

Topical Steroid Withdrawal: Perspectives of Dutch Healthcare Professionals

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Topical steroid withdrawal (TSW) is a highly controversial condition, typically reported following prolonged and/or frequent use of topical corticosteroids. Despite growing public awareness, knowledge of topical steroid withdrawal remains limited. Therefore, this study aimed to explore the perspectives of Dutch healthcare professionals (HCPs) on topical steroid withdrawal. A web-based survey was conducted among 168 Dutch HCPs. The results show that erythema (64.1%) and a burning sensation (60.3%) were the most frequently selected symptoms associated with TSW. The majority of respondents (69.6%) attributed TSW symptoms to atopic dermatitis (AD) flares and/or the adverse effect of topical corticosteroid use. Only a small percentage (12.2%) firmly believed that TSW is a distinct clinical entity, while 17.6% believed that it does not exist. Preferred treatments included using other topical immunomodulators, reinitiating and subsequently tapering topical corticosteroids, and providing non-drug and psychological support. While HCPs felt confident in addressing concerns about topical corticosteroids and topical steroid withdrawal, approximately one-quarter (24.2%) preferred not to treat patients refusing topical corticosteroids. This study highlights variations in perception among HCPs and the need for robust research to establish clear diagnostic criteria and guidelines regarding TSW. Finally, improved awareness and open communication between HCPs and patients are essential when addressing topical steroid withdrawal.

Key words: atopic dermatitis; topical corticosteroids; topical steroid withdrawal; topical steroid withdrawal syndrome.

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Topical corticosteroids (TCS) are the most frequently prescribed agents to treat various dermatological conditions. Topical steroid withdrawal (TSW) is a highly controversial condition, often described as a new or worsening cutaneous eruption, following the use of TCS (1). TSW may either occur after discontinuation of

SIGNIFICANCE

Topical steroid withdrawal is gaining attention as public awareness grows. It is a controversial condition and may happen after long-term use of steroid creams. We surveyed 168 Dutch healthcare professionals to explore their knowledge and views on topical steroid withdrawal. Most saw topical steroid withdrawal symptoms as part of an eczema flare or side effects of steroid cream use. Only a small number believed topical steroid withdrawal is a separate condition. Treatment preferences varied, and some professionals were reluctant to treat steroid-avoiding patients. Our findings show that clearer guidelines and better communication are needed to support both patients and professionals dealing with topical steroid withdrawal.

TCS, or when increased frequency or dosage of TCS is required to prevent symptoms from appearing and may take months to years to resolve (2–6).

TSW is characterized by erythema, burning pain, desquamation, pruritus, crusting, oozing, papulopustular lesions, and oedema (2–5, 7). A recent systematic review proposed that TSW manifests in 2 distinct variants with different histologic features: a papulopustular variant and an erythematous variant. However, in both cases the underlying pathophysiology remains unknown (4). TSW affects more women than men, where the facial use of TCS for cosmetic reasons may be a confounding factor (2, 4, 5, 7).

TSW has recently become a topic of increasing interest on (social) media platforms. Between 2016 and 2020, the number of mentions of the hashtag #topicalsteroid-withdrawal increased by 274%, with TikTok emerging as a major platform (8, 9). Additionally, the International Topical Steroid Addiction Network (ITSAN) has been founded to raise awareness of TSW and a joint statement on TSW has recently been revised (3, 10).

Despite the growing public awareness, knowledge concerning TSW is currently limited. To date, there is no consensus on the clinical or histological diagnostic criteria, risk factors, treatment options, or the underlying pathophysiological mechanism (3, 7, 11). Additionally, symptoms often overlap with other conditions, resulting in healthcare professionals (HCPs) questioning the existence of TSW and patients possibly misdiagnosing

themselves (3, 7, 12, 13). For example, a recent Swedish questionnaire study showed that 84% of TSW cases are self-diagnosed by patients (14).

The aim of this study was to explore the perspectives of HCPs in the Netherlands regarding their knowledge of and attitudes towards TSW.

METHODS

This cross-sectional study collected data on the views of HCPs regarding TSW using a web-based survey, created in Qualtrics, to collect anonymous data. The survey was designed to include different types of HCPs who may encounter TSW in clinical practice and was based on the study by Barlow et al. (12). It was distributed nationally among dermatologists, dermatology residents, skin therapists, and specialist nurses and was carried out via the Dutch Association for Dermatology and Venereology (NVDV). Respondents who solely filled out the demographic questions were excluded from further analysis. All other respondents, including those who completed only part of the survey, were included.

Data were collected on the HCPs' job description, years of experience, and whether they worked in a (non-) academic hospital. The survey included several topics related to TSW, such as the prevalence, symptoms, risk factors, hypotheses, potential treatments, and attitudes towards TSW. The survey consisted of multiple-choice questions, multiple-answer questions, and 5-point Likert scales (strongly disagree=0, disagree=1, neutral=2, agree=3, strongly agree=4). Additionally, 6 open-ended questions were included.

Statistical analysis

To enhance interpretability, mean Likert scores were categorized as follows: 0–1.4=disagree, 1.5–2.4=neutral, and 2.5–4=agree. Frequencies and mean Likert scores were analysed for all respondents, as well as being

stratified by hospital setting (academic/non-academic) and whether respondents had TSW in their differential diagnosis. For Likert scores, the Mann–Whitney *U* test was used to determine statistical differences between stratified groups. For multiple-choice and multiple-answer questions, the Pearson χ^2 test and, when not applicable, the Fisher test and the Fisher–Freeman–Halton exact test were used. Missing values were not used in the analysis. Data were analysed with IBM SPSS Statistics 29.0.1 (IBM Corp, Armonk, NY, USA). *P*-values of <0.05 were considered statistically significant.

RESULTS

Data were collected between 26 May and 19 June 2024. A total of 182 respondents started the web survey, of whom 14 were excluded due to having answered only demographic questions. The web survey was filled out by 168 respondents, of whom 147/168 respondents completed the full survey.

Respondents included 116 (69.1%) dermatologists, 17 (10.1%) skin therapists, 12 (7.1%) dermatology residents, 12 (7.1%) specialist nurses, and 11 (6.6%) categorized as "other", which included general practitioners, research physicians, and pharmacists. Of all HCPs working in a hospital setting ($n=140$), 33 (23.6%) worked in an academic hospital. All characteristics are presented in **Fig. 1**.

Prevalence

Half of the respondents had seen patients with self-diagnosed TSW several times a year (52.4%), followed by never (38.7%), several times a month (18.3%), and several times a week (0.6%). In addition, the majority of respondents had never considered TSW in their differential diagnosis (71.4%), followed by several times a year (27.4%), several times a month (1.2%), and

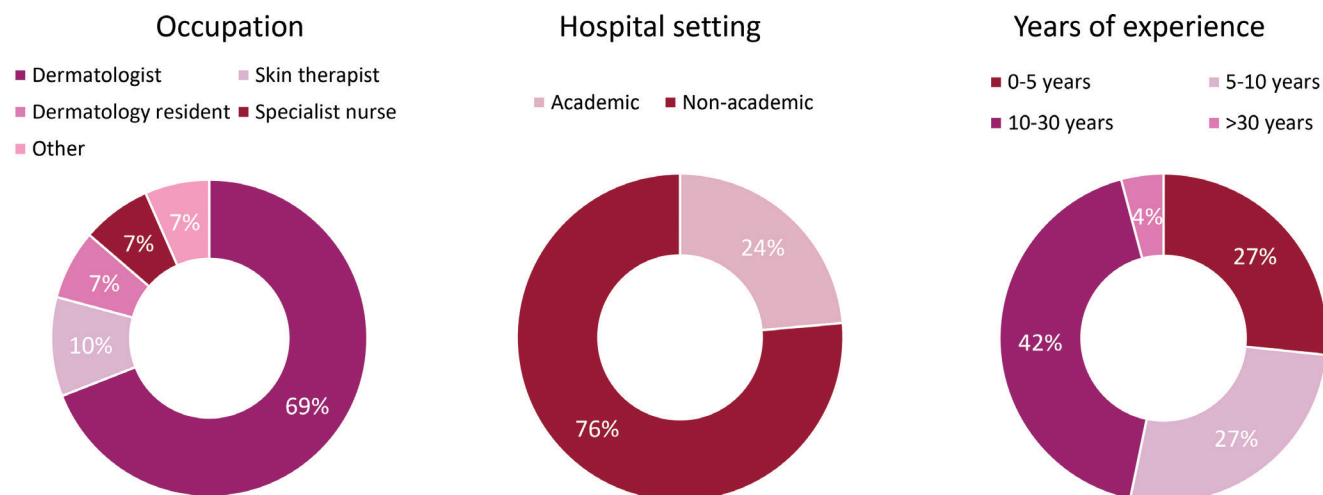


Fig. 1. Characteristics of all respondents.

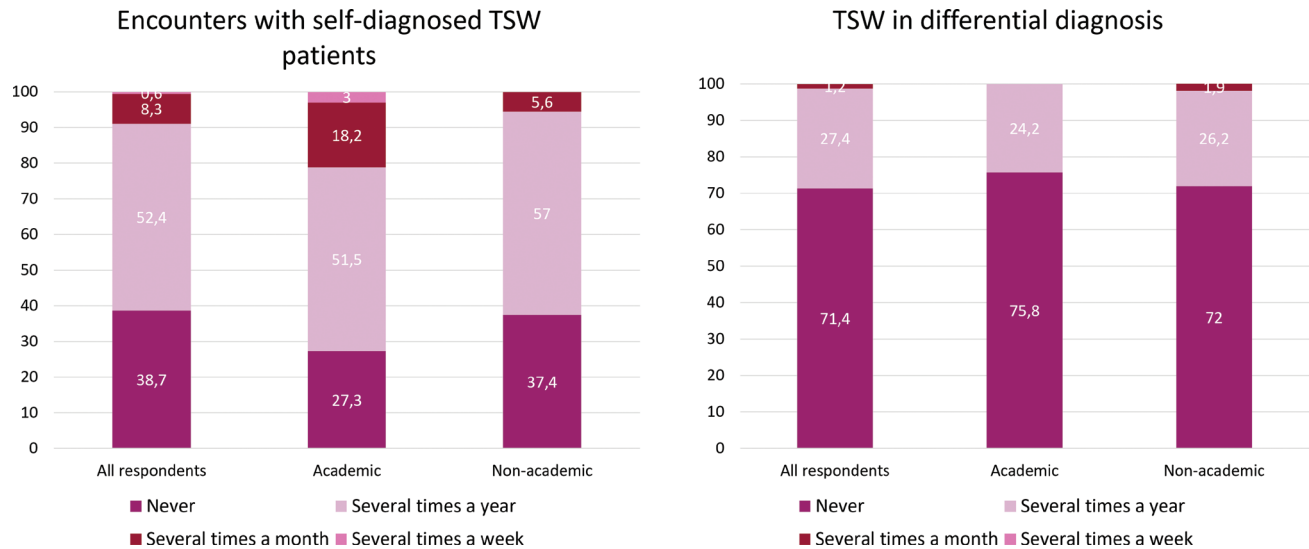


Fig. 2. Prevalence of topical steroid withdrawal (TSW) cases according to all respondents.

several times a week (0.0%) (Fig. 2). Stratified analysis shows that respondents working in academic hospitals had more encounters with patients with self-diagnosed TSW ($p=0.037$). Overall, 27.4% ($n=46$) of respondents reported an increase in the prevalence of possible TSW cases in the past year.

Symptoms

The most frequently selected symptom associated with TSW was erythema (100/156, 64.1%), followed by burning/painful/stinging skin (94/156, 60.3%) (Table I). No statistically significant differences were observed when stratifying for academic vs non-academic hospitals (Table SI). Respondents who had previously considered TSW in their differential diagnosis selected erythema and papulopustular lesions more frequently than those who had not.

Risk factors

Regarding possible risk factors contributing to TSW, respondents agreed with: “abruptly stop TCS use” (mean: 2.6 standard deviation [SD] $\pm$ 1.1) (Fig. 3; Table SIII). Respondents working in an academic hospital more frequently disagreed with “potent TCS use” as a risk factor while those working in a non-academic hospital were neutral (mean: 1.4 SD $\pm$ 1.3 vs 1.9 SD $\pm$ 1.0, $p=0.026$). Respondents who had previously considered TSW in their differential diagnosis agreed with “potent TCS” (mean: 2.5 SD $\pm$ 0.8), “long-term frequent TCS use” (mean: 2.8 SD $\pm$ 0.7), and “TCS use on face or genitals” (mean: 2.5 SD $\pm$ 1.0) as risk factors.

Hypotheses

The most selected possible hypotheses of TSW were: “undertreatment of underlying skin disease” (78/148,

52.7%) and “adverse effect of TCS use” (57/148, 38.5%) (Table I). Additionally, respondents agreed to the following: “flaring underlying skin condition” (mean: 3.2 SD $\pm$ 0.9), “(worsening) adverse effects TCS” (mean: 2.7 SD $\pm$ 0.9) and “rebound vasodilatation” (mean: 2.6 SD $\pm$ 0.8) (Table SIII). A total of 37/147 (36.7%) respondents indicated that they perceived a comparable reaction, as with TSW, when discontinuing other

Table I. Symptoms, hypotheses, and treatment options of TSW according to all respondents

	All respondents, n (%)
Symptoms	156 (100)
Erythema	100 (64.1)
Burning/painful/stinging	94 (60.3)
Oozing and crusting	50 (32.1)
Papulopustular lesions	47 (30.1)
Desquamation and xerosis cutis	48 (30.8)
Pruritus	40 (25.6)
Oedema	30 (19.2)
Skin infections	18 (11.5)
Other	10 (6.4)
Not sure	43 (27.6)
Hypotheses	148 (100)
Undertreatment of underlying skin disease	78 (52.7)
Adverse effect of TCS use	57 (38.5)
TSW does not exist	26 (17.6)
TSW is a clinical entity	18 (12.2)
Other	23 (15.5)
Not sure	27 (18.2)
Treatment options	150 (100)
Other topical immunomodulators	117 (78)
Reinitiating TCS, subsequently tapering	104 (69.3)
Non-drug treatments	84 (56.0)
Psychological support	68 (45.3)
Systemic immunosuppressant	66 (44.0)
UV-therapy	41 (27.3)
Antibiotics	36 (24.0)
Prednisone	21 (14.0)
Antihistamines	14 (9.3)
Keeping TCS ceased	10 (6.7)
Non-conventional	7 (4.7)
(Neuropathic) pain medication	1 (0.7)
Other	14 (9.3)

TCS: topical corticosteroids; UV: ultraviolet.

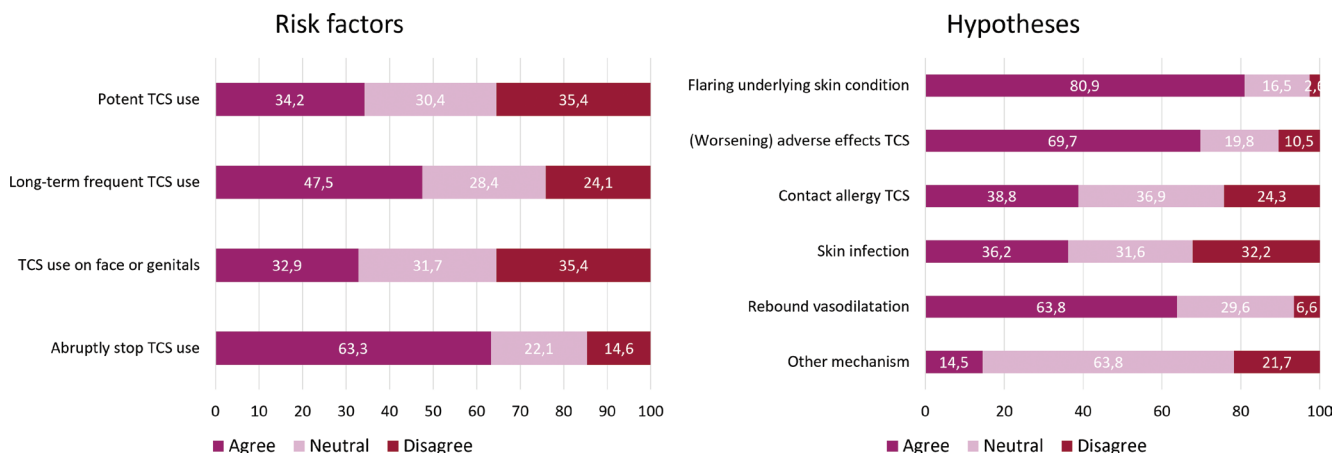


Fig. 3. Risk factors and hypotheses of topical steroid withdrawal (TSW) according to all respondents.

pharmaceutical agents. Respondents working in an academic hospital selected the hypothesis "TSW does not exist" more frequently than respondents working in a non-academic hospital (40.0% vs 13.3%, $p=0.001$). Respondents who had previously included TSW in their differential diagnosis selected the following hypotheses more frequently compared with those who had not: "adverse effect of TCS use" (64.4% vs 27.2%, $p<0.001$), "TSW is a clinical entity" (22.5% vs 7.8%, $p=0.013$), and "other" (24.8% vs 11.7%, $p=0.048$).

Treatment options

The most frequently selected treatment options for TSW were "other topical immunomodulators" (117/150, 78.0%), "reinitiating TCS, subsequently tapering" (104/150, 69.3%), "non-drug treatments" (84/150, 56.0%), and "psychological support" (68/150, 45.3%)

(Table I). Respondents working in a non-academic hospital more frequently chose "non-drug treatments" as a treatment option than those working in an academic hospital (62.2% vs 41.9%, $p=0.046$) (Table SII). When a respondent had TSW in their differential diagnosis they selected "non-conventional" as a treatment option more frequently than those who had not (11.1% vs 1.9%, $p=0.026$).

Attitudes

Regarding attitudes towards TSW, respondents agreed with: "psychological support can be of importance" (mean: 3.0 SD $\pm$ 0.7) and "confident addressing concerns about TCS and TSW" (mean: 2.6 SD $\pm$ 0.9) (Fig. 4). Respondents disagreed with: "more cautious prescribing TCS" (mean: 1.4 SD $\pm$ 1.1). Respondents working in a non-academic hospital agreed with the statement

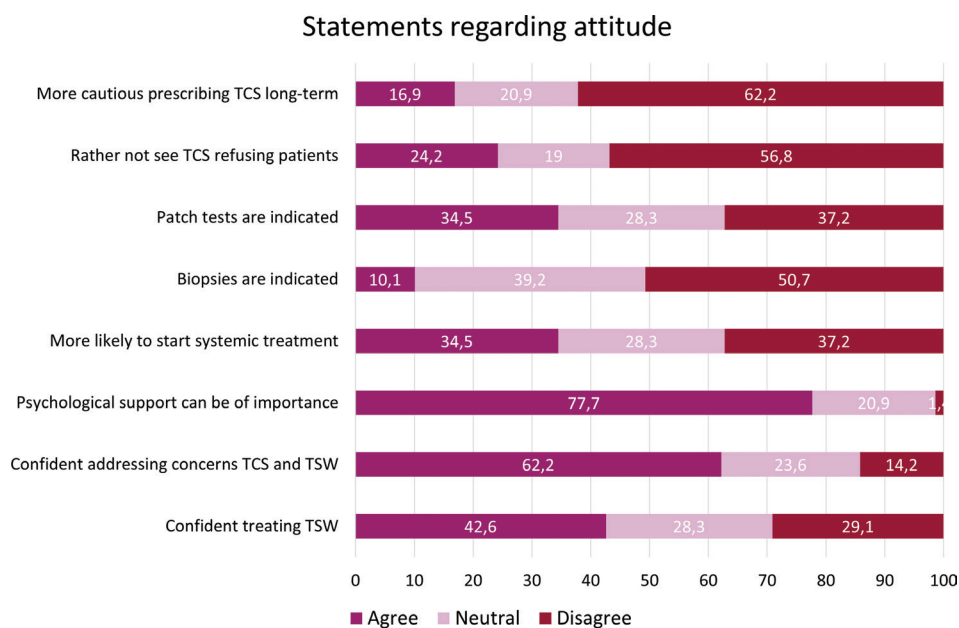


Fig. 4. Statements of attitudes of all respondents towards topical steroid withdrawal (TSW).

"confident addressing concerns about TCS and TSW" (mean: $2.6 \text{ SD} \pm 0.8$ vs $2.4 \text{ SD} \pm 1.3$, $p=0.032$) and disagreed with the statement "rather not see TCS refusing patients" (mean: $1.4 \text{ SD} \pm 1.0$ vs $2.2 \text{ SD} \pm 1.1$, $p=0.001$) whereas respondents working in an academic hospital were neutral (Table SIV). Respondents who had TSW in their differential diagnosis agreed with "confident treating TSW" (mean: $2.5 \text{ SD} \pm 1.1$ vs $2.0 \text{ SD} \pm 1.1$, $p=0.006$) while those who had not were neutral. Additionally, respondents who had TSW in their differential diagnosis disagreed with "rather not see TCS refusing patients" (mean: $1.2 \text{ SD} \pm 1.0$ vs $1.7 \text{ SD} \pm 1.0$, $p=0.009$) and were neutral to "more cautious prescribing TCS" (mean: $1.8 \text{ SD} \pm 1.0$ vs $1.2 \text{ SD} \pm 1.1$, $p=0.001$) while those who had not, disagreed with this statement.

DISCUSSION

In this study, 168 Dutch HCPs shared their views and experiences regarding TSW through a web survey. Erythema (64.1%) and burning sensation (60.3%) were the most frequently selected symptoms associated with TSW. Most respondents (103/148, 69.6%) acknowledged that symptoms attributed to TSW might reflect flares of underlying AD and/or known adverse effects of TCS use, rather than constituting a distinct clinical entity. Preferred treatments included using other topical immunomodulators, reinitiating and subsequently tapering TCS, and providing non-drug and psychological support. While HCPs felt confident in addressing concerns about TCS and TSW, approximately one-quarter (24.2%) preferred not to treat patients refusing TCS.

Knowledge of TSW and its prevalence is limited. In our study, 38.7% of all respondents reported that they had never seen a patient with self-diagnosed TSW, and 71.4% had never included TSW in their differential diagnosis. However, 28.6% had considered TSW at some point, although only 12.2% regarded TSW as a distinct clinical entity – reflecting the uncertainty among Dutch HCPs and suggesting it is often acknowledged as a patient-driven concern rather than a formally recognized diagnosis. A higher prevalence of self-diagnosed TSW patients was found in academic hospitals, potentially reflecting the referral of more complex cases. Barlow et al. (12) found higher prevalence rates: 77.7% of United Kingdom (UK) dermatologists had occasionally seen a patient with TSW, followed by 13.2% several times a month, 6.6% never, and 2.5% several times a week. However, this study had a low response rate and included self-selected respondents, which may have resulted in a biased selection of dermatologists who were more interested in or exposed to potential cases of TSW. Additionally, Barta et al. (5) reported that 79% of adults and 43% of children had experienced TSW. However, these numbers likely overestimate the prevalence considering the retrospective design and the fact that respondents were drawn

from patient associations such as ITSAN. In our study, HCPs appear to encounter potential cases of TSW less frequently. This may be due to the unavailability of over-the-counter TCS in the Netherlands.

More than half of our respondents selected erythema (64.1%) and burning, painful, or stinging skin (60.3%) as the most frequent symptoms, aligning with previous studies on TSW (4, 5, 15, 16). However, Hwang and Lio (2) identified papulopustular lesions as the second most common symptom. Interestingly, 2 reviews and 1 case report have described TSW as occurring in cycles of acute erythema and oedema, followed by desquamation (6, 17, 18). The dissemination of selected symptoms in this study reflects the broad and often overlapping spectrum of TSW symptoms, which complicates the distinction of TSW from other dermatological conditions. Hajar et al. (4) reported that the histology of the presumed variants is distinct, with the erythematous variant resembling AD, and the papulopustular variant resembling rosacea. However, in general, histology remains inconclusive in differentiating TSW from its differential diagnoses (2, 4, 6).

Our findings suggest that respondents agreed only with inappropriate discontinuation of TCS as a possible factor for TSW. This is consistent with the respondents' disagreement with: "more cautious about prescribing TCS". In contrast, larger studies have proposed other risk factors, such as TCS use on the face or genital area and prolonged/frequent or high-potency TCS use, which were supported in our study only by respondents who had considered TSW in their differential diagnosis (2, 4, 5, 15, 16). Two systematic reviews, by Hajar et al. (4) and Hwang and Lio (2) assessed a total of 45 articles on TSW. However, the articles were heterogeneous, low-quality studies, characterized by a lack of rigorous methodology and missing data. Moreover, these studies could not determine the potency, exact duration, frequency, and amount of TCS used. Further research is required to identify the risk factors associated with TSW.

Previous studies reported varying hypotheses regarding TSW (6, 7, 17). Some claim that TSW is a distinct clinical entity, while others describe it as a heterogeneous group of conditions, such as flares of an underlying skin disease or a paradoxical worsening of adverse effects (2, 4, 12, 15). In our study, most respondents (69.6%) acknowledged that symptoms attributed to TSW might reflect flares of underlying AD and/or known adverse effects of TCS use. However, respondents working in academic hospitals were more likely to report that TSW does not exist. Our findings align with Barlow et al. (12), where 61% of the respondents believed that patients presenting with TSW symptoms were experiencing a relapse of AD due to discontinuation of TCS. Tan et al. (6) reviewed proposed mechanisms underlying TSW but concluded that current evidence is insufficient. Nevertheless, they suggested it would be reasonable to

consider TSW, as similar reactions have been observed with other treatments, which was also reported by 37.7% of our respondents. More recently, Shobnam et al. (19) proposed TSW as a distinct iatrogenic dermatopathy, possibly resulting from prolonged TCS use leading to a form of endogenous chemical irritation due to overproduction of oxidized NADH (NAD⁺).

Treatment options most frequently selected by our respondents were "other topical immunomodulators" and "reinitiating TCS and subsequently tapering", while only 6.7% would keep TCS discontinued. Although no consensus exists on optimal treatment, the view of the patient community is to abruptly discontinue TCS (6, 7, 20). Tan et al. (6) reviewed available literature and described that discontinuing TCS, either abruptly or tapered, is the most recommended approach. However, outcomes were inconsistent and the studies were of low quality. Hajar et al. (4) reported that 95% of their studies recommended keeping TCS discontinued, and Brookes et al. (15) reported that 95% of their patients were treated with non-steroidal medication because of TCS refusal. Notably, almost half (45.3%) of our respondents indicated that psychological support can be of importance. This finding is consistent with recommendations in the literature (4, 15, 17). Recently, Shobnam et al. (19) proposed that targeting NAD⁺ with metformin or berberine could be potential treatment options for patients with TSW. However, further research is needed to confirm this.

Interestingly, 24.2% of our respondents, and approximately half of those working in an academic hospital, agreed with the statement "rather not see TCS refusing patients", whereas Barlow et al. (12) found that only 2% of their respondents agreed with a similar statement. Moreover, only 14.2% of our respondents indicated a lack of confidence in addressing concerns related to TSW, contrasting with the 38.8% reported by Barlow et al. (12). However, the variations and neutrality in the responses to our survey suggest otherwise. In general, respondents in the UK appear to be more open to the idea of management without TCS, and more aware of their uncertainty regarding TSW. Furthermore, our study reveals a significant discrepancy between the prevalence of self-diagnosed patients and the frequency of TSW in differential diagnoses. Together with the fact that most HCPs perceive TSW as a flare of the underlying skin condition, and the discrepancy between doctors' views and patients' beliefs, the perceived deterioration in the patient–doctor relationship becomes understandable (1, 7, 20).

This study has several limitations. First, respondents who completed this survey may have held stronger views leading to an underestimation or overestimation of TSW prevalence. Second, as the existence of TSW remains questionable, some questions may have lacked nuance, potentially affecting responses. Third, although many neutral responses reflected the uncertainty over

TSW, excluding a "neutral" option might have forced more decisive answers. Additionally, the survey did not address TSW onset, distribution, or prognosis. Lastly, as the results are based on Dutch HCPs, they may not be generalizable to other populations.

This study identifies the knowledge and attitudes of Dutch HCPs regarding TSW. Our results show varying perspectives among HCPs. The discrepancy between patients' self-diagnosis of TSW and its inclusion in HCP differential diagnoses, together with the fact that most HCPs view TSW as undertreatment of an underlying skin disease, highlights the gap between patients' experiences and doctors' beliefs. This underscores the need for robust research to establish clear diagnostic criteria, guidelines, and risk factors. Finally, improved awareness and open communication between HCPs and patients are essential when addressing TSW.

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