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

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Abstract

Background: Topical Steroid Withdrawal Syndrome (TSWS) is a distinct adverse effect of prolonged use of topical corticosteroids (TCSs). It is a medically contested condition within the dermatological community and consequently, has a limited evidence base and a paucity of high quality research. Amongst the ‘patient community’ awareness has been increasing, with rapid growth in social media posts on TSWS 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 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.

Objective: This study aimed to identify the range, extent and type of evidence on TSWS in the research literature and social media platforms using an EGM.

Methods: The MEDLINE and Embase (via Ovid), CINAHL (via EBSCOhost), ProQuest Dissertations & Theses and Conference Proceedings Citation Index (CPCI-S and CPCI-SSH via Web of Science) databases were searched. The final search was run in November 2023. Study titles, abstracts and full texts were screened by two reviewers and a third was consulted to resolve any differences. Blogging sites – Wordpress, Medium and Blogspot – and Google were searched; Instagram and Reddit were searched for the 100 most recent posts on specific dates in February 2023. Blog titles, Instagram and Reddit posts were screened for relevance by two reviewers. A data extraction tool was developed on EPPI Reviewer and data extraction was undertaken by one reviewer, checked by a second and any inconsistencies resolved through discussion. We did not undertake quality appraisal of included studies and social media evidence. EPPI-Reviewer and EPPI-Mapper were used to generate the interactive EGM.

Results: Eighty-two academic publications and 223 social media posts were included in the EGM. The research evidence mainly addressed the physical symptoms of TSWS (skin), treatments and to a lesser extent, risk factors and disease mechanisms, while the social media evidence primarily focused on the physical symptoms (skin and non-skin), mental health symptoms, relationships, activities of everyday living, beliefs and attitudes, and treatments.

Conclusions: The EGM shows that research evidence is growing on TSWS but remains lacking in a number of important areas: longer-term prospect observational studies to assess the safety of prolonged use of TCSs and prevent addiction; qualitative research to understand the lived experience of TSWS; and longitudinal research on the patient’s ‘TSWS journey’ to healing. The inclusion of social media evidence is a methodological innovation in EGMs and recognises the increased presence of #topicalsteroidwithdrawal on social media and how it can be used to better understand the patient perspective and ultimately, provide better care for people with TSWS.

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Conclusion: The EGM shows that research evidence is growing on TSWS but remains lacking in a number of important areas: longer-term prospect observational studies to assess the safety of prolonged use of TCSs and prevent addiction; qualitative research to understand the lived experience of TSWS; and longitudinal research on the patient's 'TSWS journey' to healing. The inclusion of social media evidence is a methodological innovation in EGMs and recognises the increased presence of #topicalsteroidwithdrawal on social media and how it can be used to better understand the patient perspective and ultimately, provide better care for people with TSWS.

Keywords: Topical Steroid Withdrawal Syndrome; Evidence Gap Map; Social media; Blogs; Instagram; Reddit;

INTRODUCTION

Topical corticosteroids (TCSs) are prescribed for many skin disorders, including chronic conditions such as atopic dermatitis, the most common form of eczema. Prolonged use of TCSs can lead to adverse addiction effects, most notably Topical Steroid Withdrawal Syndrome (TSWS). Topical Steroid Withdrawal (TSW), also known as Topical Steroid Addiction (TSA), can be described as a ‘distinct adverse effect’ of prolonged use of TCSs [1-3]. Although TSA and TSW are used interchangeably in the literature, TSWS comprises both the addiction phase and the withdrawal phase. The addiction phase is when the skin is symptom-free while using TCSs, and the withdrawal phase usually occurs within days or weeks of discontinuing the TCSs when symptoms may worsen beyond pre-treatment [4-6]. People have reported using an increased quantity and potency of TCSs over months to years to control their skin condition [1, 6]. On withdrawal, individuals may experience a rebound with more extensive and more severe skin manifestations which are also morphologically different from the original skin condition [4-5].

Despite the addiction effects being first recognised by Sneddon [7] in 1969, the concept of TSWS is a controversial one [5, 8], as “doubts still exist whether this condition is legitimate” [9]. There is no clear or accepted diagnostic criteria for TSWS, and for many clinicians, it can be challenging to distinguish it from other conditions (e.g. allergic contact dermatitis) [5, 10], and some see it as an “exacerbation of the underlying skin disease” [2:551). That said, in 2021 the National Eczema Society and British Association of Dermatologists [11] published a joint statement on TSWS and, in the same year, the Medicines & Healthcare products Regulatory Agency (MHRA) issued a Drug Safety Alert advising patients to seek medical help if experiencing redness, burning, itching, stinging or peeling of the skin on stopping TCSs [12]. The MHRA requested that warnings and precautions for use on TCSs were added to the Summary of Product Characteristics and Patient Information Leaflet for prescription-only and pharmacy-only medicines. The National Eczema Association in the US has also recognised TSWS as a potential serious side effect of using TCSs [13], as has DermNet in New Zealand [14].

Although the MHRA described TSWS as ‘rare’, it is estimated to occur in approximately 12% of people with atopic dermatitis who use TCSs [4]. Evidence for the increasing awareness of TSWS is demonstrated by the rapid growth in social media posts and discussions on TSWS [3, 15-16] and the introduction of online communities such as ITSAN (International Topical Steroid Awareness Network) and Scratch That, UK. It suggests that people living with TSWS are using social media for information and support, particularly as patients have reported feeling ignored, dismissed or blamed by their doctors for inappropriate use of TCSs [17-18]. For many dermatologists and clinicians, however, social media is perceived negatively as a key source of misinformation [8, 19] and a driver of patient self-diagnosis [20]. In contrast, Bowe et al suggested that an awareness of the influence of social media platforms on perceptions of TCSs could help ‘bridge the doctor-patient gap’ [15] and arguably, it offers one way to gain a greater understanding of people’s experiences of living with the symptoms of TSWS: “[p]atients want professionals to recognise the impact of symptoms experienced and feel that recognition would be an important first step to better management” [18:2].

AIM

The purpose of this study was to identify the range, extent and type of evidence on topical steroid withdrawal syndrome (TSWS) in the research literature and compare the topics identified with the subjects of posts in a number of social media platforms. The overall objectives of the study were to:

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

METHODS

Design

An EGM is a systematic evidence synthesis product [21] that provides an overview of the available evidence on a particular topic, theme or policy area. EGMs are used to highlight gaps in the evidence base, show where there is an abundance of evidence and increase the discoverability and use of the evidence. EGM methodology seeks to show what evidence is available, not what the evidence says. As part of the ‘Big Picture’ review family, Campbell et al [22:6] asserts that “[n]o other review methodology has developed a systematic approach to identifying gaps in the evidence with this level of rigor and transparency.” This EGM aimed to identify the range, extent and type of evidence about TSWS both in the research literature and on social media platforms. The scope of the EGM was defined by a years-research topics framework with the rows as years and the columns as research topics. The framework was developed by examining the literature, drawing on Howells et al’s proposed building blocks for high quality research in TSW [18], and by consulting with our public collaborator (AS) who has lived experience of TSWS. Additional topics were added if identified within the included evidence. The social media evidence from Instagram and Reddit was restricted to one year – 2022 – reflecting our decision to select a sample of the most recent posts using the popular hashtag, #topicalsteroidwithdrawal, on specific dates. We carefully considered the ethical implications of this study and did not submit for institutional review board approval because the study involved publicly available data and no analysis was undertaken. The EGM protocol was uploaded to Open Research Exeter (ORE), the University of Exeter’s online repository [23].

Patient and public involvement

Our public collaborator (AS) who has lived experience of TSWS, contributed throughout the process from question development to manuscript preparation.

Search Methods

Searches were conducted to identify published and unpublished literature via academic databases, websites and through blogs and social media (Instagram and Reddit)

Published and unpublished research

We searched MEDLINE and Embase (via Ovid), CINAHL (via EBSCOhost), ProQuest Dissertations & Theses and Conference Proceedings Citation Index (CPCI-S and CPCI-SSH via Web of Science) between the 17th and 26th August 2022 using a combination of subject headings and free text terms for steroids, topical application, and terms for withdrawal/addiction. The database searches were updated in November 2023. The full search strategies are available in Multimedia Appendix 1. We carried out forwards and backwards citation chasing of included studies using Epistemonikos (for reviews) and Scopus. We searched for the phrases ‘topical steroid withdrawal’ and ‘’topical steroid addiction’ on Google using the approach recommended by Briscoe & Rogers [24] for additional relevant studies. All results were exported into EndNote 20 for screening.

Blogs

We searched for blogs using ‘topical steroid withdrawal’ and ‘topical steroid addiction’ in combination with the word ‘blogs’ on Google. We also carried out a targeted search for topical steroid withdrawal on the blogging sites Wordpress, Medium and Blogspot. Blog searches were carried out in October 2022. There were no date or other limits applied to the blog searches. Searching for blogs as opposed to blog posts offered the possibility of understanding the experience of TSWS from a longitudinal perspective and following individuals through the withdrawal process [25].

Instagram and Reddit

We searched for the 100 most recent posts featuring #TopicalSteroidWithdrawal that included text on 2nd February 2023. These were copied into an Excel spreadsheet for screening and coding, along with the date of the post and a URL link. Posts not relating to topical steroid withdrawal, posts advertising products, posts that were not in English, or posts that only included links or hashtags were excluded. We searched for the 100 most recent and relevant posts under the subreddit Topical Steroid Withdrawal (r/TS_Withdrawal). The text, date and URL were entered into an Excel spreadsheet for screening and coding. Searches on Reddit were carried out on 7th and 8th February 2023. Searching for the most recent and relevant posts on specific dates was chosen to simulate 'real-world' Instagram and Reddit viewing behaviour [26-27].

Inclusion criteria

Studies, blogs and social media posts were included if they met the following criteria:

Population

People experiencing TSWS (includes infants, children and adolescents), either via complete 'sudden' cessation of TCSs or complete cessation of TCSs via 'tapering' approach.

Exposure

Topical corticosteroids (TCSs)

Outcomes

Effects of withdrawal – physical, psychosocial, knowledge and attitudes (both HCPs and people experiencing withdrawal) and information seeking and sharing by people experiencing withdrawal.

Study type/Posts

Any studies (quantitative or qualitative) that investigate topical steroid withdrawal were included. Letters, case reports, commentaries and opinion pieces were also included.

Blogs or social media posts were included if they described any aspect of the experience of living with TSWS or caring for someone with TSWS.

Exclusion criteria

Studies were excluded if they reported side effects of corticosteroids that were not specific to withdrawal. Blogs and social media posts were excluded if they did not describe personal experience relating to TSWS. They were also excluded if they described and promoted treatments for TSWS not related to personal experience, for example, posts advertising products.

Study selection

Studies located via the database searches were exported into EndNote V9. Titles, abstracts and full texts were screened independently by two reviewers (NO and MR). Disagreements were resolved by discussion. Posts from Instagram and Reddit were copied and pasted into an Excel spreadsheet and were screened independently by two reviewers. Details about blogs (URL, date coverage, number of posts, usernames) were pasted into an Excel Spreadsheet. Short summaries of the blogs were compiled and checked by two reviewers (NO and MR). Decisions about inclusion of blogs were carried out during the data extraction/coding stage.

Data extraction and mapping

Data extraction was conducted using EPPI-Reviewer [28]. The data extraction tool was informed by the research question and the structure of the map; it was piloted on a sample of included academic publications and social media posts and modified through team discussion. Data extraction was undertaken by one reviewer (NO) and checked by a second (MR), and any inconsistencies were resolved through discussion. Data were extracted on type of evidence, location of evidence, type of review, study design, population (age), steroids used, duration of TCSs use, length of time 'off' TCSs, areas of body affected, reasons for stopping TCSs, diagnosis, names of conditions, and research topics. Given the scope of the research evidence and the inclusion of social media data, we did not undertake quality appraisal.

EPPI-Reviewer [28] and EPPI-Mapper software [29] were used to generate the interactive EGM. The EGM uses a years-research topics framework (years – rows, research topics – columns) and within each cell of the grid, the evidence is presented as bubbles according to type, with the colour and size of the bubble indicating the type and amount of evidence available within that cell of the grid respectively. The filters of the map enables map users to change the type of evidence displayed based on, for example, authors, population age and location of evidence.

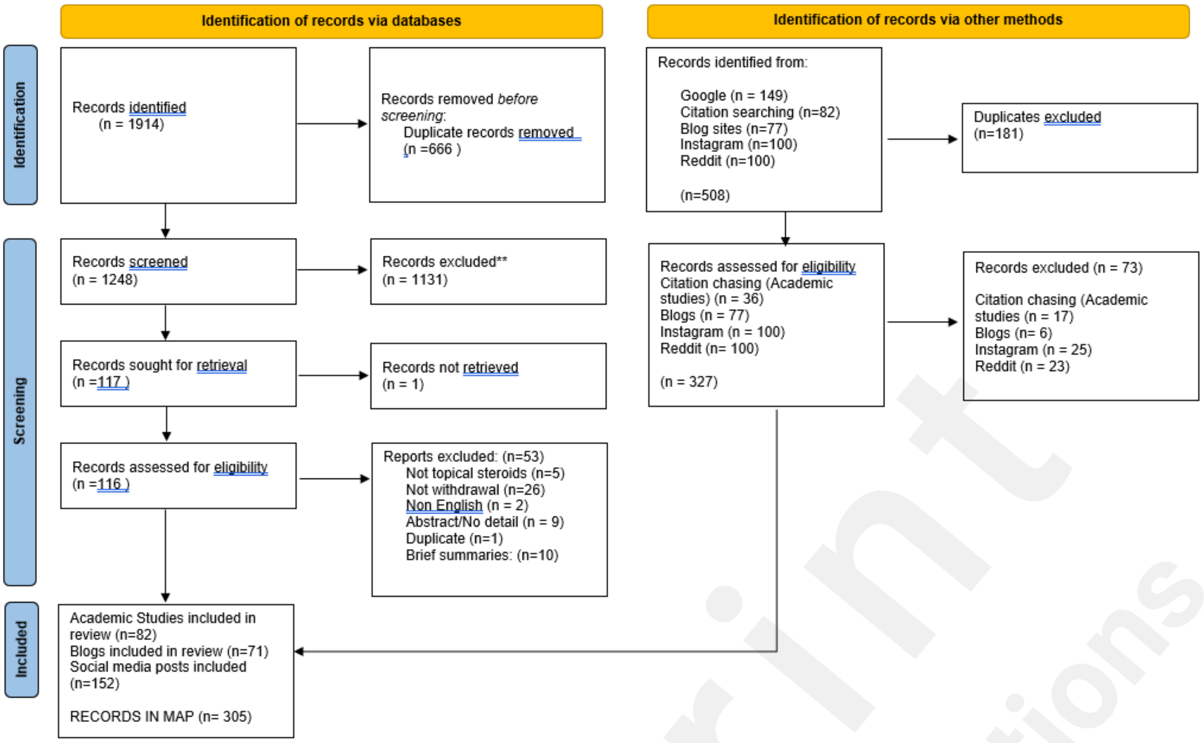
RESULTS

Results of the search

The databases searches identified 1914 records. After duplicates were removed, 1248 titles and abstracts were screened. After excluding irrelevant records, 116 full texts were screened, with another 36 being screened following citation searching. Finally, 82 records were included for the map.

Of the 100 Instagram posts captured, 76 contained relevant information about experience of topical steroid withdrawal. Of the 100 Reddit posts captured, 77 contained relevant information about experience of topical steroid withdrawal. Of the 77 blogs identified through blog searching and internet searches, 71 met the inclusion criteria. The PRISMA diagram shows the flow of records throughout the screening process (see Figure 1) [30].

Figure 1 PRISMA

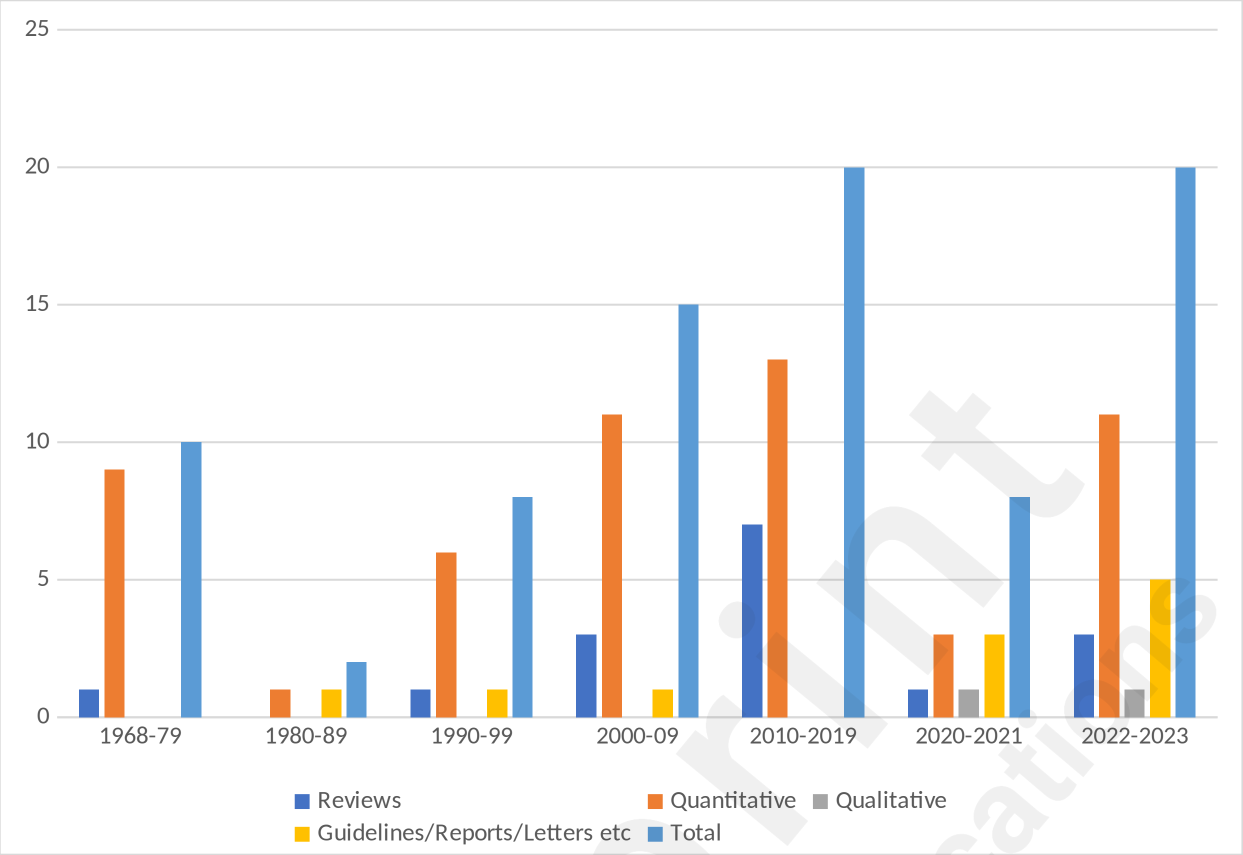


Results of the map

The interactive EGM [31] comprises two distinct types of evidence: (i) research evidence published in academic journals; and (ii) evidence published by people (or their carers/family members) living with TSWS on social media. There were 82 publications by academics/clinicians and 223 social media posts (includes Instagram, Reddit and Blogs) by people living with TSWS or by carers/family members.

The 82 publications by academics/clinicians were published over a period of 55 years from 1968 to 2023 (see Figure 2), with one study published in 1969 (Sneddon, 1969) and increasing to 20 in 2022-23. The research evidence published by academics/clinicians included reviews (n =16), quantitative studies (n = 54), qualitative studies (n = 2) and Guidelines/Reports/Discussions/Editorials (n = 10). There were only two systematic reviews and 14 non-systematic reviews. The quantitative studies comprised mostly case reports/histories (n = 34), and no Randomised controlled trials (RCTs). The research evidence was located in 14 countries: the US (n = 37), the UK (n = 13), Australia (n = 7), Japan (n = 6), India (n = 4), Taiwan (n = 3), Singapore (n = 2), Ireland (n = 2), China (n = 2), France (n = 2), Canada (n = 2), South Africa (n = 1), Tunisia (n = 1) and Germany (n = 1).

Figure 2 Number of academic publications and years of publication



There were 71 blogs and 152 Instagram and Reddit posts included: the blogs were published between 2011 and 2022 and the Instagram and Reddit posts were published between 2022-2023 which reflects the decision to sample Instagram and Reddit posts on specific dates. The social media evidence was located in 11 countries: the US (n = 21), the UK (n = 19), Australia (n = 7), Canada (n = 5), New Zealand (n = 2), Singapore (n = 2), Ireland (n = 1), Taiwan (n = 1), South Africa (n = 1), Portugal (n = 1) and Belgium (n = 1). However, it was not always possible to know in which country the social media posts originated.

The majority of the research evidence focused on adults (61%), followed by children aged 4-12 years (22%), infants aged 0-3 years (16%) and young people aged 13-18 years (11%). Likewise, adult experience of TSWS was more highly represented in the social media evidence (56%) with only 6% of posts focusing on young people, children and infants. Both the research evidence and the social media evidence did not always report the TCSs used (49% & 53%) and Table 1 shows those that were most used when specified.

Table 1. Most used topical steroids reported in research evidence and social media evidence

Steroids used	Research evidence (%)	Social media evidence (%)
Betamethasone	34	10
Clobetasol	23	9

Hydrocortisone	19	16
Triamcinolone	18	6
Fluocinolone	16	0
Mometasone	16	8
Systemic steroids	16	7

It was not always possible to determine how long people had been using TCSs but 33 publications reported people using TCSs for up to 10 years and 13 reported more than 10 years of use. In the social media evidence, there were 25 posts that indicated up to 10 years of use and 40 posts that indicated more than 10 years. The main area of the body affected, as reported in the research evidence, was the face (48%), then the legs (19%) and arms (18%). In the social media evidence, it was the face (22%), followed by the legs (11%), but 22% of the posts reported that the entire body was affected. The main reason for stopping TCSs, according to the research evidence, was doctor's advice to stop (12%), followed by lack of durable benefit (7%), no longer effective (7%) and required to participate in a study (5%). The main reason for stopping in the social media evidence was awareness of TSWS as a condition (15%); other reasons were no longer effective (7%), awareness of side effects (e.g. skin thinning) (4%) and lack of durable benefit (2%). Diagnosis by a clinician/dermatologist was recorded mostly in the research evidence (31%) and less so in the social media evidence (4%), where self-diagnosis was greatest (17%) and with the support of social media (11%). Patch testing was reported in both the research evidence (13%) and social media evidence (1%). There were also cases where a diagnosis of TSWS had not been confirmed in the social media evidence (4%), where individuals reported that they were unsure if they were experiencing TSWS or something else.

Risk factors

The risk factors for TSWS featured in the research evidence and highlighted 'prolonged use of moderate to high potency TCSs' (41%) and 'prolonged and frequent use of TCSs' (39%) as most recognised. History of atopy (18%) and inflammatory skin conditions (14%) were also reported. In contrast, risk factors did not feature strongly in the social media evidence with only 5% of posts referring to prolonged and frequent use of TCSs.

Physical symptoms (skin and non-skin)

A range of skin symptoms of TSWS were reported in the academic publications: rash (including redness, papules, erythema) (72%), itch (46%), burning/stinging (43%), scaling (42%), pustules (40%), telangiectasias (36%), edema (36%) and dryness/flaking (29%). The social media evidence reported similar symptoms but with some variation: rash (38%), itch (37%), dryness/flaking (36%), oozing/crustiness (31%), burning/stinging (19%), cuts (18%), edema (17%), skin pain (other than burning pain) (17%), thickening of outer layer of skin (12%) and smell (11%).

The most common non-skin symptoms of TSWS reported in the research evidence were increased hair growth (13%), sleep loss (11%), temperature regulation 11%) and lymphadenopathy (10%). A wider range of symptoms were reported in the social media evidence with sleep loss (24%), temperature regulation (17%), fatigue and muscle weakness (13%), pain (including nerve pain) (9%), mobility issues (7) and lymphadenopathy (4%).

Mental health symptoms

In the research evidence, 12% of the academic publications reported depression, anxiety and stress, 11% reported suicidal thoughts and 6% reported emotional fluctuations. Interestingly, the social media evidence, captured two additional aspects of mental health - self-image (both negative and positive) (20%) and resilience (20%). These were followed by depression, anxiety and stress (19%), emotional fluctuations (11%), and suicidal thoughts (2%).

Relationships

How living with TSWS impacted adults' and children's relationships with others was not addressed in the research evidence, apart from one qualitative study which acknowledged its impact on relationships within the home and with doctors and dermatologists. In contrast, this featured strongly within the social media evidence; relationships at home (20%), at work and in education (3%), with doctors and dermatologists (20%), with other therapists (4%), and other people with TSWS – often via social media (14%).

Beliefs and attitudes

The beliefs and attitudes towards TCSs, TSWS and information on TCSs and TSWS featured most strongly in the social media evidence. The belief in the importance of perseverance for coping with TSWS was emphasised (22%), followed by the need for 'alternative' sources of information on TSWS (14%) and the belief that the information on TCSs from doctors was inadequate (9%). Mistrust of medical professionals featured (9%), along with the perception that doctors do not believe that TSWS exists (7%) and fears of steroids and medications (5%). The research evidence was sparse but fear of steroids and medications was reported (7%), alternative sources of information on TSWS (6%) and belief that TSWS does not exist (6%).

Activities of everyday living

Living with TSWS affected people's everyday lives and not surprisingly, this was captured by the social media evidence across all the domains: with social life (14%), work (14%), self-care (11%), holidays/leisure (6%) and college/school (5%). In contrast, the research evidence gave little attention to how TSWS impacted work (4%), college/school (2%) and social life (2%).

Treatments

Complete cessation of TCSs was the favoured strategy in both the research evidence (55%) and the social media evidence (23%). Tapering off TCSs featured more in the research evidence (27%) than in the social media evidence (5%). Using systemic steroids as a treatment was reported in the research evidence (13%) but less in the social media evidence (2%); and restarting TCSs was reported in the social media (4%) but less in the research evidence (6%). Some of the pharmacological treatments mentioned in the research evidence were niche (mentioned only once) such as Montelukast, adrenocorticotropic hormone (ACTH), platelet rich plasma (PRP), intravenous immunoglobulin (IVIG) and Nicardipine, and were not mentioned in the social media evidence at all. Not surprisingly, the research evidence tended to report greater use of pharmacological treatments, while the social media evidence highlighted the treatments most used by people living with TSWS, as shown in Table 2.

Treatment costs and Outcome measures

Treatments costs were only mentioned in a small proportion of the social media evidence (7%) and in the research evidence (2%). There was little on outcome measures with 5% using the Dermatology Life Quality Index and 1% using self-assessed questionnaires. The social media evidence showed that people were recording their feelings of progress on the ‘TSW journey’ to recovery (10%), and a smaller proportion (4%) referred to ‘being healed’ - reaching the end of the TSW journey.

Table 2. Treatments for TSWS in research evidence and social media evidence

Treatments used	Research evidence (%)	Social media evidence (%)
Antihistamines	28	10
Antibiotics	40	9
Cyclosporine	10	4
Dupilumab	10	5
Methotrexate	2	2
Emollients/moisturisers	29	26
Alternative remedies	10	23
Bathing interventions	6	21
Diet changes	12	13
Clothing interventions	1	9
Hot/cold treatments	17	9
Psychological therapy/support	22	0.5
Online support	5	16

DISCUSSION

This EGM presents the developing body of research evidence on TSWS, enabling a timely insight into the topics of interest to the medical and dermatological community. The research evidence was distributed across a number of the topics but there were many where evidence was clearly lacking such as diagnosis, prevention, epidemiology, relationships, activities of everyday living, beliefs and attitudes, treatments costs and outcome measures. The EGM also presents a sample of the social media evidence on TSWS which concentrated on the physical symptoms (skin and non-skin), mental health symptoms, relationships, activities of everyday living, beliefs and attitudes, and treatments. This, by implication, highlights additional topics that need greater attention from academics and clinicians and confirms the need for research on the patient's lived experience of TSWS.

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 medical and dermatological communities. The need for consensus on diagnostic criteria has been recognised as a 'priority' by a few authors [18, 32] and arguably, without these, it is not possible to understand the incidence, prevalence and distribution of TSWS. In 2014, Fukaya et al [4:136] stated that there were "no statistics regarding the prevalence of TSA" and this remains the case. The challenge of diagnosing TSWS was reiterated [1, 9-10, 12, 33-34] and the main differentials were atopic dermatitis itself, allergic contact dermatitis and infection. Sheary [1: 214) observed that many of the symptoms of TSWS may also be seen in severe atopic dermatitis but argued that the process of differential diagnosis relies on a thorough understanding of patient history and physical examination. Unsurprisingly, most cases of TSWS are self-diagnosed rather than by a clinician or dermatologist [10], which was confirmed by the social media evidence. Sheary [1:214) proposed a set of diagnostic criteria as a starting point for discussion and future research: it comprised (i) essential criteria; (ii) key diagnostic criteria; (iii) additional supporting features that may be present. The essential criteria are history of long-term regular use of TCSs, itch and erythema. Lio & Chandan's [10:37) key diagnostic criteria (equivalent to Sheary's 'essential' criteria) are burning, confluent erythema and history of frequent and prolonged TCSs use. These proposals, along with Guo et al's [35] proposed work on diagnostic criteria using a modified Delphi approach, could provide a way forward for the medical and dermatological communities to engage with the issue of agreeing recognised diagnostic criteria.

Given that addiction precedes withdrawal, prevention of addiction to TCSs is of paramount importance. According to Sheary [2] it is 'not widely accepted' within the medical community that there may be withdrawal symptoms associated with TCSs cessation, and she argues that this may be because TCSs have been traditionally recommended for 'intermittent flares of symptoms' rather than long-term use. However, the EGM indicates that patients can use TCSs for years. For example, in a recent survey, people with eczema reported using TCSs for over 15 years [36], and in another study, length of use of TCSs for some people could be up to 40+ years [1]. Sheary [1:551] observed that TCSs 'overuse' has never been defined and arguably, neither has 'prolonged use'. That research has not investigated prolonged use of TCSs has been shown by a recent ‘umbrella review’ on safety of TCSs in adults and children with eczema [37] which found limited high-quality evidence for long-term use of TCSs. The data on prolonged use was limited as many RCTs were of short duration and did not include follow-up beyond two-four weeks of treatment. Axon et al [37:8) recommended that “…longer-term prospect observational studies are better placed to exploit longer-term safety of TCS and should be designed with years rather than months of follow-up to add useful information to the field.” Understanding the impact and safety of prolonged use of TCSs has not been prioritised, as argued by Peacock [38:174], who contends that large-scale research funding has, for decades, primarily focused on product development for pharmaceutical companies.

From the existing research evidence in this EGM, prolonged and frequent use of TCSs and prolonged use of moderate or high potency TCSs were identified as risk factors for TSWS. Yet this has to be juxtaposed with the dominant focus of the published medical literature on the safety of TCSs, reporting on patient ‘misuse’/’abuse’, ‘inappropriate use’ or ‘underuse’ [39] and how to encourage ‘correct use’ [40]. The ‘reluctance to use topical steroids as recommended’ [41:1] has been dismissed by many dermatologists as ‘steroid phobia’, as has TSWS [8]. Arguably, this narrative of blame filters through to GPs who can ‘struggle’ [38] to support people experiencing TSWS and need guidance from dermatologists on the safe use of TCSs “…in terms of potency, frequency, duration and area of TCS application” [32:1].

The research evidence devoted considerable attention to the physical ‘skin’ symptoms of TSWS which concurred, in the main, with the social media evidence. However, the social media evidence expanded on ‘other’ physical symptoms, mental health symptoms of TSWS, treatments used, and how it impacted on activities of everyday living and relationships. This gap in the research evidence can be explained by the lack of qualitative research with only two qualitative studies on TSWS published in the last fifty years. The research evidence also addressed treatments to manage TSWS which tended to be pharmacological, some of which were also mentioned in the social media. The social media evidence revealed that people with TSWS were using a range of non-pharmacological treatments which included emollients and moisturisers and bathing interventions, and then ‘alternative remedies’ which could encompass acupuncture, hypnotherapy and homoeopathy, for example. Interestingly, the research evidence on pharmacological treatments such as Dupilumab reported treatment improvements after relatively short periods such as eight, 13 and 31 weeks [42]. ‘Successful’ treatments were less ‘linear’ in the social media evidence, particularly in the blogs, where people with TSWS often reported a ‘rollercoaster’ experience of recovery over many months and even years, that could be punctuated with debilitating flares of symptoms such as itch, flaking and oozing. With only one prospective cohort study in the EGM [3], there is clearly a need for more longitudinal research on the patient's 'TSWS journey' to healing.

Psychological therapy/support was one of the treatments that clinicians recommended for people with TSWS but this hardly featured in the social media evidence. Online support was important for people with TSWS which is possibly an artefact of social media being a form of online support and a reflection of the quality of the doctor-patient relationship. Those who felt that their experiences and concerns were disregarded by their doctors and dermatologists often turned to social media for support and information [17].

Arguably, regardless of whether dermatologists and clinicians accept TSWS as a distinct clinical entity, there are important reasons why they need to engage with patients' stories of living with TSWS from the social media. To dismiss people living with TSWS as 'misusers' and 'misinformed' means that they may be left alone to deal with the symptoms of TSWS and consequently, may 'seek inappropriate alternative therapies'' [32] that could be detrimental to their care and impact their recovery from TSWS [5].

Strengths and limitations

This study represents the first EGM in TSWS and responds to calls for a better understanding of TSWS. It aims to be an important resource to guide both researchers and clinicians in the prioritisation of research topics for further research. Mapping both research evidence and social media evidence is a methodological innovation in the production of EGMs. The inclusion of social media evidence was in recognition of the increased presence of #topicalsteroidwithdrawal on social media [15], and how social media content could contribute to understanding the patient perspective of TSWS. Social media is increasingly used by qualitative health researchers and there has been some interest in social media within the dermatological community [43]. In the EGM, there is only one example of researchers reviewing social media blogs to understand children's experiences of TSWS [44]. Due to the amount of social media content available on TSWS, we decided that a sample of social media evidence was the only feasible approach for this EGM and therefore, it provides a single snapshot of the social media evidence. Furthermore, bloggers, and people using Instagram and Reddit are a self-selecting sample who are clearly proficient with technology, so it is difficult to know how reflective they are of those living with TSWS. This does not devalue their accounts but means that there are likely to be many people's experiences of TSWS that are not shared on social media. There were also some cases – bloggers in particular – who presented with a self-diagnosis of TSWS but were unsure whether their symptoms were TSWS, and it was challenging to judge the veracity of their accounts. The ephemeral nature of social media data should also be noted and some of our selected Instagram and Reddit posts were removed after inclusion in the EGM. As an EGM dealing with a range of academic publications and social media evidence, we did not conduct a critical appraisal [22]. The low quality of the existing research evidence has been noted [5, 9, 16] and there is undoubtedly, an urgent need for high quality qualitative and quantitative research. However, this EGM offers an overview of the TSWS research landscape and an insight into what people living with TSWS are discussing on social media.

Conclusions

TSA, as an adverse effect of TCSs, was first identified in 1969 and yet over fifty years later, TSWS remains controversial and contested in the dermatological and medical communities. This EGM shows that TSWS has attracted increased research attention over the years but high quality research is lacking. The evidence gaps highlight priorities for future primary research which are: longer-term prospect observational studies to assess the safety of prolonged use of TCSs and help prevent addiction; qualitative research to understand the lived experience of TSWS; and longitudinal research on the patient’s ‘TSWS journey’ to healing. However, it is crucial that future research in TSWS is underpinned by work that determines agreed diagnostic criteria for TSWS.

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Conflicts of interests

None declared.

Contributors

KS, JTC, NO, MR, & AS conceived of the project and co-developed the framework for the Map; MR carried out the systematic search of the literature and social media; MR & NO selected the academic publications and social media evidence. MR & NO extracted and checked the data. NO & MR drafted the manuscript and all authors revised and commented on the manuscript. All authors read and approved the final manuscript.

Multimedia Appendix 1

Search strategy

Legends

Figure 1. PRISMA

Figure 2. Figure 2 EGM Research Evidence and Social Media Evidence by Research Topics and Years of Publication

Figure 3 Number of academic publications and years of publication

Table 1 Most used topical steroids reported in research evidence and social media evidence
Table 2 Treatments for TSWS in research evidence and social media evidence

Supplementary material

File 1: The original protocol for the study
File 2: Search Strategy

Supplementary Files

Multimedia Appendixes

Search Strategy.
URL: http://asset.jmir.pub/assets/1bf8a7e04b1dec0778928e576dfab5d5.docx