

Tackling misinformation in social media: the example of topical steroid withdrawal (TSW)

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Disclosures of interest

Mikael Alsterholm has received speaker honoraria and/or been in advisory boards for AbbVie, Almirall, Eli-Lilly, Essity, Galderma, LEO Pharma, Pfizer, and Sanofi-Genzyme, and is/has been an investigator for AbbVie and Sanofi-Genzyme.

Misinformation & disinformation

- ***Misinformation***: Information that is false, but not necessarily harmful or intended to be harmful.
- ***Disinformation***: Disinformation is false and intended to (or inevitably does) cause harm.
- ***Infodemics***: overproduction of data from multiple sources, causing a torrent of online information containing either false and misleading information or accurate content.

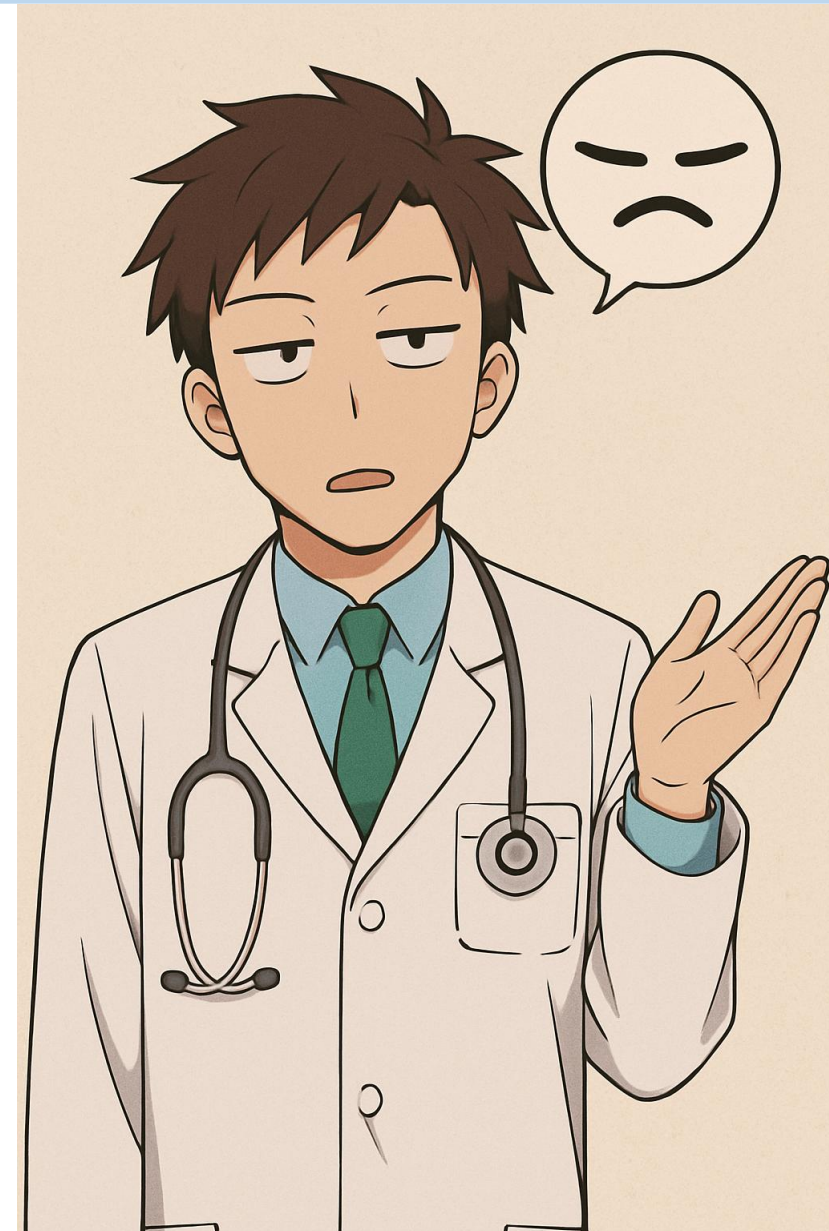
Jeng W et al. Strengthening scientific credibility against misinformation and disinformation: Where do we stand now? J Control Release. 2022 Dec;352:619-622. doi: 10.1016/j.jconrel.2022.10.035.

Borges do Nascimento IJ et al. Infodemics and health misinformation: a systematic review of reviews. Bull World Health Organ. 2022 Sep 1;100(9):544-561. doi: 10.2471/BLT.21.287654.



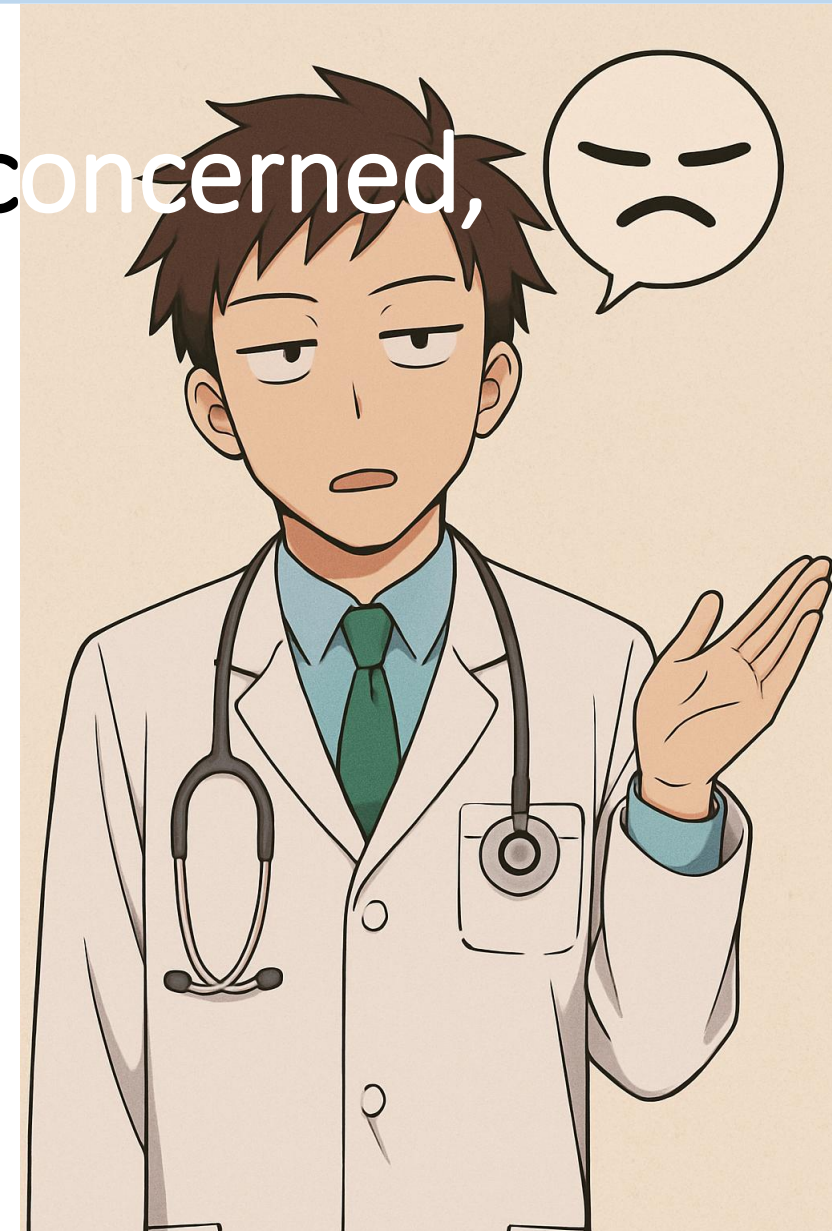
Should I worry about...

- the safety and effect of vaccines?
- consuming gluten?
- health hazards of sunscreens?
- topical steroid withdrawal?

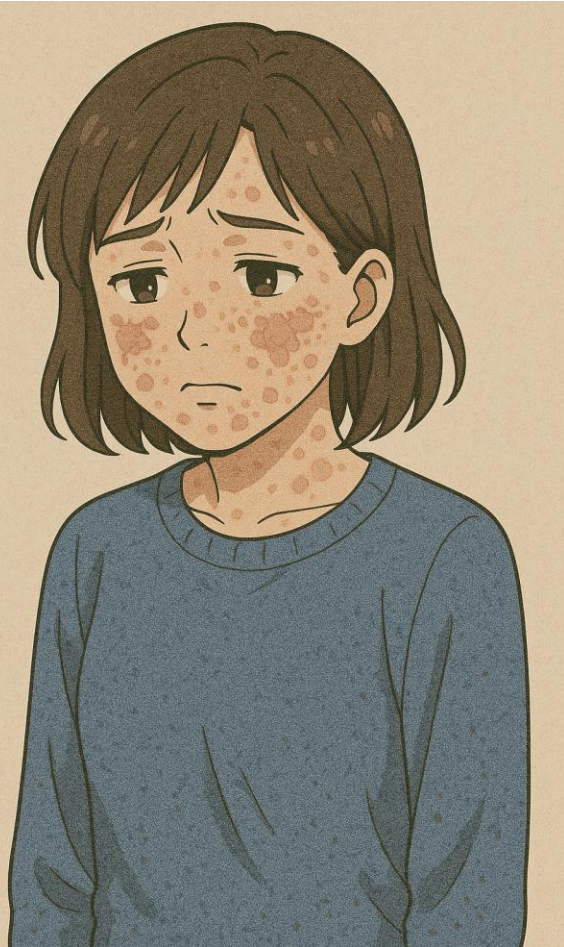


Why is the healthcare provider unconcerned, uncommitted or dismissive?

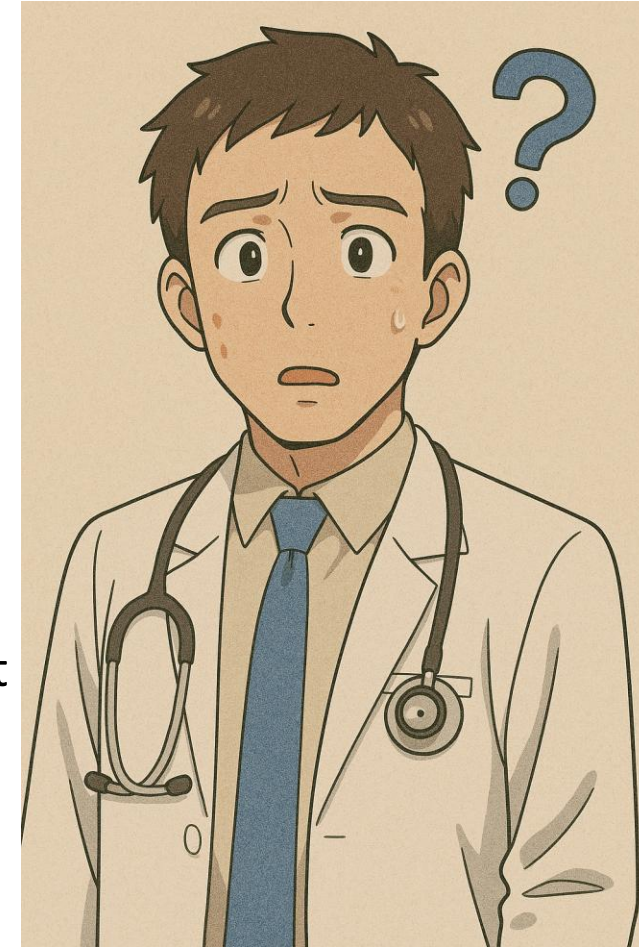
- Social media claims have been scientifically proven to be exaggerated or false.
- Social media claims are not supported by the collective experience of healthcare providers.
- There is ***no evidence*** to support social media claims ***due to lack of research***.
- Healthcare providers are ***required to base their recommendations on evidence***.



The example of topical steroid withdrawal (TSW)



- Major concerns regarding topical steroids and severe symptoms attributed to TSW
 - Strong belief in abundant and impactful social media content
 - Confusion and request for help
-
- Healthcare provider unfamiliar with the concept
 - Few scientific publications to support TSW
 - No recognised diagnostic criteria
 - Confusion and intention to help



Topical steroid withdrawal (TSW)

- Adverse reaction to the withdrawal of topical steroids.
- Erythema.
- Burning or painful sensation from the skin.
- Symptoms also reported during topical steroid use.
- No recognised diagnostic criteria.
- Is there a distinct pathophysiological mechanism?

1. Hajar T et al. A systematic review of topical corticosteroid withdrawal ("steroid addiction") in patients with atopic dermatitis and other dermatoses. *J Am Acad Dermatol*. 2015 Mar;72(3):541-549.e2. doi: 10.1016/j.jaad.2014.11.024.

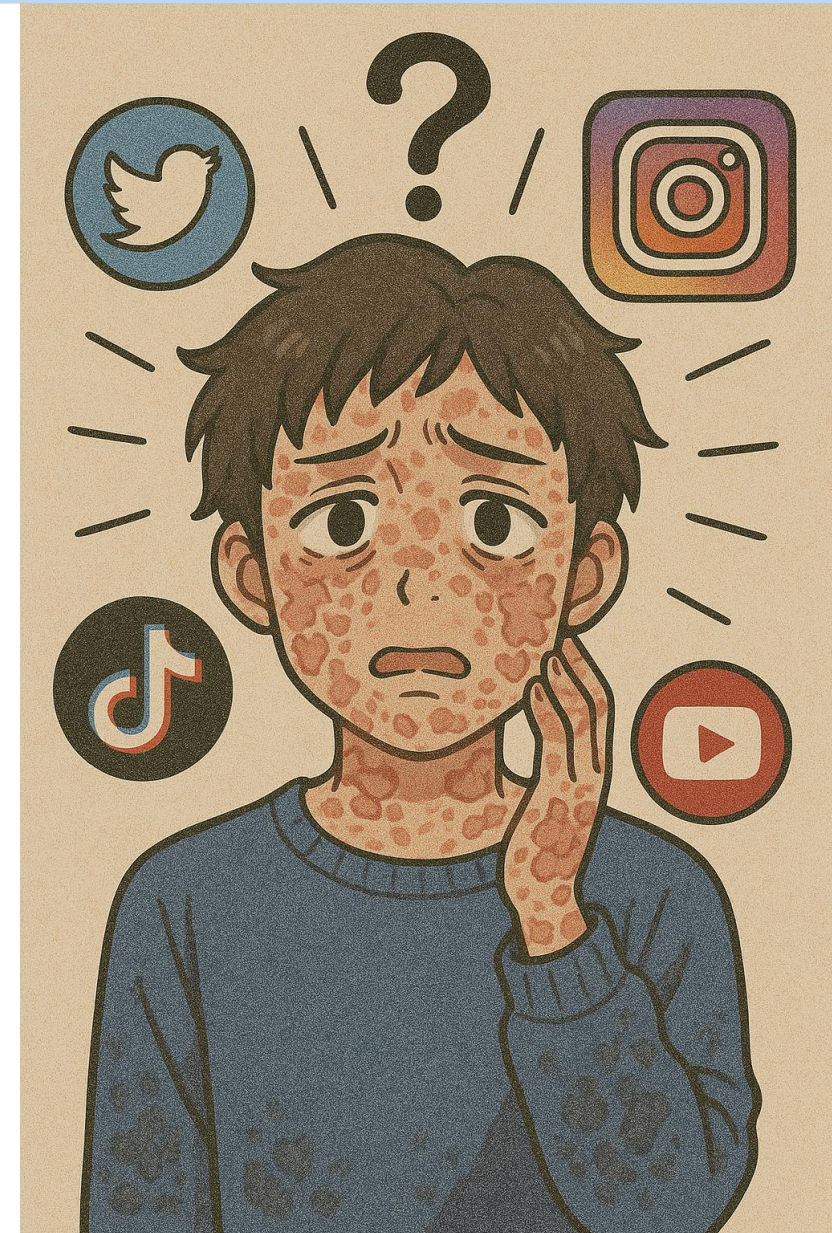
2. Hwang J, Lio PA. Topical corticosteroid withdrawal ('steroid addiction'): an update of a systematic review. *J Dermatolog Treat*. 2022 May;33(3):1293-1298. doi: 10.1080/09546634.2021.1882659.



Topical steroid withdrawal in social media

- Rapidly increasing amount of content with immense reach.
- Content based on personal accounts.
- TSW is not defined.
- Topical steroid abstinence is promoted.
- Misinformation about implausible underlying causes and alternative treatments for atopic dermatitis.
- Dermatologists are not providing content.

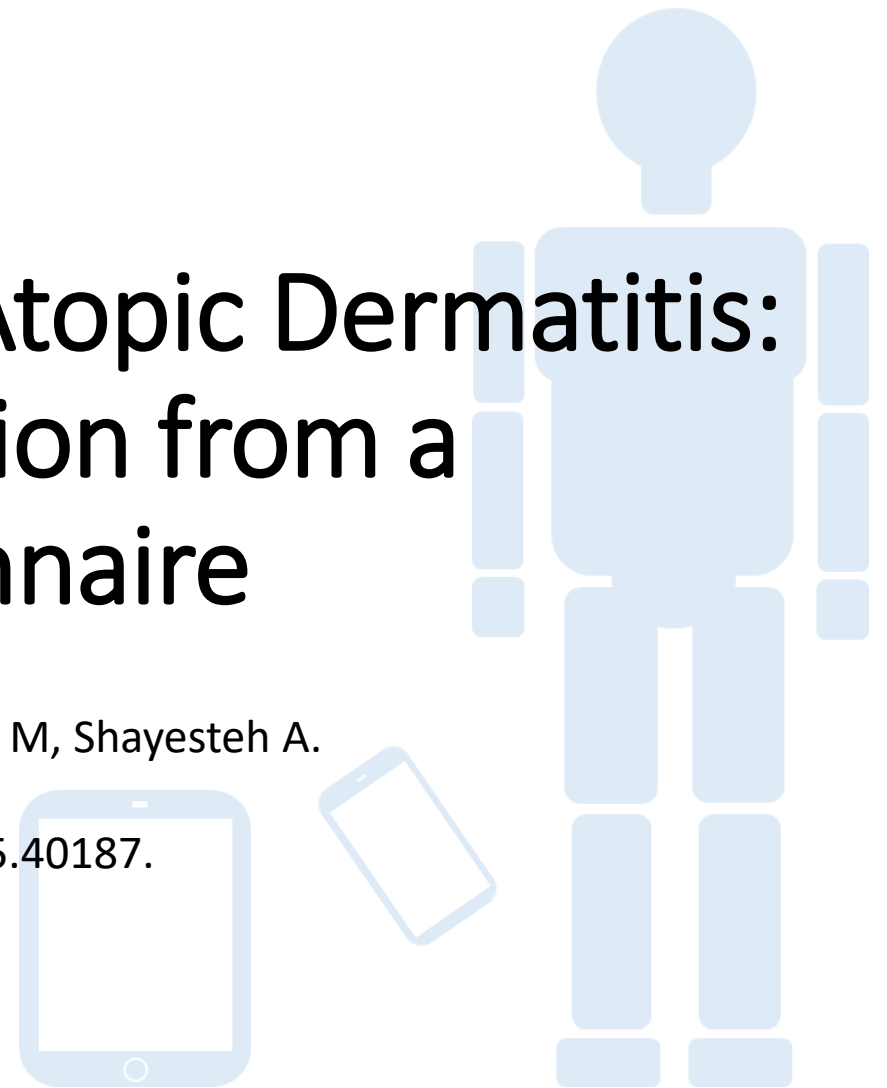
1. Finnegan P, Murphy M, O'Connor C. #corticophobia: a review on online misinformation related to topical steroids. Clin Exp Dermatol 2023; 48: 112-115.
2. Haddad F, Abou Shahla W, Saade D. Investigating Topical Steroid Withdrawal Videos on TikTok: Cross-Sectional Analysis of the Top 100 Videos. JMIR Form Res 2024; 8: e48389.
3. Nickles MA, Coale AT, Henderson WJA, Brown KE, Morrell DS, Nieman EL. Steroid phobia on social media platforms. Pediatr Dermatol 2023; 40: 479-482.
4. Orr N, Rogers M, Stein A, Thompson Coon J, Stein K. Reviewing the Evidence Base for Topical Steroid Withdrawal Syndrome in the Research Literature and Social Media Platforms: An Evidence Gap Map. J Med Internet Res 2024; 26: e57687.
5. Taieb A. Topical Steroid Withdrawal: The Challenging Transition from Patient Self-Diagnosis on Social Media to Medical Science and Care. Acta Derm Venereol 2025; 105: adv43455.1.
6. Bowe S, Masterson S, Murray G, Haugh I. Topical steroid withdrawal through the lens of social media. Clin Exp Dermatol 2022; 10.1111/ced.15194.



Topical Steroid Withdrawal in Atopic Dermatitis: Patient-reported Characterization from a Swedish Social Media Questionnaire

Alsterholm M, Af Klinteberg M, Vrang S, Sigurdardottir G, Sandström Falk M, Shayesteh A.

Acta Derm Venereol. 2025 Jan 3;105:adv40187. doi: 10.2340/actadv.v105.40187.



Aim

- To investigate the patients' own characterisation of TSW and their experience of the manifestations

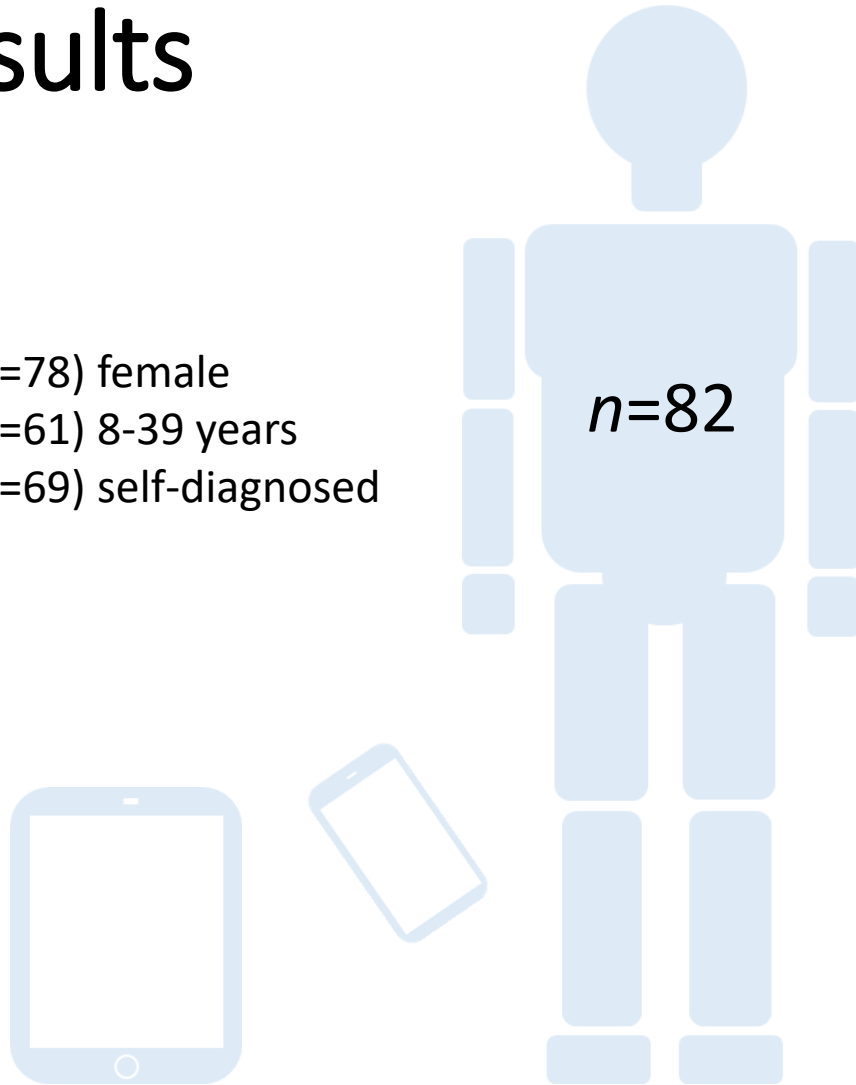
Method

- 47-item digital questionnaire (SurveyMonkey®) posted in a TSW-themed Swedish Facebook group
- 4 weeks, spring 2023
- ≥ 18 years, reporting AD and TSW
- Anonymous participation
- Link to the questionnaire free to share



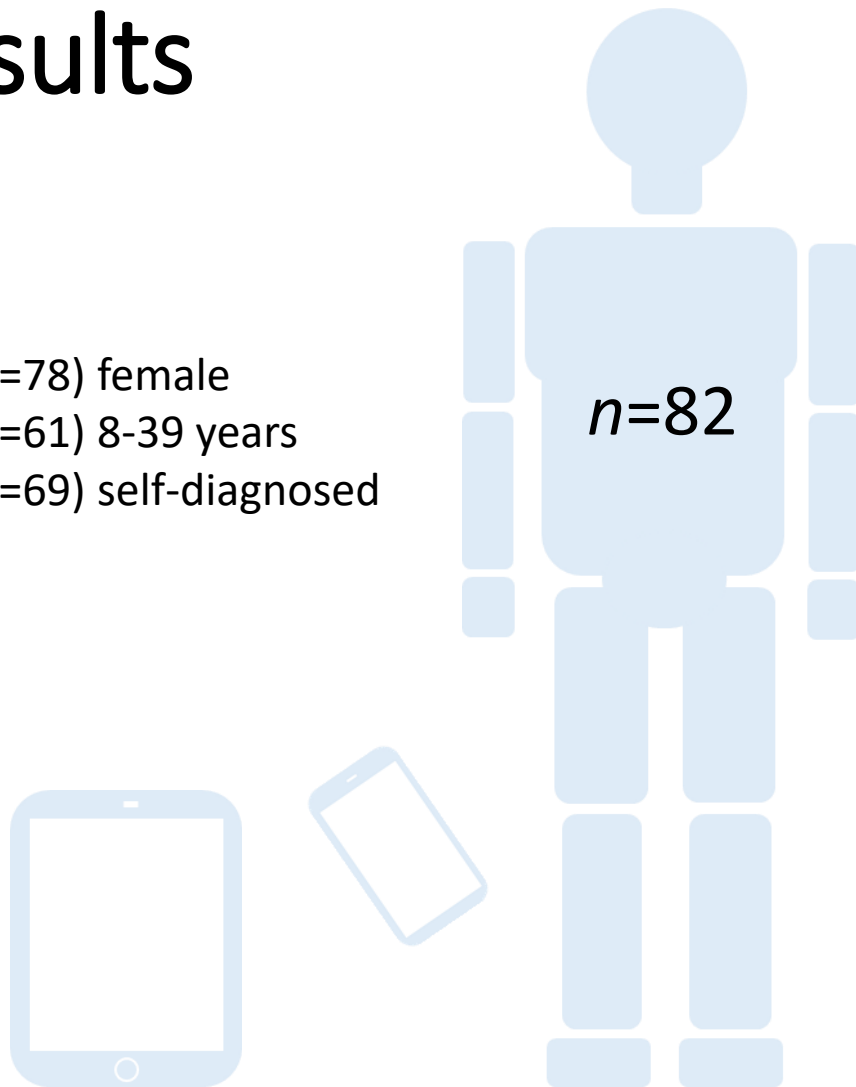
Results

95% ($n=78$) female
74% ($n=61$) 8-39 years
84% ($n=69$) self-diagnosed



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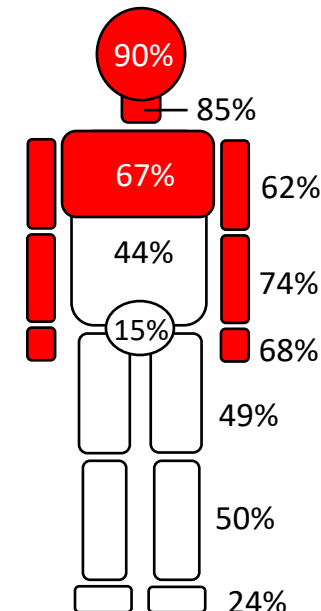
Text analysis of patients' definitions of TSW

Most common topics		Example of answers
Dependency	63%	'The skin is addicted to corticosteroids'
Skin symptoms	23%	'Red, itchy skin'
Reactions	20%	'Reaction to cortisone treatment'

Most common signs

Erythema	98%
Peeling skin	92%
Dryness	92%
Oozing	88%
Crusting	52%

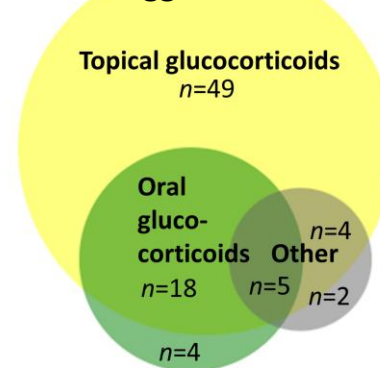
Area involvement



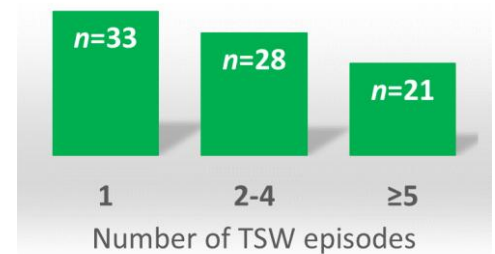
Most common symptoms

Pruritus	96%
Sleep disturbance	95%
Burning skin	90%
Stinging skin	89%
Skin pain	84%

Trigger factors ^a

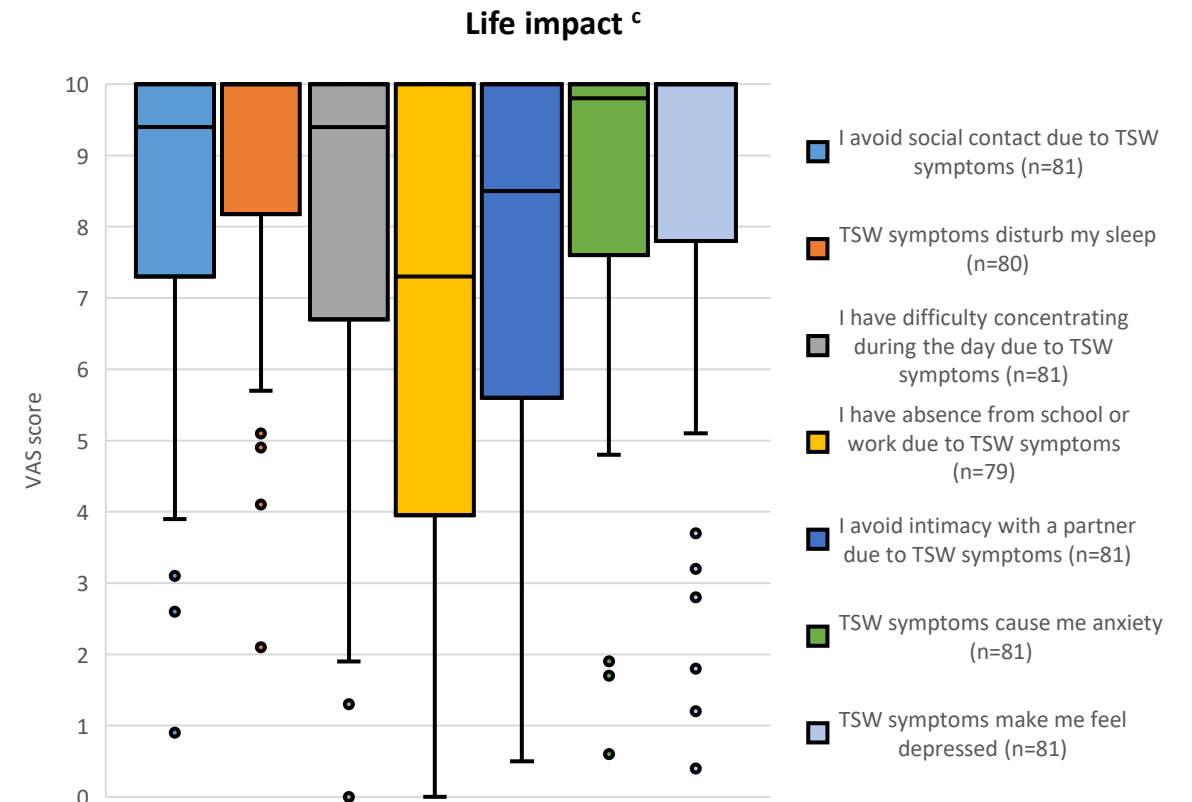
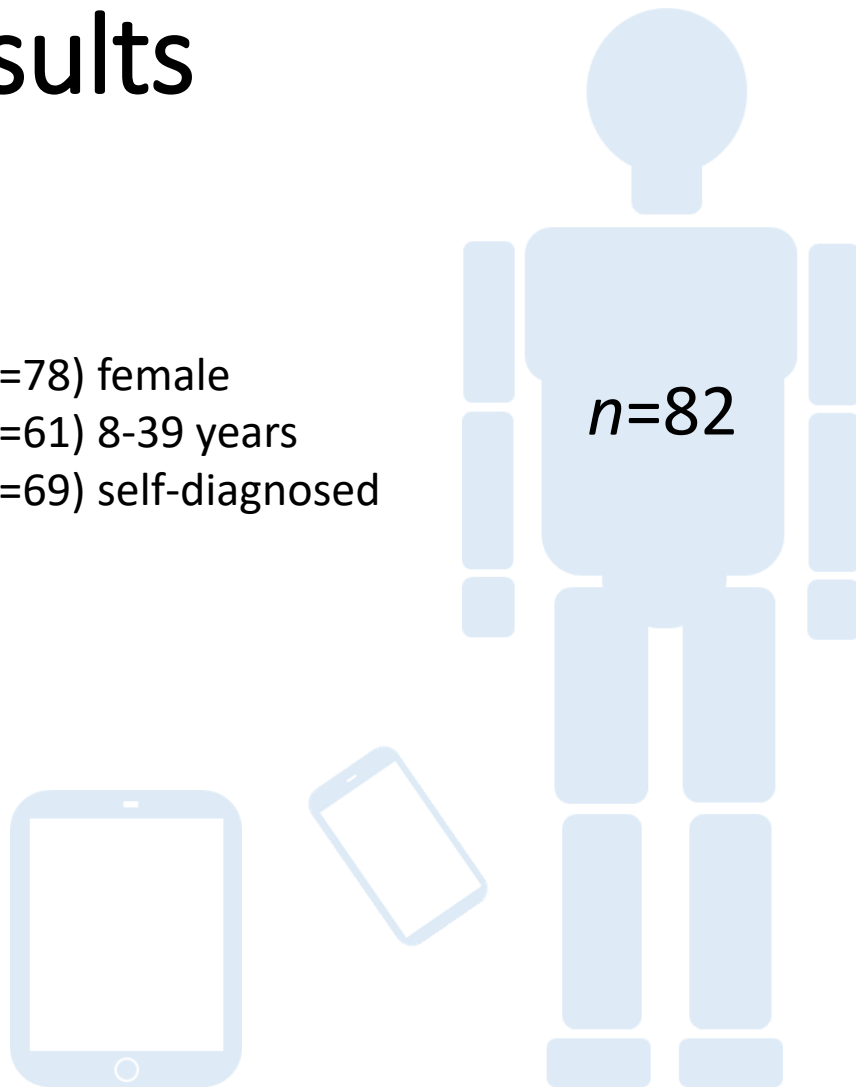


Recurrence ^b



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To manage TSW uncertainty, healthcare providers can

- ***Acknowledge and validate*** the concerns and the symptoms attributed to TSW
- ***Explain the current evidence-base*** of proposed explanations for symptoms
- ***Perform research*** to obtain more knowledge
- Be present on social media to ***provide relevant medical information based on evidence***



To manage TSW uncertainty, healthcare providers cannot

- Validate explanations for symptoms that lack scientific support.
- Recommend actions that lack scientific support or support in proven experience.



Key points

- ***TSW social media infodemics*** cause ***apprehension*** and ***diminish trust*** in healthcare providers.
- ***TSW information*** is currently of ***poor quality***.
- ***Research*** can ***improve*** the quality of ***information***.
- Healthcare providers need to ***address TSW concerns, with evidence, where they can be heard***.

Co-workers



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