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Investigating Topical Steroid Withdrawal Syndrome Videos on **TikTok** #TSW

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Introduction

Social media is increasingly integrated into healthcare delivery, aiding in **awareness** while also contributing to the **spread of misinformation**.

TikTok: fastest-growing platform with over 1 billion monthly active users.

- “For You Page” feature on TikTok:
 - Curated content based on personal interests.
 - Helps video creators reach more viewers.
 - Enables users to easily find millions of relevant videos.
- **Health care–related** content on TikTok has vast reach and high engagement.

Topical Steroids in Dermatology

Commonly used first-line treatment for conditions like atopic dermatitis, eczema, and psoriasis.

Misuse occurs despite established protocols for indications and usage.

Improper use and abrupt discontinuation can lead to adverse effects, **rarely** including topical steroid withdrawal (TSW).



Topical Steroid Withdrawal Syndrome

TSWS

TSWS is not widely recognized as its own entity, nor does it have diagnostic criteria or defined pathology.

Consensus: a history of long-term and regular topical steroid use

Itching or burning of the skin, and erythema

Symptoms are often worse than the pretreatment condition, appearing days to weeks after discontinuing steroid use and extending beyond the area treated with topical steroids.

Topical Steroid Withdrawal Syndrome

Important to differentiate the **specific topical steroid**, the **extent of body surface area** affected and **the time of use** when assessing TSW.

Underlying conditions, not just topical steroid use, can also cause new atopic issues.

Topical Steroid Withdrawal Syndrome

Referred to by patients as ‘topical steroid withdrawal’, ‘topical steroid withdrawal syndrome’, ‘red skin syndrome’ or ‘topical steroid addiction’.

Patients share experiences on social media under “topical steroid withdrawal (TSW),” a hashtag with 622.7 million views on TikTok, **though it is not yet formally defined as a separate condition.**



Investigating Topical Steroid Withdrawal Videos on TikTok: Cross-Sectional Analysis of the Top 100 Videos

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Given the fact that TSW videos have such a wide reach on TikTok, the videos' credibility and accuracy need to be evaluated and scrutinized.

The study aims to analyze the top 100 videos on the topic of TSW on TikTok, possible recurrent themes or definitions of this condition, and the video quality.

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1. Queried hashtag #topicalsteroidwithdrawal on TikTok
 2. First 100 “Top Videos” included
 3. Two independent reviewers assessed all videos; a third reviewer resolved discrepancies

Videos extracted on January 15, 2023

4. Assessed the demographics, the content and also the quality of the videos using three scoring scales:
 - DISCERN (15 questions, each scored 1–5; average score 1–5)
 - JAMA (4 questions, each 0 or 1; total score 0–4)
 - Global Quality Scale (GQS) (single choice 1–5)

Results

Only 10 videos gave a clear definition of TSW:

Four out of them defining it as an addiction to topical steroids, and the loss of skin tolerance to it, which culminates in the development of the condition.

Table 2. Main data extracted from the 100 videos on TikTok (N=100)^a.

	Not mentioned, %	Mentioned, %
Mention the condition as “TSW ^b ”	81.0	19.0
Definition of TSW	90.0	10.0
Cause of disease	83.0	17.0
TSW as a disability	96.0	4.0
Duration of withdrawal symptoms	75.0	25.0

Reasons for Discontinuation

Not mentioned in 90% (n=90) of videos.

Remaining 10% (n=10) reasons:

Aggravation of condition (4%, n=4)

Ineffectiveness (2%, n=2)

Steroid phobia (1%, n=1)

Pregnancy (1%, n=1)

Change of environment (1%, n=1)

Personal decision (1%, n=1)

Advised by a friend (1%, n=1)

Onset:

4% directly after stopping steroids

7% after 6–18 months

Duration (mentioned in 25 videos): 3 months up to 3 years.

Symptoms

Symptoms (n=60)

Short-term symptoms

Itchiness	22 (22.0)
Peeling, shedding, and flaking	19 (19.0)
Dryness and dehydration	19 (19.0)
Pain	13 (13.0)
Redness, burning, and red skin syndrome	15 (15.0)
Oozing and pus	10 (10.0)
Limitation of movement	7 (7.0)
Tiredness	5 (5.0)
Mental health issue	5 (5.0)
Bleeding	2 (2.0)
Sweating	2 (2.0)
Hair loss	2 (2.0)
Insomnia	4 (4.0)
Scaling and crusting skin	3 (3.0)
Irritated skin and allergy to food	1 (1.0)
Elephant skin	1 (1.0)
Spider veins	1 (1.0)

Long-term complication

Inability to go to work	10 (10.0)
Mental health issues such as unspecific mental problems, panic attack, PTSD ^b , suicidal attempt	7 (7.0)

Table 4. Mean (SD) and the range of the video parameters.

	Mean (SD)	Range
Video length (in seconds)	61.58 (55.97)	5-218
Days on TikTok	269.69 (138.09)	56-711
Number of views	2017229.10 (4825328.89)	20,300-38,500,000
Number of daily views	10141.27 (17934.30)	76.44-76056.34
Number of likes	489702.60 (3407573.30)	153-33,900,000
Number of comments	961.61 (1813.10)	0-9823
Number of shares	1200.65 (3244.26)	0-26,100
Number of saves	3215.08 (12695.86)	2-118,000
DISCERN	1.63 (0.56)	1-3.46
<i>JAMA</i> ^a	1.30 (0.56)	1-3
GQS ^b	1.71 (0.84)	1-4

Principal Findings

Lack of Key Information

- Most TikTok videos omit crucial details (initial condition, specific steroid used, duration of usage, reason for discontinuation).
- Only 18% disclosed initial condition, 7% identified steroid, 14% mentioned duration, 11% gave reasons, 5% indicated method of discontinuation.

Improper Use & Discontinuation

- Duration of usage often long-term, raising concern for misuse.
- Abrupt discontinuation repeatedly mentioned; tapering rarely discussed, despite its importance in preventing withdrawal symptoms.

Definition & Onset of TSW

- Only 10% provided a clear definition; many vaguely differentiated TSW from eczema.
- Onset varied: some reported immediate symptoms post-discontinuation, others mentioned a delay of months.
- Raises question whether reported symptoms reflect TSW or flare-ups of existing conditions.

Symptoms & Side Effects

- Primarily broad, nonspecific descriptions (itchiness, rash).
- “Red skin syndrome” frequently cited as a potential hallmark.
- Mental health disturbances were mentioned but are also known in long-term steroid use, not necessarily withdrawal.

Inconsistent Management

- Video creators proposed varied, low-evidence treatments (homemade creams, Chinese medicine, “no moisture” regimen).
- Contradicts established guidelines emphasizing proper skin hydration and dermatologist supervision.

Key Findings

Quality of Videos

- Average DISCERN (1.63), JAMA (1.30), GQS (1.71)—all indicate poor or very poor quality.
- Video length, daily views, and total views show positive correlation with higher quality scores.
- 100% produced by personal accounts, no significant professional or verified medical content.

High Reach, Potential Misinformation

- Videos collectively viewed over 201 million times.
- Popularity on TikTok underscores its role as a gateway for health information, especially among younger audiences.
- Lack of professional involvement risks fueling steroid phobia and misinformation.

Call to Action

- Health care professionals should engage more on TikTok to provide evidence-based information.
- A standardized definition and clearer guidelines for TSW are needed to ensure consistent, accurate health messaging.

Conclusion

TSW TikTok videos have a massive reach but are of notably poor quality and inconsistent content.

The lack of reliable information may exacerbate steroid misuse, phobia, and mismanagement.

Greater professional presence and standardized definitions could mitigate misinformation and improve patient outcomes.

Future Work

Criteria to distinguish AD from TSW, what is different clinically?

Draw out the severity of their initial condition (AD), and whether they had severe recalcitrant disease which may be associated with increased risk of TSW.

What may have contributed to the reluctance to visit healthcare professionals.

How to increase our presence and visibility on social media to combat misinformation and ultimately help patients.

THANK YOU

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