

Deciphering topical steroid withdrawal as studied on a Facebook group

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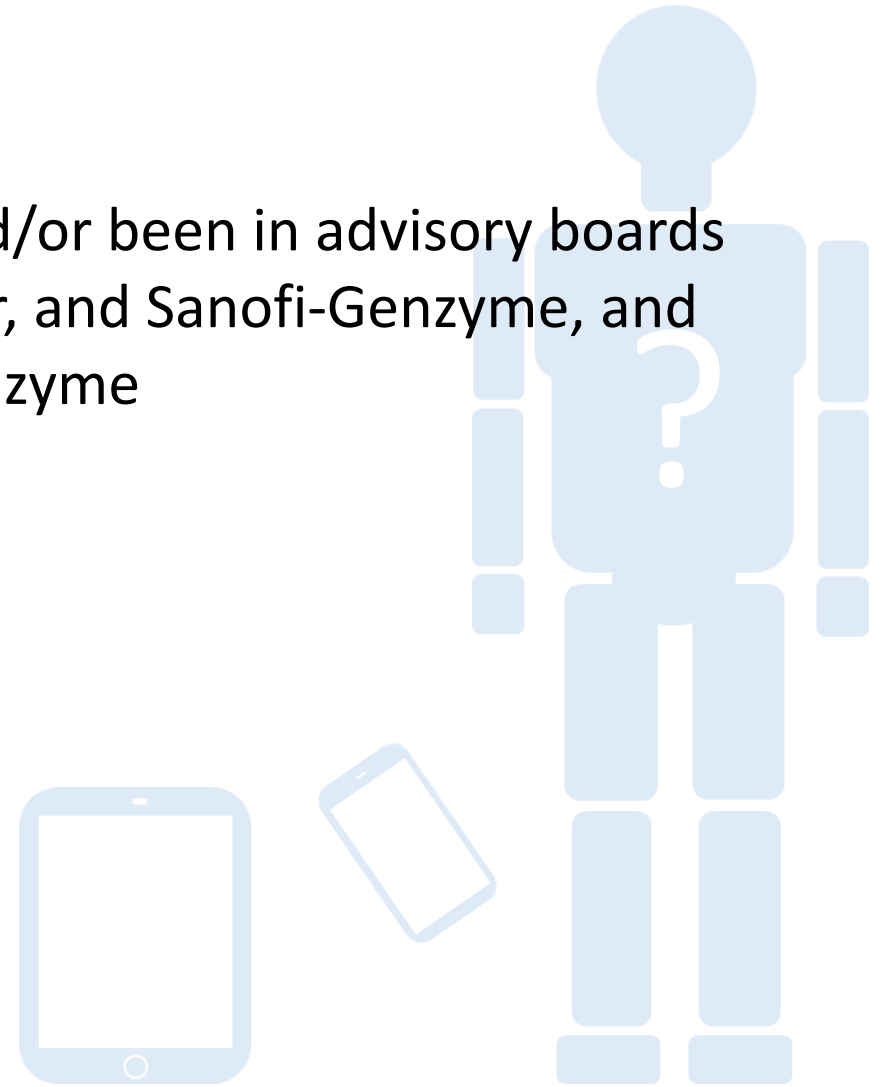
⁵ Department of Dermatology and Venereology in Östergötland, and Department of Biomedical and Clinical Sciences, Linköping University, Linköping, Sweden

⁶ Vasakliniken Dermatology Clinic, Gothenburg, Sweden



Disclosures of interest

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



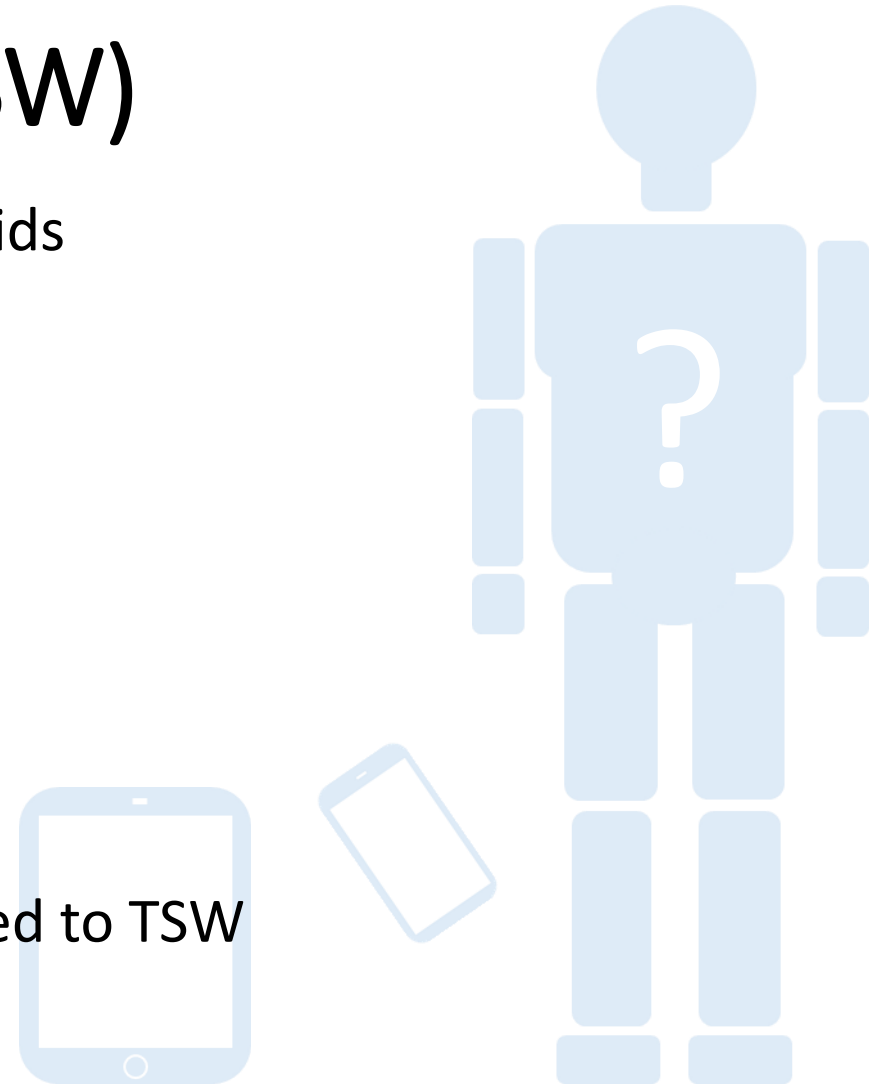
Topical Steroid Withdrawal (TSW)

- Adverse reaction to the withdrawal of topical steroids
- Erythema
- Burning or painful sensation from the skin

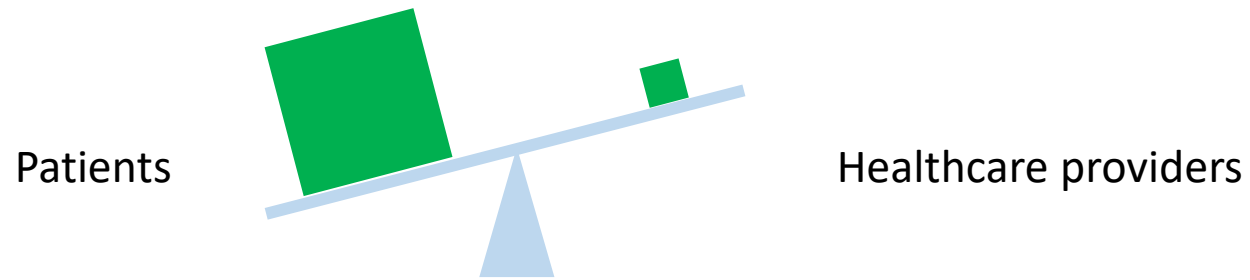
- Symptoms also reported during topical steroid use

- No recognised diagnostic criteria
- Is there a distinct pathophysiological mechanism?

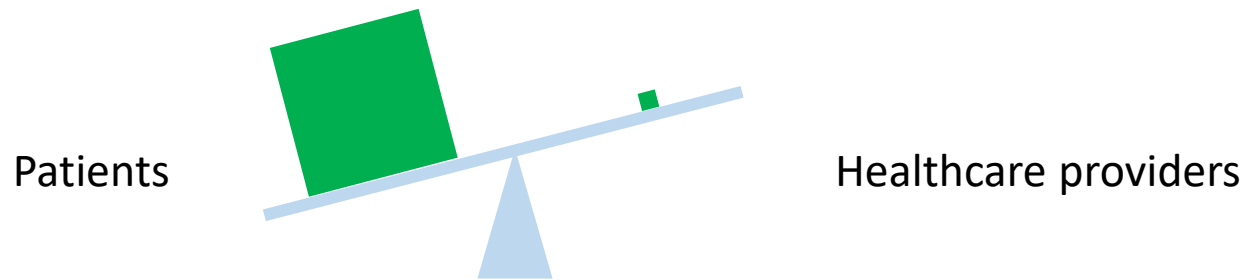
- Other possible explanations for symptoms attributed to TSW



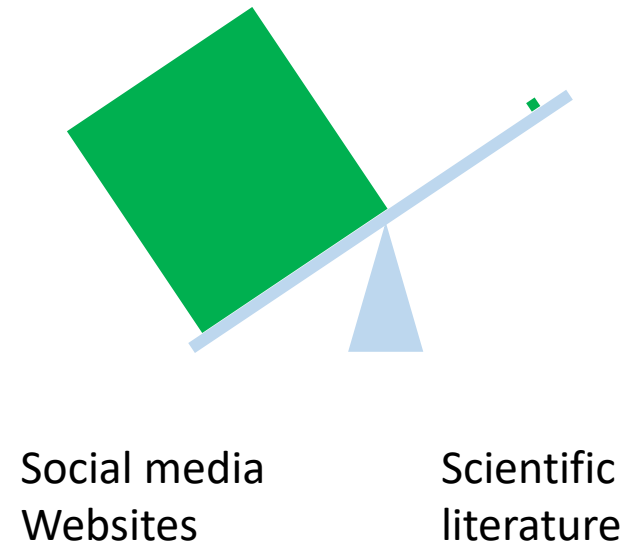
Concerns regarding topical steroid safety



Engagement in the TSW discussion



TSW information sources

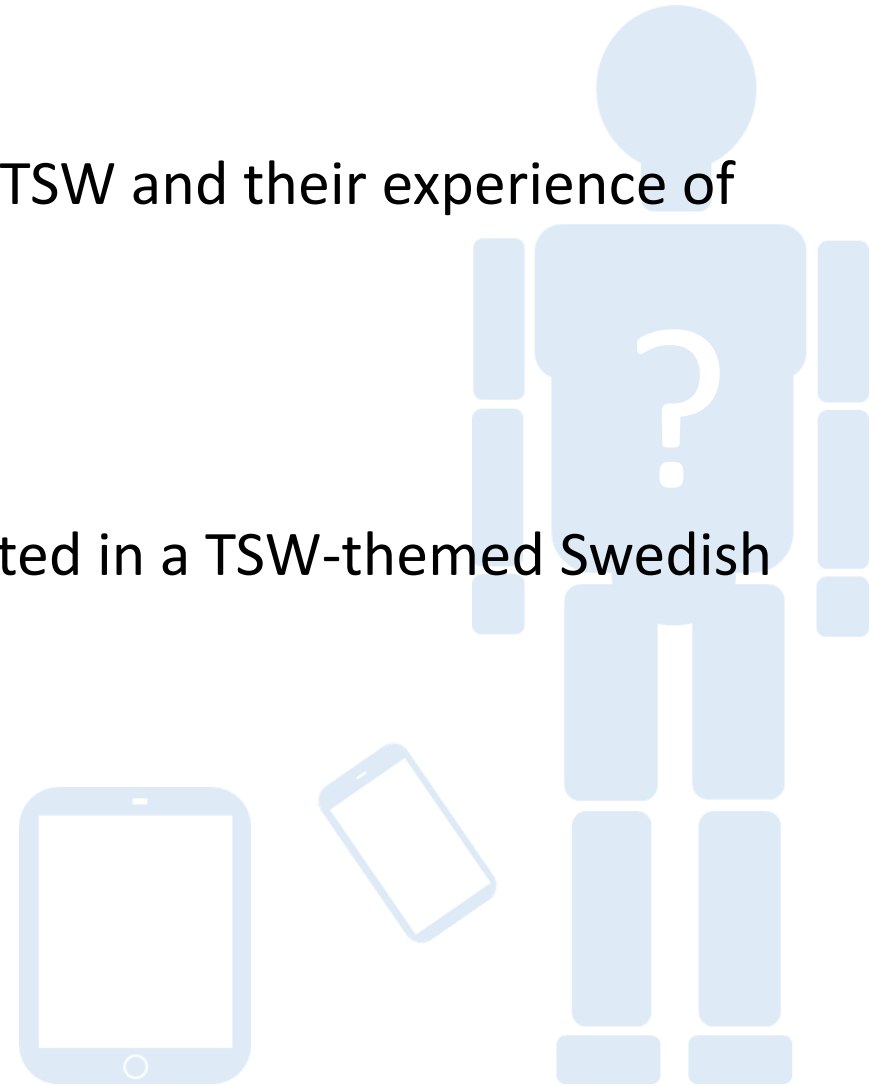


Aim

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

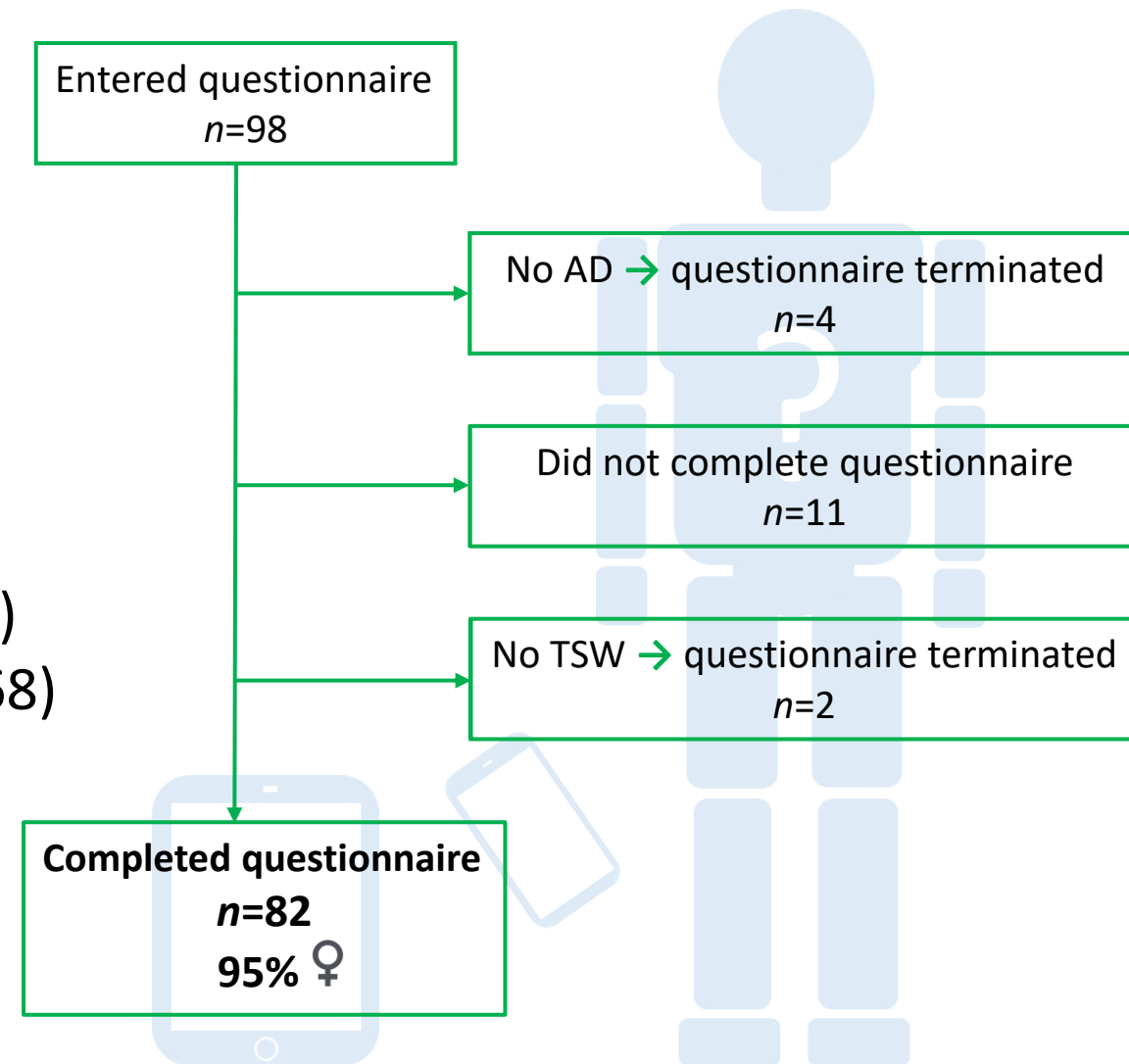
Method

- 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

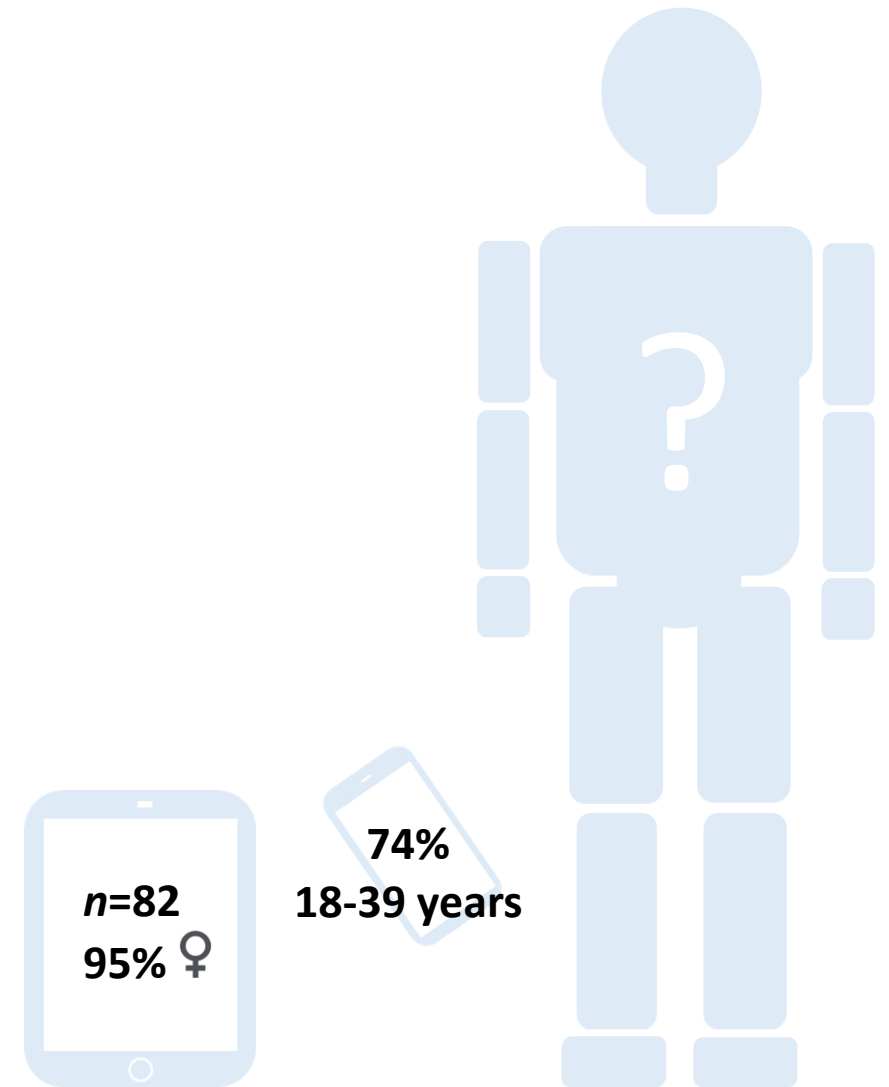
- 82 participants
- 95% ($n=78$) female
- 74% ($n=61$) were aged 18-39 years
- Medical history consistent with AD
- Ongoing symptoms attributed to AD 74% ($n=61$)
- Ongoing symptoms attributed to TSW 83% ($n=68$)
- Ongoing symptoms of AD and TSW 65% ($n=53$)
- 84% ($n=69$) self-diagnosed with TSW



Results

Reported skin signs

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



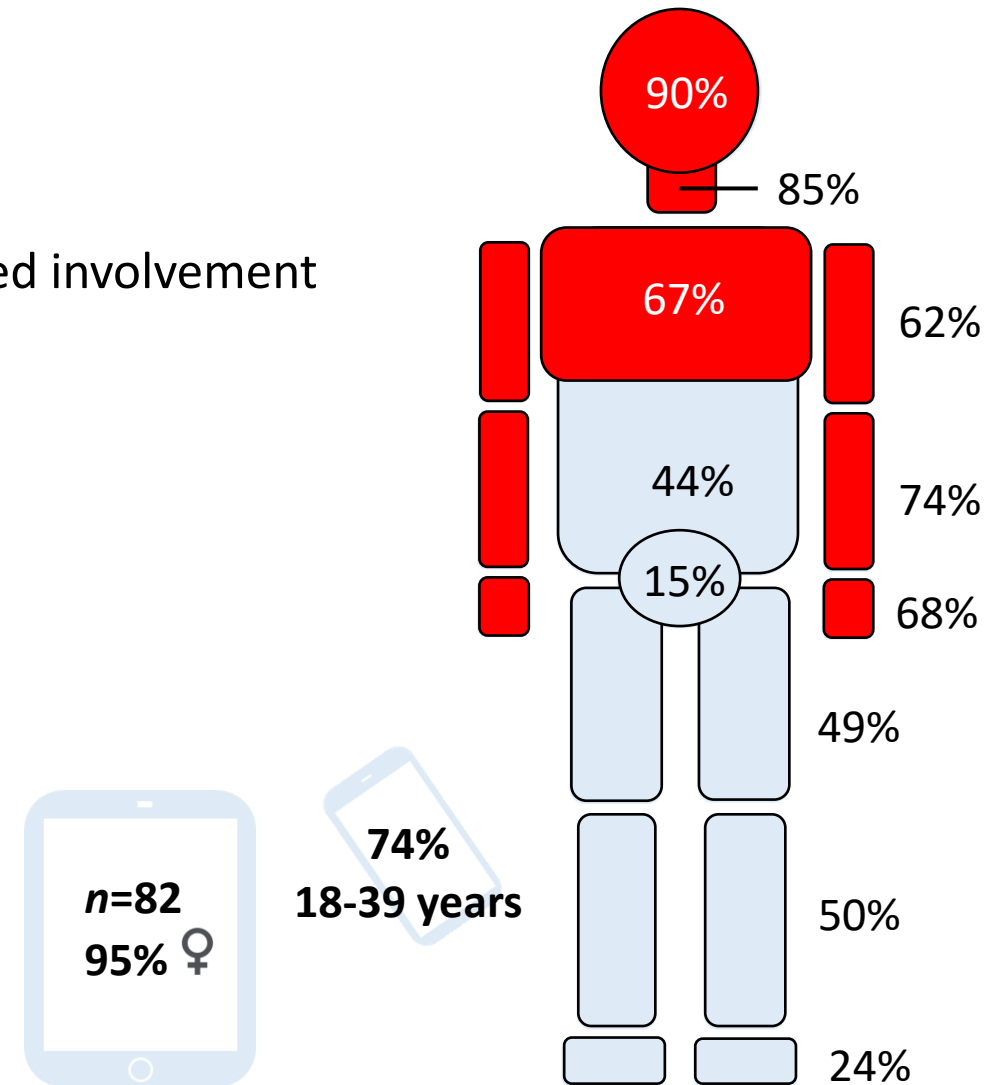
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Distribution

■ > 50% of participants reported involvement



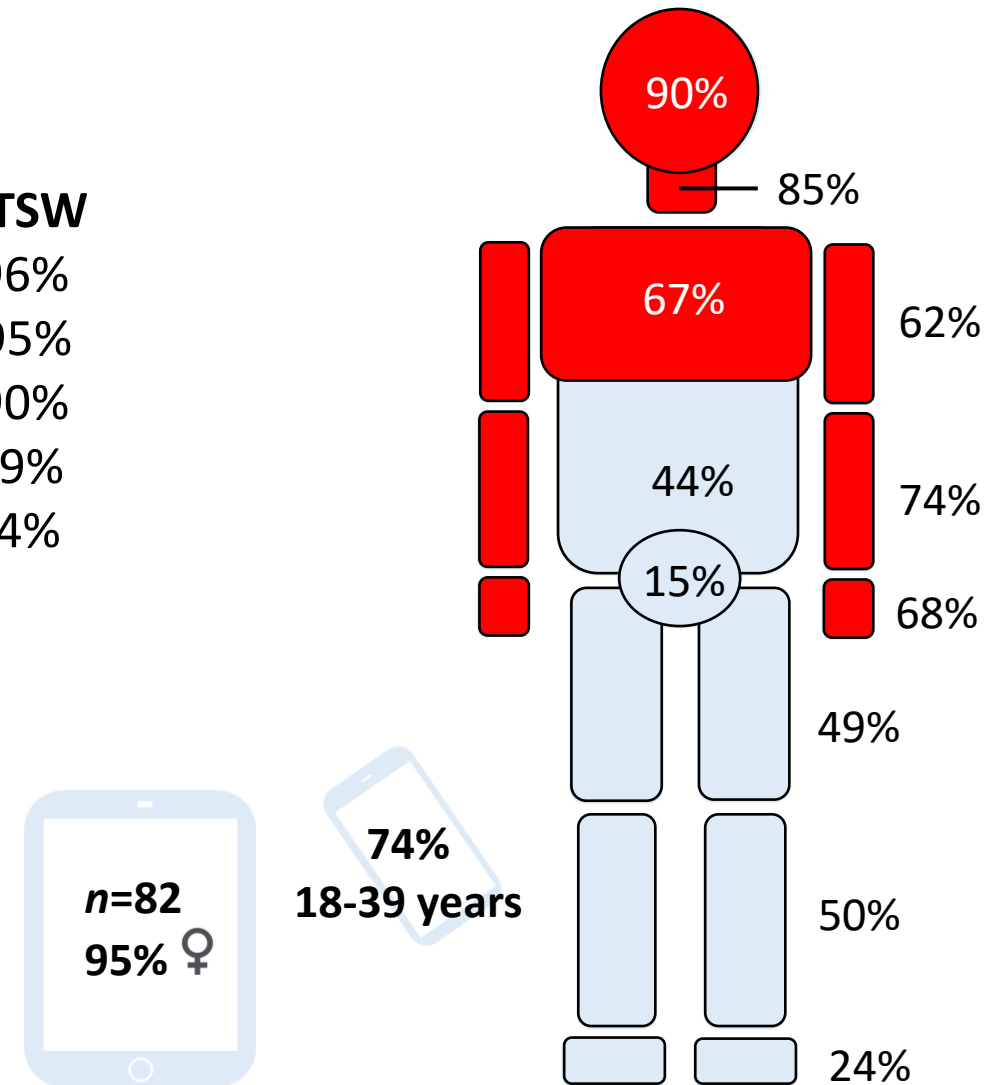
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Symptoms attributed to TSW

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



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Reported skin signs

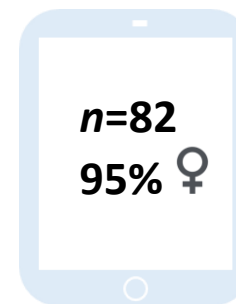
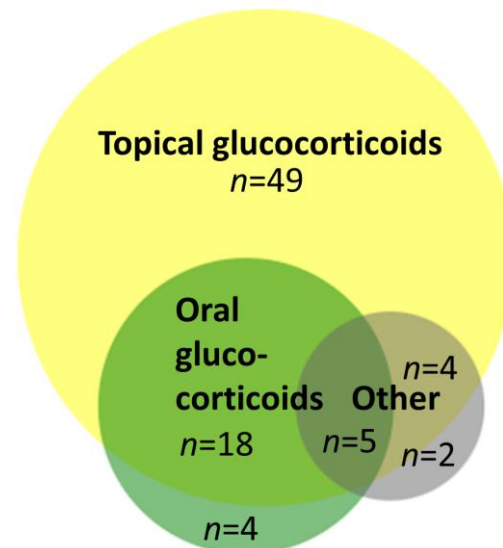
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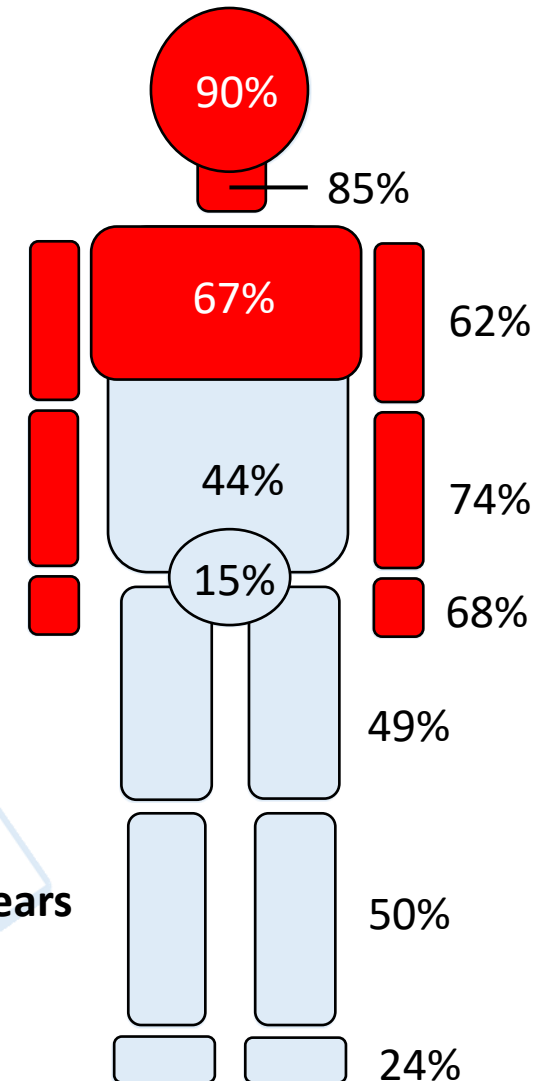
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Reported trigger factors

- Ongoing use of topical steroids 21%



74%
18-39 years



Results

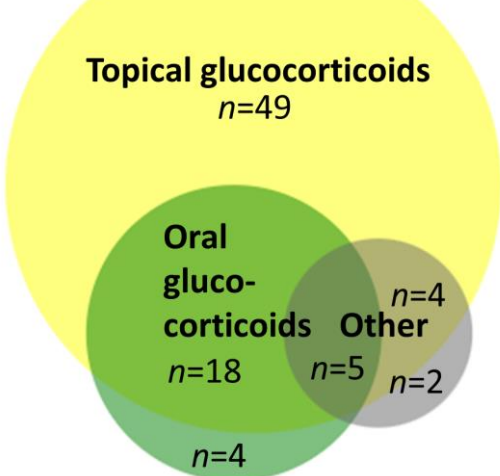
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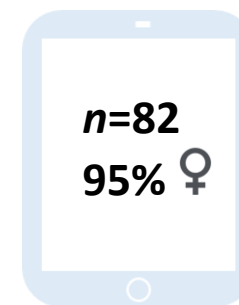
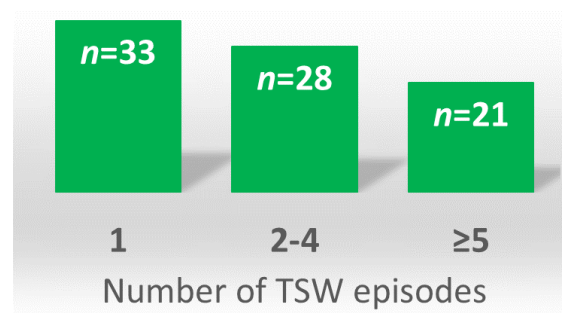
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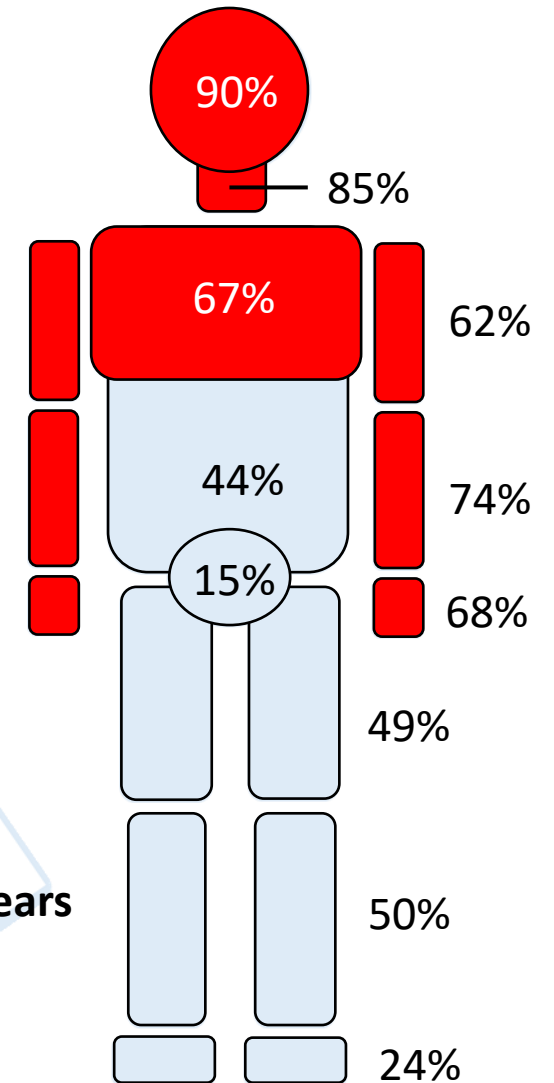
Reported trigger factors



Reported recurrence

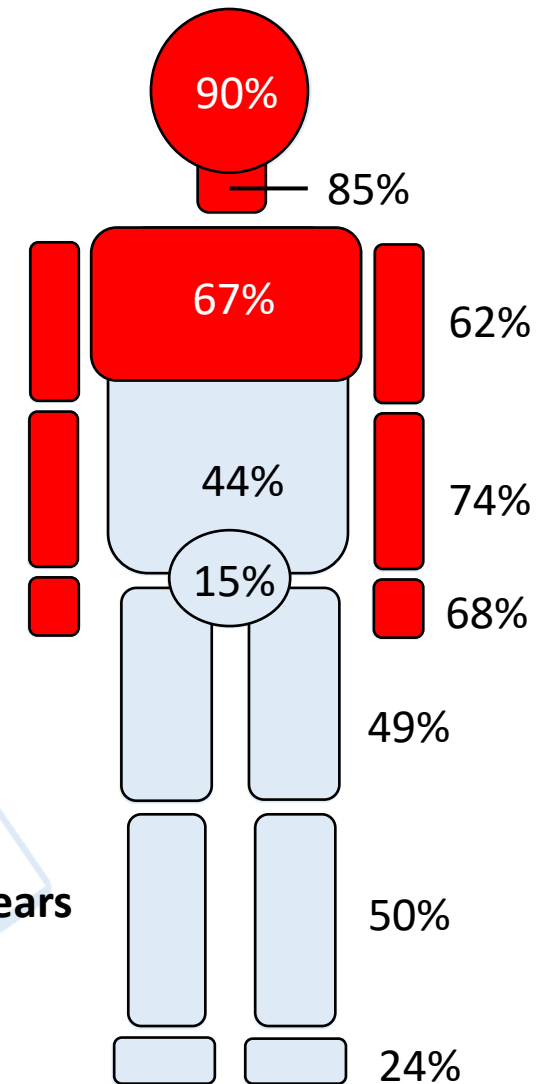
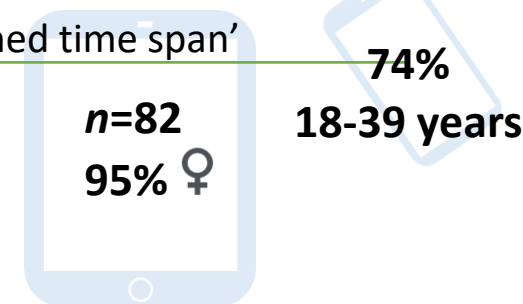


74%
18-39 years

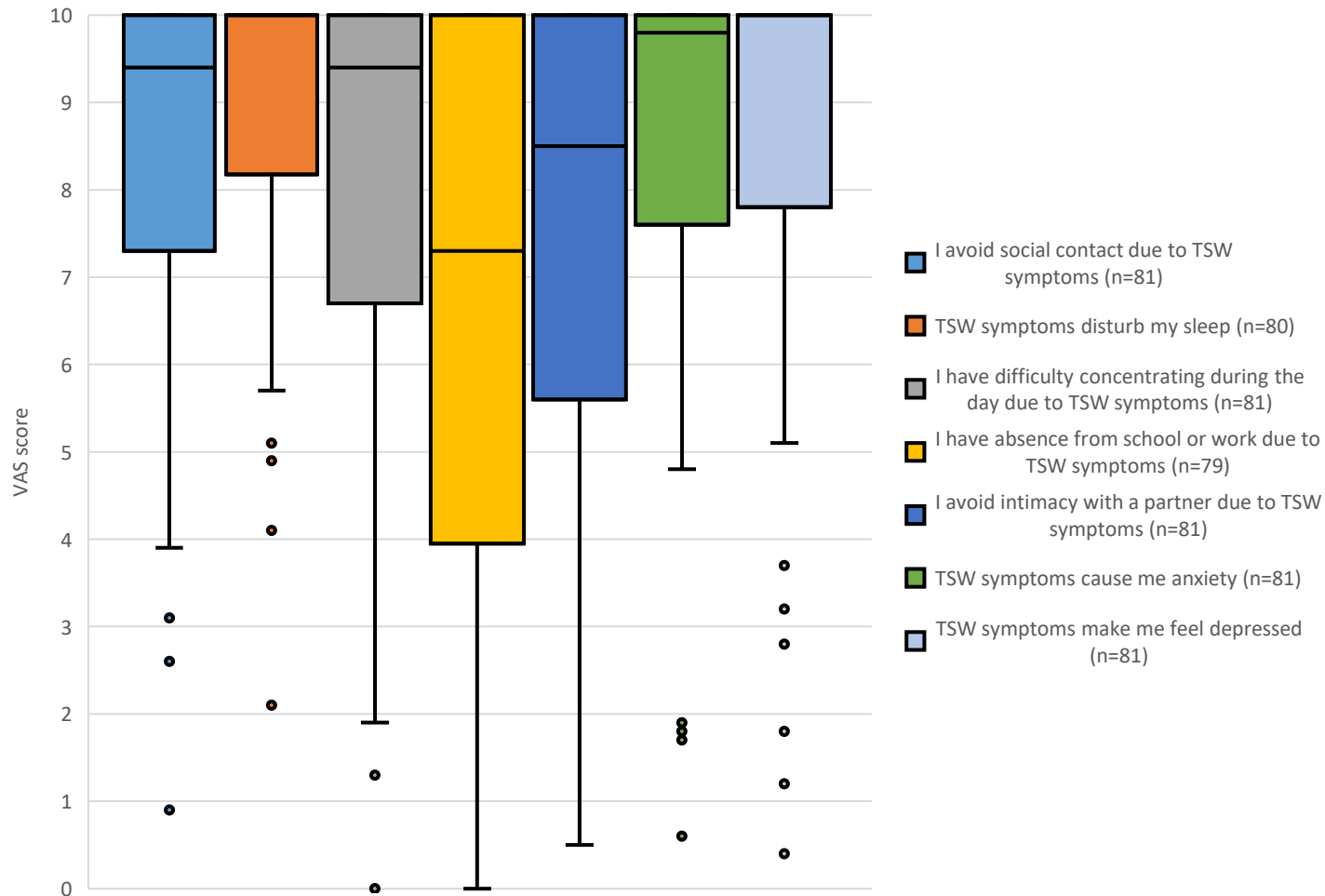


‘How would you define the term TSW?’

Topics	n (%)	Example of answers
Topic 1: Dependency	50 (63)	‘The skin is addicted to corticosteroids’
Topic 2: Skin symptoms	18 (23)	‘Red, itchy skin’
Topic 3: Reactions	16 (20)	‘Reaction to cortisone treatment’
Topic 4: Emotional response	8 (10)	‘Anxiety, no sleep’
Topic 5: General symptoms	7 (8.9)	‘Difficulty regulating body temperature, a burning feeling’
Topic 6: Long-term symptoms	5 (6.3)	‘Comes and goes during an undefined time span’

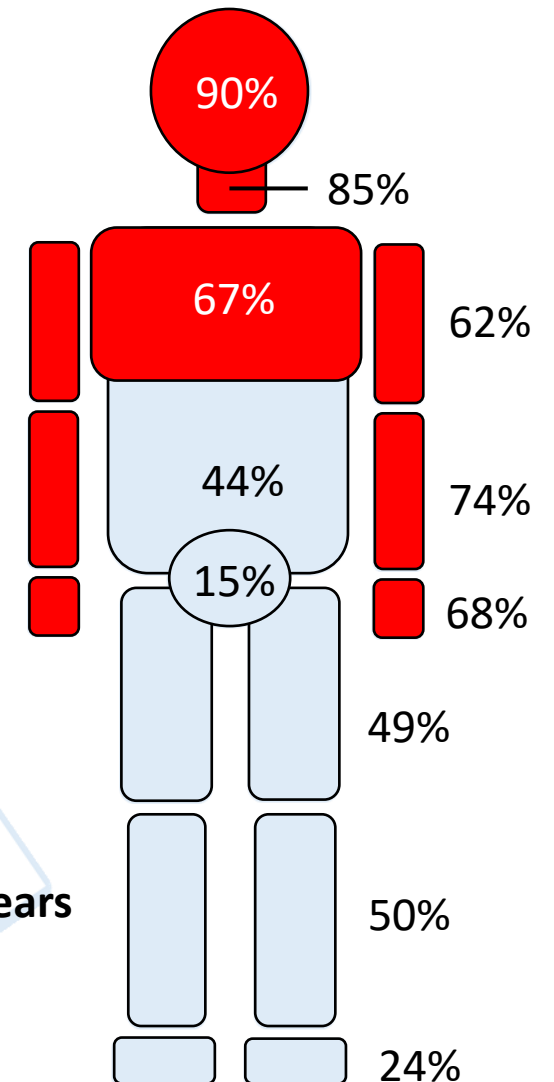


Life impact



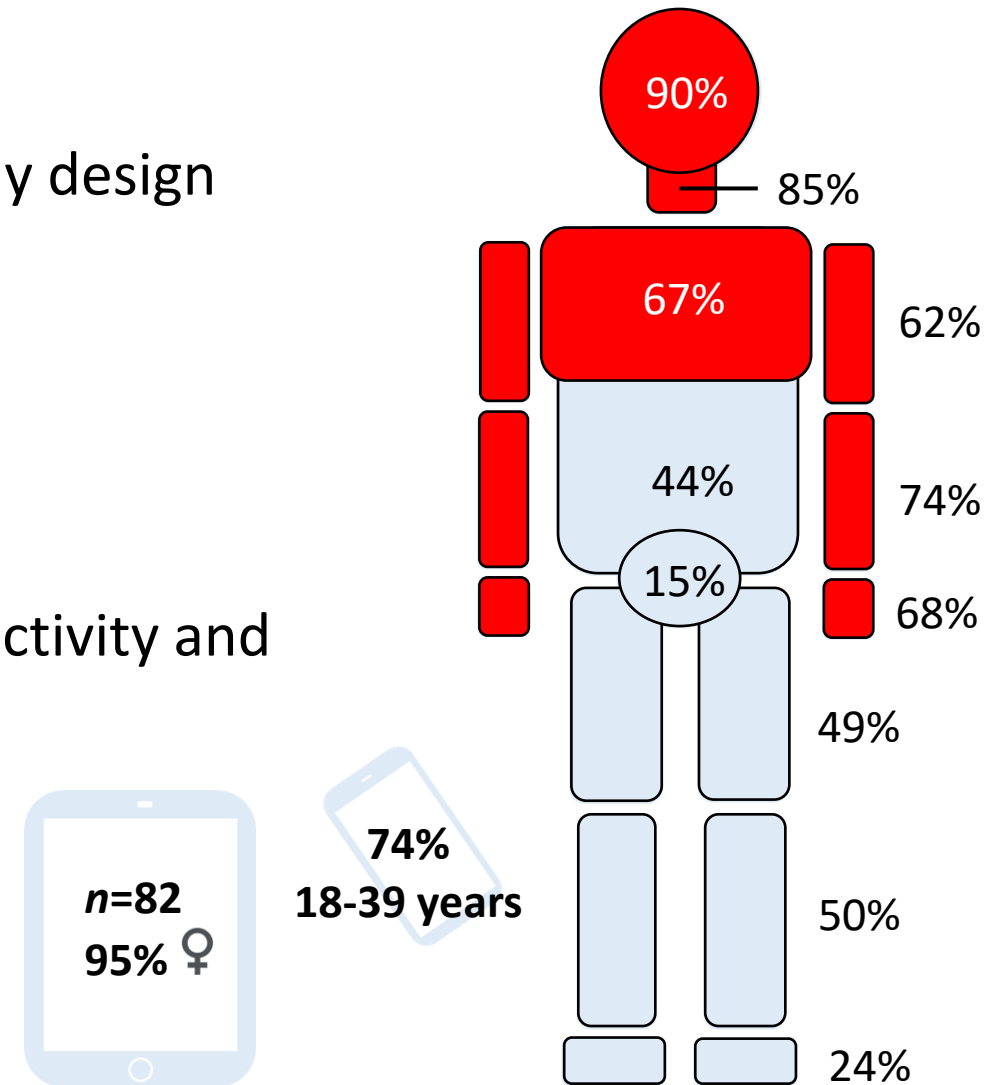
n=82
95% ♀

74%
18-39 years



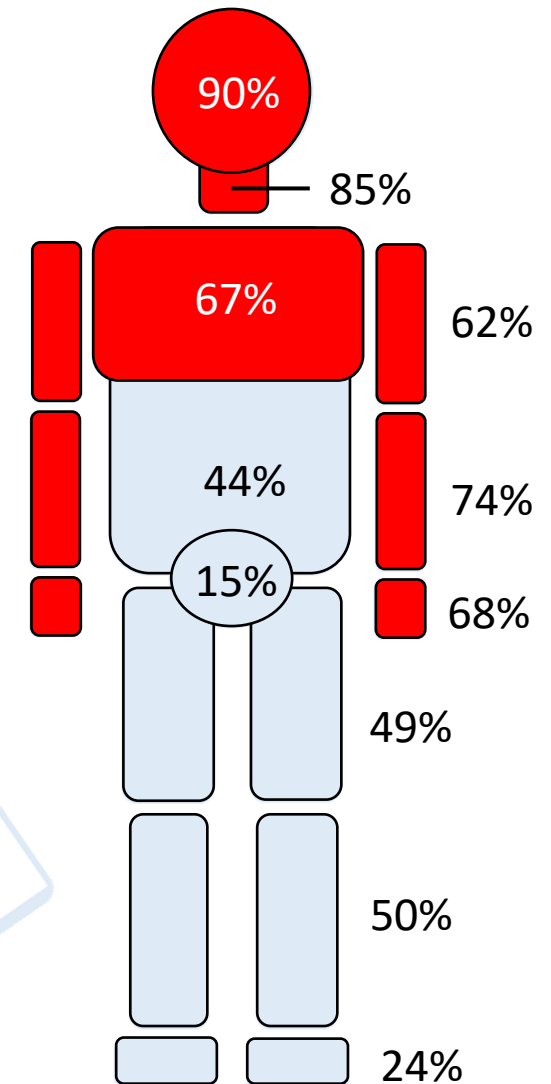
Limitations

- A response rate cannot be calculated with this study design
- All data is self-reported
- Potential selection biases:
 - Selection for AD
 - Age- and sex-differentiated social media habits
 - Severity of symptoms may affect social media activity and motivation to participate



Conclusions

- This study presents a **detailed account** of self-reported skin signs and symptoms attributed to TSW as they are characterised, experienced, and understood by patients with AD, self-diagnosed with TSW
- The participants defined TSW as **dependency** on topical steroids as well as **adverse reactions** to their use
- Self-reported **manifestations of TSW are similar to those of AD** but appeared to be distinguishable for the participants

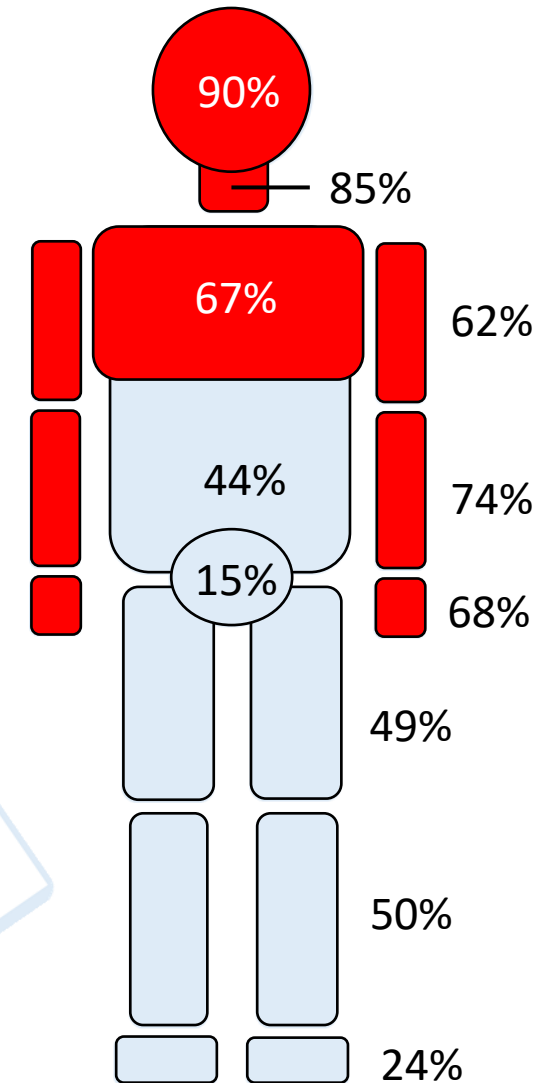


Conclusions

- New aspects for further investigation:
 - **the recurring symptoms**
 - **the continued use of topical steroids despite symptoms**
 - **how do patients distinguish flaring AD from TSW?**

- Characterisation of symptoms attributed to TSW is needed for **healthcare provider engagement** and **future research**

- Awareness of symptoms attributed to TSW can help healthcare providers improve the management of concerns regarding topical steroid use



Thank you!

Alsterholm M et al. Topical Steroid Withdrawal in Atopic Dermatitis: Patient-reported Characterization from a Swedish Social Media Questionnaire.
Acta Derm Venereol. 2025 Jan 3;105:adv40187

