



BMJ Open Qualitative analysis of topical corticosteroid concerns, topical steroid addiction and withdrawal in dermatological patients

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ABSTRACT

Objective To explore the phenomenon of topical corticosteroid (TCS) phobia and comprehensively understand the factors driving TCS concerns, in particular pertaining to steroid addiction and withdrawal.

Design Prospective qualitative study using 1:1 in-depth semistructured interviews and analysed using grounded theory.

Participants Patients with a prior experience of TCS use for a dermatological condition recruited from a tertiary academic dermatology clinic, or through word of mouth and online social media platforms.

Results 26 participants encompassing those with positive, neutral and negative opinions towards TCS were interviewed. 13 reported having topical steroid addiction or withdrawal. The drivers of TCS concerns could be categorised into seven themes: attitudes towards TCS (comprising beliefs and knowledge about TCS), availability of alternatives, treatment inconvenience, personality, patient's ongoing evaluation of clinical response to TCS, doctor–patient relationship and healthcare-seeking behaviour. Of mention, patients placed high value and trust on their own experiences with TCS, such as their perceived experienced side effects. The doctor who failed to acknowledge the patient's opinions and instead emphasised the safety of TCS was often viewed as dismissive, resulting in a deteriorating patient–doctor relationship.

Conclusion Provision of knowledge and education is important but may be ineffective if the basis for TCS concern regarding safety is reasonable, or when the patient has a firmly established belief supporting his/her concern. In such instances, failure to acknowledge and respect the patient's decision to avoid TCS could worsen the doctor–patient relationship.

BACKGROUND

Topical corticosteroids (TCS) are prescribed widely in fields like allergy, ophthalmology and dermatology for various inflammatory and allergic conditions. Excessive TCS concern is recognised as a clinical problem and can lead to suboptimal treatment,¹ use of harmful alternatives² or excessive food

Strengths and limitations of this study

- Topical steroid addiction and withdrawal is a controversial topic and qualitative interviewing allowed deeper insights into patient's experiences and concerns.
- Trustworthiness of the data was ensured through a rigorous process of memo writing, reflexive documentation, checking of the framework with interviewees and an adequate sample size to achieve theoretical saturation.
- However, the associations between topical corticosteroid concerns, demographics and disease factors could not be objectively quantified in this study.
- Although purposive sampling was conducted to sample a wide spectrum of patient and disease characteristics, the results may not be generalisable to the entire population.

restriction.³ A recent systematic review of dermatological patients reported a prevalence of TCS concerns ranging from 21% to 84%¹ with studies using the TOPICOP (topical corticophobia) score^{4–6} reporting an average score of 40%–44%.^{7–9} TCS concerns may also include a fear about topical steroid addiction and withdrawal (TSA/TSW). Although TSA/TSW is a controversial entity within the dermatological community,¹⁰ it has a growing online community on social media platforms and websites such as the 'International Topical Steroid Awareness Network (ITSAN)'.¹¹

Cross-sectional studies report an association between steroid concerns and female gender,^{7 8 12} while no consistent relationship was noted for age,^{7 8 12 13} education level^{8 12} and disease severity.^{13 14} These quantitative studies however provide an incomplete understanding of the phenomenon which can impede the development of strategies to improve TCS adherence. For instance,

steroid phobia is commonly attributed to patient's misinformation about TCS. In a randomised controlled trial, however, education clarifying misconceptions, discussing risks/benefits and teaching safe usage of TCS improved knowledge, but failed to improve the fear and behavioural domains of the TOPICOP score and did not improve adherence.⁷ This suggests the presence of other factors driving TCS concerns.^{7 15}

The purpose of this study is to explore and elucidate the social, emotional and experiential contributors to TCS concerns by employing qualitative inductive methods to derive a more comprehensive explanation of TCS concerns.

METHODS

Participants

Participants were recruited from the National University Hospital, Singapore, a tertiary academic dermatological centre in Asia that serves approximately 17 000 self-paying and government-funded dermatology patients annually. Inclusion criteria included having a skin condition, previous or current usage of topical steroids and aged between 13 and 99 years. Anticipating that patients with strong TCS concerns may not present to a dermatologist, we reached out to TSA/TSW advocacy groups on social media platforms such as Instagram and Facebook.

Data collection

1:1 or 1:2 in-depth semistructured interviews¹⁶ were conducted primarily by two authors, with audio recordings transcribed for analysis. Both interviewers were residents from the dermatology and medicine division with an ongoing dermatological practice. Observers for the interviews (who could also ask questions or provide inputs) included a medical student and a dermatology senior consultant. All interviewers were trained in gathering qualitative information. The interviews explored personal experiences with topical steroids, side effects, changing perceptions and interactions with healthcare professionals (online supplemental file 1). Initial interview guides were less structured allowing for spontaneity in inquiry.

Data analysis

Data analysis followed a grounded theory approach.^{17 18} This was chosen for its ability to develop a multidimensional theory grounded from systematically obtained data. The process started with line-by-line coding followed by analytical focused coding. Team discussions were conducted after five to six interviews, following which the interview guide was revised to reflect team learnings and a new set of participants recruited through theoretical sampling. This constant comparative process of data collection was repeated until theoretical saturation, where no new themes were identified.

Similar codes were categorised into higher ordered themes through axial coding and organised into a

framework. These were performed independently by two authors, and the results assessed for convergence. The final constructs were reviewed by all authors for consensus. Analysis was performed in ATLAS.ti V.8.0.¹⁹ The study was designed and reported following the Consolidated Criteria for Reporting Qualitative Research guidelines for qualitative studies.

Patient and public involvement

The themes and framework derived was presented to a random selection of participants to assess the face validity of the model and to streamline for theoretical parsimony. Participants were given the opportunity to suggest and propose changes prior to the finalisation of the results. No patient or public was otherwise involved in the study design or conduct.

RESULTS

A total of 26 participants were recruited between June 2020 and March 2021. Seventeen participants were recruited from the dermatological clinics while nine were recruited through word of mouth and online social media platforms. One patient declined participation. All participants at some point had been attended to and prescribed topical steroids by a dermatologist.

Fifteen interviews were conducted via Zoom teleconferencing with the rest in person. Mean age was 33.8 years (SD 13.6) and mean duration of TCS use was 9.3 years (SD 8.5). The mean TOPICOP score was 45.8 (SD 17.8) in males and 56.0 (SD 8.4) in females, with a range of 0–100 and higher score indicating greater steroid phobia. Other patient demographics and disease characteristics are shown in table 1. Mean interview duration was 34.9 min (SD 15.4, range 8–65). Based on the data, 4 patients had a positive attitude towards TCS, 6 patients had a neutral attitude and 16 patients had a negative attitude towards TCS.

Analysis showed that the drivers of TCS concerns could be categorised into seven themes: attitudes towards TCS, availability of alternatives, treatment inconvenience, personality, patients' evaluation of clinical response to TCS, doctor–patient relationship and healthcare-seeking behaviour (table 2 in brief, online supplemental file 2 in detail).

Attitudes towards TCS

Attitudes towards TCS: beliefs about TCS

Beliefs about TCS incorporated the perceived benefits ('it really works'), perceived risks ('the skin [is] getting slightly thinner') and the perceived lack of benefit such as the lack of durability of response ('It seems to be that currently steroids [are] only helping the symptoms... it doesn't solve the root issue') (table 2.1).

More than two-thirds of the patients reported known side effects of TCS such as 'the skin surrounding the area will become lighter' and 'skin thinning'. Two participants reported systemic side effects such as adrenal insufficiency

Table 1 Participant demographics

Variable		Frequency (total n=26)
Recruitment site	Dermatology clinics	17
	Word of mouth/social media platforms	9
Age	Mean (SD)	33.8 (13.6)
Gender	Male	12
	Female	14
Race	Chinese	21
	Malay	3
	Indian	1
	Caucasian	0
	Other	1
Education	Primary school	1
	Secondary school	3
	Junior college/polytechnic/institute of technical education	8
	Bachelor's degree	13
	Master's/doctorate	1
Diagnosis	Eczema	23
	Psoriasis	1
	Cheilitis	1
	Prolonged drug hypersensitivity syndrome	1
Duration of disease (years)	Mean (SD)	13.4 (9.99)
Highest potency TCS	Class 1 (least potent)	3
	Class 2	0
	Class 3	2
	Class 4	11
	Class 5	6
	Class 6	1
	Class 7 (most potent)	1
	Unsure	2
Duration of TCS use (years)	Mean (SD)	9.34 (8.48)
TOPICOP (male)	Mean (SD)	45.8 (17.8)
TOPICOP (female)	Mean (SD)	56.0 (8.4)

TCS, topical corticosteroid; TOPICOP, topical corticophobia.

and osteoporosis from prolonged steroid use. Of note, some also attributed non-specific symptoms such as the body becoming 'weaker' and, generically, 'damaged skin' to TCS without elaboration.

Durability of response was a concern for 12 of 26 participants, reporting 'temporary relief' before starting to 'flare up again', having to use 'stronger' and 'higher dosage', and fear of being 'reliant on creams', and not solving the 'root cause'.

Attitudes towards TCS: knowledge of TCS

A patient's knowledge towards TCS is influenced by the source of information and the patient's critical appraisal

of that information. Participants acquired knowledge from a variety of sources, ranging from healthcare professionals, friends and family to online searches and social media groups (table 2.2).

Importantly, while information from the doctor was the most valuable source of information for 10 patients, eight cited their own experiences as being more important and trustworthy than the information from the doctor, 'I think the most important is your own experience... the cream might work for someone else... doesn't mean that it is a solution for everybody.'

The degree of counselling received when prescribed corticosteroid steroids was variable. While most recalled being informed by their physician, pharmacist or through patient information leaflets, some felt that the information was inadequate, 'nobody told me there is a side effect to it until I started realising that something is not right' or that they were unable to 'comprehend the side effects [at that time]'

Critical appraisal and trust in a particular source of information also influenced the value of the acquired knowledge. Some participants described themselves as taking at face value what the dermatologist says to be true, 'I'm more of a follower, so I just follow whatever the doctor says,' 'they are supposed to help me, so I trust them completely.' Other participants described a more critical attitude that arose from their evaluation of the treatment, 'But after a while, my skin still didn't get better then I will start questioning [the treatment with TCS].'

Availability of alternatives

Some cited the lack of effective alternatives as a factor to continue use despite their concerns, 'Without steroids, basically the rashes just doesn't go off at all... I have no other ways.' Others cited alternatives such as 'natural healing', 'Traditional Chinese Medicine' (TCM) and 'collagen' supplements. An extreme alternative included 'no moisture therapy', which involved 'no moisturising, no skincare' and only 'intermittent showers', which were endorsed by some patients advocating for TSA/TSW (table 2.3).

A participant with prolonged drug hypersensitivity syndrome described the side effects of TCS as a lesser evil compared with the systemic immunosuppressants he was also taking, 'I feel that there's definitely the risk of applying topical steroids... but it is quite mitigated and not as huge as, you know, compared to taking [immunosuppressive] medications orally.'

Treatment inconvenience

Treatment inconvenience was a minor theme that factored into two participant decisions, citing TCS application as 'inconvenient' and 'troublesome' (table 2.4).

Personality

Trait personality is known to influence information-seeking behaviour.^{20 21} by moderating the relationship between attitudes and behaviour.²²⁻²⁴ This was hinted at in our analysis of the earlier interviews, and so in the later interviews we added the Ten-Item Personality Inventory.²⁵ Patients who self-reported as having TSA/TSW

Table 2 Abbreviated table of themes and quotations explaining the factors influencing the attitudes and usage of TCS

Theme	Representative quote
Attitudes towards TCS	
2.1 Attitudes towards TCS: beliefs about TCS	
Perceived benefits	'I will say it improved my quality of living because it helped to ease the condition of my rashes.' 'Because once when we try the cream, it really works.'
Perceived risks	'I've noticed this... if you keep applying the steroid creams, the skin surrounding the area will become lighter.' 'Just the skin getting slightly thinner, at the usual spots that I apply [TCS]...because when I scratch, it's easier to bleed.'
Perceived lack of benefit (eg, lack of durability of response)	'Benefits [of TCS] are temporary relief, can live a normal life for a few weeks maybe, then it starts to flare up again.' 'It seems to be that currently steroids [are] only helping the symptoms... it doesn't solve the root issue, only the symptom.'
2.2 Attitudes towards TCS: knowledge of TCS	
Sources of information	'My friend actually told me; eh you shouldn't use steroid cream.' 'Mainly also because I also googled online.'
Critical appraisal of information	'But after a while, my skin still didn't get better then I will start questioning [the treatment with TCS].' 'I'm more of a follower, so I just follow whatever the doctor says.'
2.3 Presence of alternatives	
Presence of alternatives	'I would rather that it naturally heals... I find that natural healing is still the best.' 'Without steroids, basically the rashes just doesn't go off at all... I have no other ways of getting rid of it other than steroid creams.'
2.4 Treatment inconvenience	
Treatment inconvenience	'So inconvenience is one [reason for non-use]... 30 minutes applying lotion and cream or 30 minutes getting another nap, I would choose a 30 minute nap.' 'Every day you need to do it [apply creams], so it's really tiring and that's why sometimes I tend to skip it.'
2.5 Personality	
Personality type (eg, openness to experience)	'What I've noticed of people who have become so called addicted or dependent on steroids is that they tend to be sensitive individuals in general.' (An advocate for TSW who actively reaches out to those with TSA/TSW) 'Some people are more sensitive, it's like a psychological thing, a distorted perception of topical steroids, that they are no good.'
2.6 Patient's evaluation of clinical response to TCS	
Patient's evaluation of clinical response to TCS	'I realized like it keeps getting worse and not better... that was when the first red flag occurred and then I thought like maybe is steroid really the way to go?' 'I think just, deep down, I knew it wasn't working anymore... So I just felt it wasn't working and I decided to just stop... it was an internal decision.'
2.7 Doctor-patient relationship	
Response of doctors to steroid concerns	'It felt like they [dermatologists] were rushing for time or something.... It felt like I was just speaking my piece, but it wasn't a two-way conversation.' 'It's well known inside the TSW community that when you go to the doctor and you show them your skin condition, while you are on withdrawal, they will just say "can you please put on steroids and don't be ridiculous?"'
Doctor-patient relationship	'After this episode of my eczema, I sort of lost respect for dermatologists...it appears like they are sort of salesmen for these big pharmas selling steroid creams.'
2.8 Healthcare-seeking behaviour	
Association with standard healthcare or dermatologist	'It [skin condition] didn't improve at all. So I was very angry at him [doctor] and I didn't go back.' 'So at that time, I didn't know what any other options I have other than steroids. So that's why I kept doctor hopping.'
Association with alternative opinions	'Nearing the withdrawal, I sought out TCM [traditional Chinese medication].' 'I started this treatment. It is a skin regenerative treatment... it helps to regenerate the skin cells or boost the whatever ATP thing in your cells so that it will start regenerating again.'

TCS, topical corticosteroid; TSA, topical steroid addiction; TSW, topical steroid withdrawal.

were observed to have higher openness to experience; however, given the small sample, we cannot draw any conclusions regarding the statistical association between personality and TCS concerns (table 2.5).

Patient's evaluation of clinical response to TCS

Beliefs towards TCS evolved over time, driven by the patient's evaluation of their response to TCS, and the benefits and side effects experienced. Twenty-two of 26 reported starting out with neutral or positive opinion towards TCS, of whom 16 had developed a negative attitude over the course of their treatment (table 2.6).

The turning point for many patients centred around the lack of improvement or worsening of their skin conditions and that 'the steroid wasn't working anymore'. The 13 participants who self-identified as experiencing or having experienced TSA/TSW all described an inflection point, where a pattern of increased usage of TCS and decreased effectiveness led to growing concerns and the decision to completely stop TCS, 'I realized like it keeps getting worse...[and] I keep using stronger stuff.... So that was when the first red flag occurred.' This was commonly accompanied by a deteriorating doctor-patient relationship.

Opinions about the impact of age on TCS concerns varied. A younger participant felt that 'if you were aged like 70, and you only had 10 years to live...who would care if you got addicted to steroids'. Whereas a participant aged 70 suggested that '[For those who] are 30 or 40 [years old], they have "bypassed" the steroid [side effects] because their skin is too strong...if you don't reach the menopausal age, you don't have that other [side] effects'.

Doctor-patient relationship

Participants reported varying quality of relationships with their doctors. Of interest, the relationship was poor quality for 8 of 13 participants with concerns of TSA/TSW (compared with 1 of 13 patients without strong TCS concerns). Some were unhappy at their doctors for prescribing TCS, 'I didn't really understand...how come they continued prescribing [TCS] to me,' others expressed distrust and felt that doctors were 'salesmen for big pharma selling steroid creams' (table 2.7).

The doctor-patient relationship was mediated by the response of the doctor to patient's steroid concerns. Many reported that their concerns regarding TCS were 'ignored' and that doctors were not 'patient enough' and lacked 'empathy'. Patients gave many examples of being 'flat out dismissed' or told that they had 'no choice' but to use TCS when they brought up their concerns towards TCS (table 2, online supplemental file 2):

'So I express my concerns about topical steroid withdrawal, moisturiser addiction... [but] I think they don't accept my opinion.'

'I was scolded by [the] doctor, he say all creams are steroid...he sounded so unfriendly.'

'It's well known inside the TSW community that when you go to the doctor...they will just say 'can you please put on steroids and don't be ridiculous?''

Often, the decision to stop TCS 'was not discussed with the [doctor]' and a few cited a general 'distrust towards the medical profession'.

There was also a desire to be heard and validated, 'I know that we will never be doctors in terms of, like, the knowledge and experience that doctors have, but we do have our experience which I hope does count...whatever insights that patients share, when it comes to TSW, that it will be taken seriously.'

Healthcare-seeking behaviour

The data suggest that patient's healthcare-seeking behaviour was influenced by their evaluation of their clinical response to TCS and relationship with their doctors. Nine of 26 participants had completely withdrawn from standard dermatology care. Reasons given for ceasing to see a dermatologist include '[dermatologist] don't accept my opinion', and 'it wasn't a two-way conversation', while one participant cited that he would continue to see a dermatologist despite withdrawing from TCS, 'to be validated'. Patients instead sought providers of alternative and complementary medicine such as TCM practitioners (table 2.8).

Framework for the use and non-use of TCS

The themes highlighted in the data coding were used to construct a framework explaining the phenomenon of TCS concern, including the reasons for use and non-use of TCS and its consequences.

In this model (figure 1), a patient's knowledge and beliefs towards TCS are influenced by their information-seeking behaviour, sources of information, perceived benefits and risks, and moderated by personality type. Together, knowledge and beliefs make up the attitude towards TCS. The availability of alternatives and the inconvenience of TCS treatment subsequently influence the eventual decision to use or avoid TCS. Patients evaluate the response of their skin to TCS, which feeds back to their beliefs about TCS. For example, patients with a positive and sustained response to TCS are more likely to have a positive belief about TCS, while those with a negative and temporary response to TCS are more likely to believe that TCS is more harmful than beneficial.

Patients' experience and response to TCS coupled with their doctor's response to their concerns influences the quality of their relationships with their doctors, and healthcare-seeking behaviours. Most patients with TSA/TSW reported deteriorating relationships with their doctors and instead sought support from online TSA/TSW groups.

DISCUSSION

In this study, we analysed the experiences of patients to explain how and why some develop TCS concerns. We

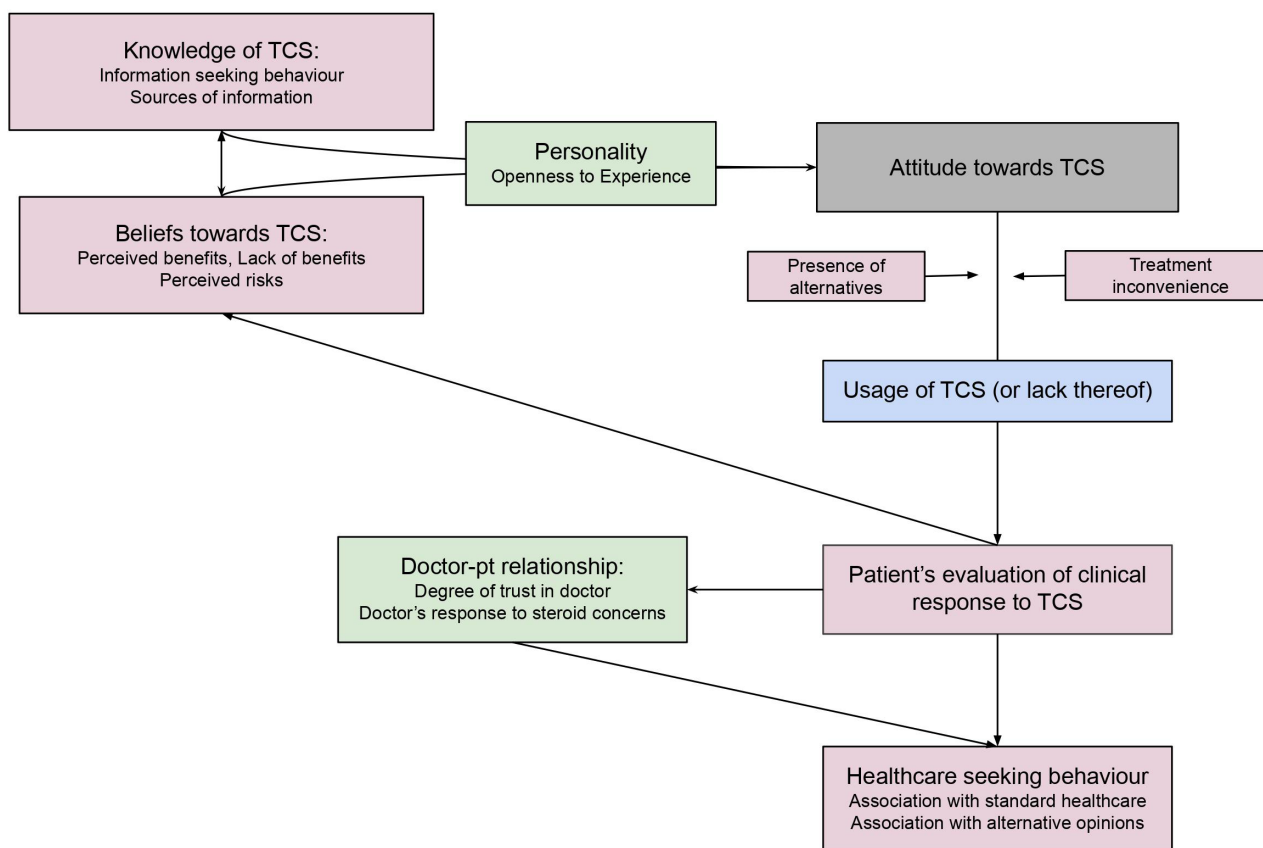


Figure 1 Derived framework explaining the use and non-use of topical corticosteroid (TCS) among patients. Pink boxes represent independent variables; grey boxes represent latent variables and green boxes are moderating variables. In this framework, knowledge and beliefs make up a patient's attitude towards TCS. An ongoing evaluation of response to TCS feeds back into their beliefs and influences their usage of TCS (or lack thereof) and healthcare-seeking behaviour. These behaviours are moderated by personality type and the doctor–patient relationship.

show that the poor handling of patient's concerns will lead to a deteriorating doctor–patient relationship and the decline in patient-centred care. This eventually results in the patient leaving standard dermatological care to seek alternatives.

Our framework shows similarities to established theories such as Fishbein and Ajzen's theory of reasoned action in which the behaviour is influenced by beliefs, evaluation of behavioural outcomes and external factors such as personality traits.^{26 27} Self-care and self-management are also important concepts in our framework and are increasingly important in the present-day doctor–patient relationship.^{28–30} Seeking of alternative opinions and treatments by patients who identified as TSA/TSW may have represented attempts at self-care and a way to recapture their sense of autonomy when traditional western treatment was ineffective. Physicians should not dismiss these actions but instead see them as attempts by patients to take ownership of their disease.

Poor treatment outcomes may be related to non-adherence^{31 32} and interventions such as smartphone applications and structured programmes have been trialled with variable improvements in adherence.^{7 33–35} However, despite their merits, a sizeable proportion of patients were still non-adherent. Our study highlights some possible reasons for this. We found that only a minority of participants expressed TCS concerns that were misguided. The majority with TCS concerns voiced medically sound reasons for avoidance including steroid atrophy, lack of sustained improvement and flares on cessation. They placed great value on their own experiences and sought confirmation of these experiences online. Standard counselling and reminders are unlikely to work when non-adherence is intentional, arising from personal experiences or beliefs that are perceived to be medically plausible and accepted by the online community.

Managing patients with marked TCS concerns therefore includes addressing the other constructs in the proposed framework. Upfront counselling about the lack of cure for most chronic inflammatory skin diseases and role of TCS in symptom control is important given that a common concern was the lack of ‘cure’ and ‘sustained improvement’. The doctor’s response to patient’s concerns is also crucial as attempts to emphasise the safety of TCS can be seen as the doctor being dismissive of the patient’s lived experiences.

The expressed desire to be emotionally validated and understood by participants with significant TCS concerns highlights the need for greater emotional validation and a reminder of our role as patient advocates. The importance of emotional validation, which is different from reassurance, has been shown to lead to more positive affect, less worry and greater satisfaction.^{36–38} Negative experiences with the physician can lead to patients stopping TCS without informing their physician, or seeking alternative treatment elsewhere, constituting a missed opportunity to optimise treatment plans.

With the emerging availability of other topical non-steroidal alternatives such as calcineurin inhibitors,³⁹ phosphodiesterase inhibitors⁴⁰ and Janus kinase (JAK) inhibitors,⁴¹ physicians will be better equipped to provide a wider range of alternatives for patients who wish to avoid TCS. Systemic medications which have been accepted by patients with TSA/TSW also include oral antibiotics and dupilumab.¹⁰ Although these may be more costly or less effective, they could be offered early in the therapeutic relationship as alternatives to TCS with appropriate counselling and management of expectations. This could lead to increased trust from the patient, building the foundation for a better doctor–patient relationship.^{42 43} Furthermore, the knowledge of these alternatives empowers the patient and increases their confidence in codirecting their care with their physicians.^{30 44}

There is significant controversy regarding the concept of steroid addiction and withdrawal (TSA/TSW) as a distinct clinical syndrome and current literature is conflicting.¹⁰ Physicians’ sensitivity and open-mindedness in discussing the topic with the patients is necessary, regardless of the plausibility or source. This is instrumental in altering the trajectory of the patient’s views on TCS and vital to the patient’s trust and healthcare-seeking behaviour. Trust building should be incorporated into the standard undergraduate and postgraduate medical curriculum, if not already done.

The strength of this study is the open interactions between interviewees and interviewers despite the former’s inherent wariness of being judged. The recruitment and interviews of participants were conducted with sensitivity, open-mindedness and often in a setting dissociated from dermatological care. The positive experience participants enjoyed is evidenced by their enthusiasm in referring us to their friends in the TSA/TSW community.

To ensure trustworthiness of the data,⁴⁵ the authors engaged in the diligent writing of memos, reflexive

documentation and kept a high level of sensitivity to the researcher’s role as co-creator of meaning. Coding was performed by multiple coders to mitigate observational and analytical bias and the resulting framework was checked with interviewees to ensure hermeneutic reliability.⁴⁶ In this study, theoretical saturation was reached well within the recommended sample size of 20–30 for grounded theory research.^{47 48}

A main limitation is the inability to objectively assess the associations between demographics, personality and disease factors like severity with degree of TCS concerns. We also had few participants with a non-eczema diagnosis. However, the data did not suggest that these patients obtained, processed and responded to TCS concerns in a different way compared with patients with eczema. By recruiting from a range of demographics, disease severities (from mild to severe erythrodermic disease) and perceptions towards TCS (from no concerns to extreme steroid phobia), we ensured that we accurately captured the spectrum to allow for analytical generalisability and transferability of results to the general population. Further areas for study include validating and quantifying this framework of TCS concerns, exploring clinical factors that may predispose a patient to better or poorer response to TCS and improving on the ability of doctors to engage patients with medication concerns.

CONCLUSION

Using qualitative methods, we showed that the conventional approach of providing more knowledge and education is incomplete and may not be effective if the basis for TCS concern is reasonable or if the patient has established a particular belief based on her own experience. This framework reports a nuanced system of factors and highlights the need for an alternative approach to better engage the patient with medication concerns. This includes an open and mutually respectful discussion, consideration of alternative therapeutics (even if these are less ideal), leveraging on the patient’s desire for self-care and autonomy and protecting the fidelity of the doctor–patient relationship.

Contributors EC conceptualised the study idea. PP, ST and NSC contributed to the design and execution of the study protocol. EC and ST conducted the interviews. NSC and JY observed the discussions. EC, ST and JY transcribed and coded the data. EC, ST, JY, PP and NSC analysed the data and agreed on the framework. EC and ST wrote the manuscript. PP and NSC supervised and revised the manuscript for important intellectual content. All authors (EC, ST, JY, PP and NSC) approved the final version of the manuscript and agree to be accountable for all aspects of the work. EC and NSC are joint senior authors. EC is the guarantor of the study.

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