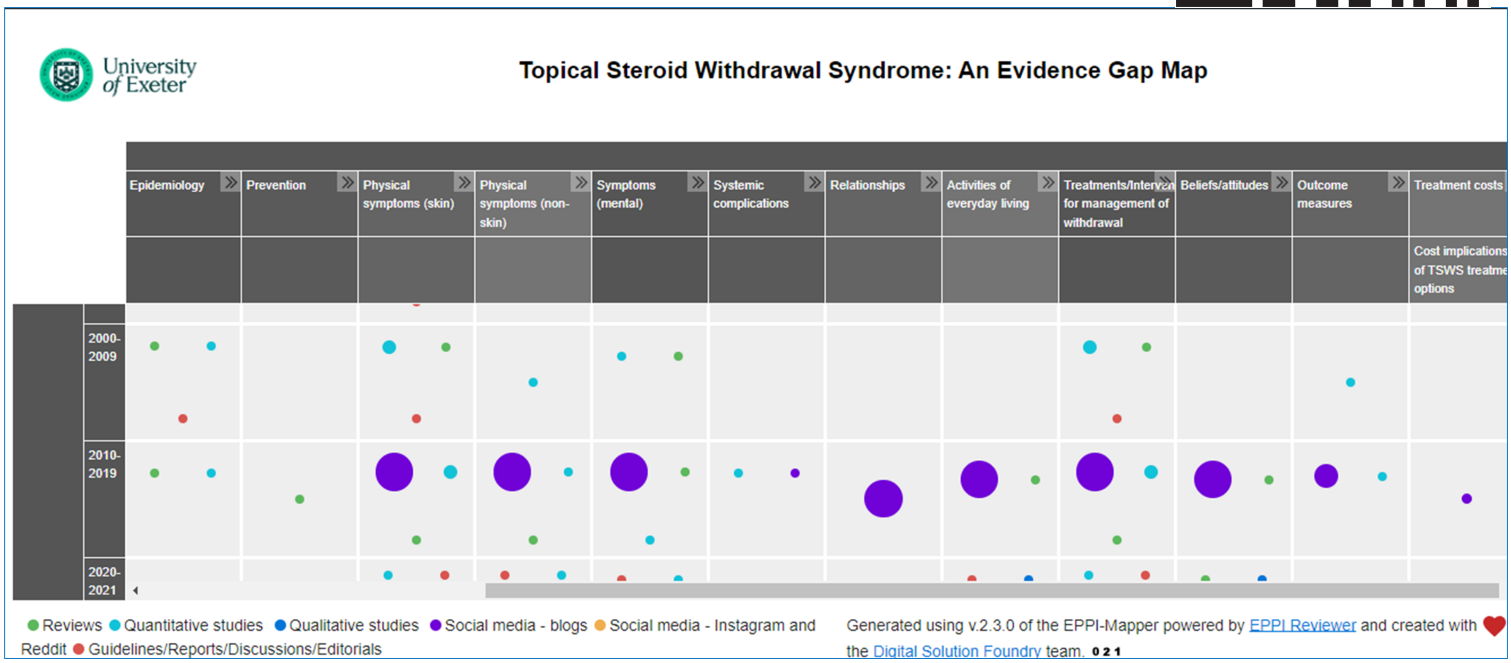

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