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Complete List of Authors:	Tan, Sean; National University Healthcare System, Dermatology Phan, Phillip; Johns Hopkins University, Law, Jeyin; National University of Singapore Choi, Ellie; National University of Singapore - Kent Ridge Campus, Dermatology Chandran, Nisha; National University Healthcare System, Dermatology
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Title: A Qualitative Analysis of Topical Corticosteroid Concerns, Topical Steroid Addiction and Withdrawal in Dermatological Patients

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Authors: Sean Yilong Tan (MBBS, MRCP)[1], Phillip Phan (PhD)[2,3], Je Yin Law[4], Ellie Choi (MBBS, MRCP)[1]*, Nisha Suyien Chandran (MBBS, MRCP)[1]*

*Co last-authors

Affiliations

[1] Division of Dermatology, Department of Medicine, National University Hospital, Singapore

[2] Johns Hopkins Business School, Baltimore, Maryland

[3] Department of Medicine, Johns Hopkins Medicine, Baltimore, Maryland

[4] Yong Loo Lin School of Medicine, National University of Singapore, Singapore

Corresponding author

Dr Ellie Choi

Division of Dermatology, Department of Medicine, National University Hospital, Singapore

ellie_choi@nuhs.edu.sg

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Abstract

Objective: To explore the phenomenon of topical corticosteroid steroid (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 semi-structured interviews and analysed using grounded theory.

Participants: Patients with a prior experience of TCS use for a dermatological condition who may or may not be on active follow up with a dermatologist. They were 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 categorized into 7 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 fails to acknowledge the patient's opinions and instead emphasizes 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.

Article Summary

Strengths and limitations

- 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 TCS 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 diseases characteristics, the results may not be generalizable to the entire population

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Background

Topical corticosteroids (TCS) are prescribed widely in fields like allergy, ophthalmology and dermatology for various inflammatory and allergic conditions. Excessive topical corticosteroid (TCS) concern is recognized as a clinical problem and can lead to suboptimal treatment,[1] use of harmful alternatives[2] or excessive food 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 score (a score designed to measure TCS phobia)[4–6] reporting an average of 40-44%.[7–9] Fears about topical corticosteroid addiction and withdrawal (TSA/TSW) is another reason for TCS concerns. 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 "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 old. 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. The study was approved by the hospital institutional review board.

Data collection

1:1 or 1:2 in-depth semi-structured interviews[16] were conducted by two authors, with audio recordings transcribed for analysis. The interviews explored personal experiences with topical steroids, side effects, changing perceptions, and interactions with healthcare professionals (supplementary file 1). Initial interview guides were less structured allowing for spontaneity in inquiry. All interviewers were trained in gathering qualitative information.

Data analysis

Data analysis followed a grounded theory approach.[17,18] This was chosen for its ability to develop a multi-dimensional theory grounded from systematically obtained data. The process started with line-by-line coding followed by analytical focused coding. Team discussions were conducted after 5-6 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 and 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 8.0.[19] The study was designed and reported following Consolidated Criteria for Reporting Qualitative Studies (COREQ) guidelines for qualitative studies.

Patient and public involvement

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

Results

26 participants were recruited between June 2020 and March 2021. 1 patient declined participation. 15 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 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 mins (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.

Table 1. Participant Demographics

Variable		Frequency (total n=26)
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/ITE	8
	Bachelor's degree	13
	Masters/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	3
	Class 2	0
	Class 3	2
	Class 4	11
	Class 5	6
	Class 6	1
	Class 7	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)

Analysis showed that the drivers of TCS concerns could be categorized into 7 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, Supplementary file 2 in detail).

Table 2. Abbreviate 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 e.g. 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 e.g. 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."

Attitudes towards TCS

Attitudes towards TCS – Beliefs about TCS (Table 2.1)

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").

More than 2/3 of the patients reported known side effects of TCS such as "the skin surrounding the area will become lighter" and "skin thinning". 2 participants reported systemic side effects such as adrenal insufficiency 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 (Table 2.2)

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 health care professionals, friends and family to online searches and social media groups.

Importantly, while information from the doctor was the most valuable source of information for 10 patients, 8 cited their own experiences as being more important and trustworthy than 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 the 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 (Table 2.3)

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” 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.

A participant with prolonged drug hypersensitivity syndrome described the side effects of TCS as a lesser evil compared to 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 (Table 2.4)

Treatment inconvenience was a minor theme that factored into 2 participants decisions, citing TCS application as "inconvenient" and "troublesome".

Personality (Table 2.5)

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 Measure (TIPI).[25] Patients who self-reported as having TSA/TSW 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.

Patient's evaluation of clinical response to TCS (Table 2.6)

Beliefs toward TCS evolved over time, driven by the patient's evaluation of their response to TCS, and the benefits and side effects experienced. 22 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.

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 increase 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 suggested 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 felt 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 (Table 2.7)

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 to 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".

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, supplementary table 1), "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 (Table 2.8)

The data suggests that patient's healthcare seeking behaviour was influenced by their evaluation of their clinical response to TCS and relationship with their doctors. 9 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 1 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 Traditional Chinese Medicine (TCM) practitioners.

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 and 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 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 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 dermatologic 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 that 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.

In our study, a minority of participants expressed TCS concerns that were misguided, and some perceived side effects that appear exaggerated. Nevertheless, many voiced medically sound concerns including steroid atrophy, lack of sustained improvement and flares upon cessation as reasons for avoidance. Patients place great value on their own experiences and seek confirmation of these experiences online. Such behaviours highlight the difficulties in addressing concerns because the bases for patients beliefs stem from personal experience or what they perceive to be medically plausible and accepted by the online community.

Counselling would need to be done sensitively as attempts to emphasize the safety of TCS can be seen as the doctor being dismissive of the patient's lived experiences. Upfront counselling about the lack of cure for most chronic inflammatory skin diseases and role of TCS in symptom control is also important given that a common concern was the lack of "cure" and "sustained improvement".

The expressed desire to be emotionally validated and understood by participants with significant TCS concerns highlights the need for greater emotional valiation 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.[31–33] 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,[34] phosphodiasterase inhibitors[35] and JAK inhibitors[36], physicians will be better equipped

to provide a wider range of alternatives for patients who wish to avoid TCS. 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.[37,38] Furthermore, the knowledge of these alternatives empowers the patient and increases their confidence in co-directing their care with their physicians.[30,39]

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 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.

This study's strength 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,[40] authors engaged in the diligent writing of memos, reflexive documentation and kept a high level of sensitivity to the researcher's role as co-constructor 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.[41] In this study, theoretical saturation was reached well within the recommended sample size of 20 to 30 for grounded theory research.[42,43]

A main limitation is the inability to objectively assess the association between demographics, personality, and disease factors with TCS concerns. 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 upon 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.

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Availability of data and materials

The datasets supporting the conclusions of this article are available from the authors on reasonable request

Ethics approval

The study was approved by the National Healthcare Group DSRB, reference number 2020/00243.

Patient consent for publication

Not applicable

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Contributorship statement

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 while ST and LJW observed the discussions. EC, ST and LJY transcribed and coded the data. EC, ST, LJY, 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 consent. All authors EC, ST, LJY, PP and NSC approved the final version of the manuscript and are in agreement to be accountable for all aspects of the work.

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Figure/table legend

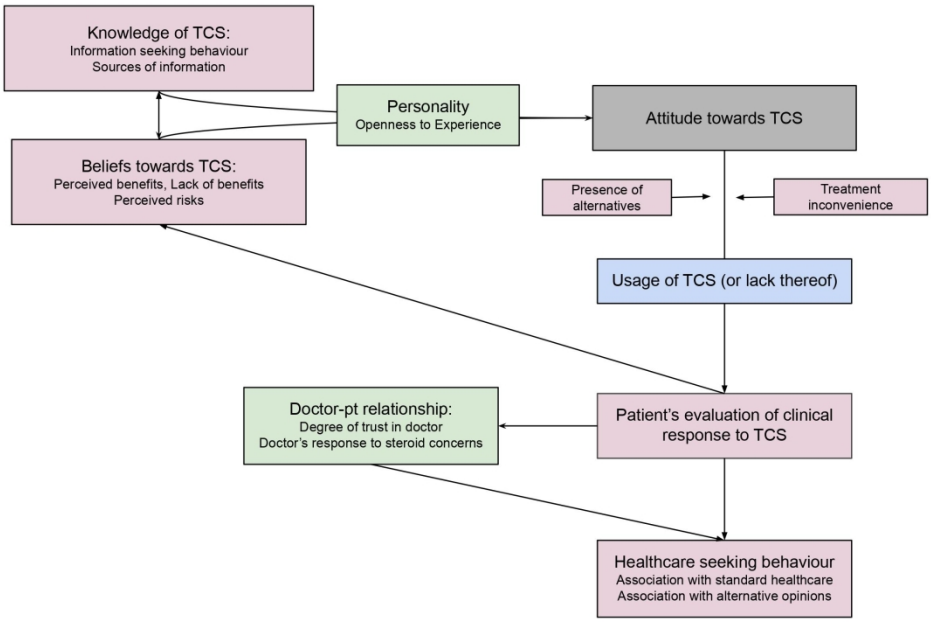
Table 1: Participant Demographics

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

Figure 1: Derived framework explaining the use and non-use of TCS among patients. Pink boxes represent independent variables; Grey boxes represent latent variable and Green boxes are moderating variables. In this framework, knowledge and beliefs make up a patient's attitude towards to 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.

Supplementary file 1. Study questionnaire and interview guide

Supplementary file 2. Full table of themes and quotations explaining the factors influencing the attitudes and usage of TCS



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Supplementary file 2. Study questionnaire and interview guide

To be filled by patient:

Dear Sir/Madam, thank you for taking time out of your day to fill in this questionnaire. Please feel free to ask us any questions along the way. Your data will be anonymized.

Part 1: General Information

Age:					
Gender:	Male		Female		
Race:	Chinese	Malay	Indian	Caucasian	Others
Highest Education Level:	Primary School	Secondary School	Junior College, polytechnic or ITE	Bachelor Degree	Masters or Doctorate

Usage of topical steroids (TCS)

This part of the questionnaire is for us to understand your progress and the factors that influence the treatment for your skin condition.

Factors affecting Adherence	Strongly disagree	Disagree	Agree	Strongly agree
I use TCS more often than what is prescribed				
I use TCS less often than what is prescribed				
I often miss applying TCS because I forget/too busy/inconvenient				
I often miss applying TCS because I consciously decide not to				
The creams/TCS prescribed for my skin condition is too expensive				
I am too busy to comply with the treatment for my skin condition				

TOPICOP© score

This part of the questionnaire is for us to understand your knowledge and beliefs, fears and behaviour towards the usage of topical steroids (TCS).

Topical Steroids (TCS)	Totally disagree	Not really agree	Almost Agree	Totally Agree
TCS pass into the blood stream				
TCS can lead to infections				
TCS make you fat				
TCS damage your skin				
TCS will affect my future health				
TCS can lead to asthma				
I don't know of any side effects but I'm still afraid of TCS				
Regarding TCS/steroid creams	**Never**	**Sometimes**	**Often**	**Always**
I am afraid of applying too much cream (TCS)				
I am afraid of putting cream (TCS) on certain zones like the eyelids where the skin is thinner				
I wait as long as I can before treating myself with TCS				
I stop treatment as soon as I can				
I need reassurance about TCS				

This section aims to measure how much your skin problem has affected your life OVER THE LAST WEEK.					
	Very much	**A lot**	**A little**	**Not at all**	**NA**
Over the last week, how **itchy, sore, painful** or **stinging** has your skin been?					
Over the last week, how **embarrassed** or **self conscious** have you been because of your skin?					
Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home** or **garden?**					
Over the last week, how much has your skin influenced the **clothes** you wear?					
Over the last week, how much has your skin affected any **social** or **leisure** activities?					
Over the last week, how much has your skin made it difficult for you to do any **sport**?					
Over the last week, has your skin prevented you from **working** or **studying**? ----- If 'No', over the last week, how much has your skin been a problem at **work** or **studying**?	Yes		No		NA
	A lot	A little	Not at all		NA
	Very much	**A lot**	**A little**	**Not at all**	**NA**
Over the last week, how much has your skin created problems with your **partner,** or any of your **close friends** or **relatives?**					
Over the last week, how much as your skin caused any **sexual difficulties**?					
Over the last week, how much of a problem has the **treatmen**t for your skin been, for example by making your home messy, or by taking up time?					

TEN-ITEM PERSONALITY INVENTORY-(TIPI)

Here are a number of personality traits that may or may not apply to you. Please write a number next to each statement to indicate the extent to which you agree or disagree with that statement. You should rate the extent to which the pair of traits applies to you, even if one characteristic applies more strongly than the other.

1 = Disagree strongly
2 = Disagree moderately
3 = Disagree a little
4 = Neither agree nor disagree
5 = Agree a little
6 = Agree moderately
7 = Agree strongly

I see myself as:

1. _____ Extraverted, enthusiastic.

2. _____ Critical, quarrelsome.

3. _____ Dependable, self-disciplined.

4. _____ Anxious, easily upset.

5. _____ Open to new experiences, complex.

6. _____ Reserved, quiet.

7. _____ Sympathetic, warm.

8. _____ Disorganized, careless.

9. _____ Calm, emotionally stable.

10. _____ Conventional, uncreative.

To be filled by doctor or patient:

Disease condition: _____ Duration of disease: _____ years

Highest potency topical steroid: _____ Duration of topical steroid use: _____

Interview Guide Version 1

Interview Guide

Good afternoon and welcome to the session. Thank you for taking the time to share with us about your skin condition.

My name is ____. I am a doctor at the National University Hospital. Assisting me is ____. The purpose of this interview is to gain an understanding into possible factors influencing usage of moisturisers and steroid creams. We are having discussions like this with other patients and groups.

There are no wrong or right answers. We expect that different people will have different opinions. Please feel free to share your point of view, even if it differs from what others have said.

We will be audio recording this session as we do not want to miss any of your comments. This information will be kept confidential, and no names or identifiers will be used in any reports. The information shared by participants in this group should be kept confidential and not disclosed or discussed outside of this group.

Opening

1. Tell me about yourself
2. Tell me about your skin condition
3. Tell me about your current treatment

Steroid concern/steroid phobia

1. What are your thoughts towards using creams to treat your skin?
2. What are your thoughts towards using topical steroids?
    a. Elaborate more
    b. What do you think about the safety of topical steroids
        i. Why do you think it might be ___ (dangerous/thin the skin/cannot use too long/whatever they suggest)
        ii. Describe your worry towards topical steroid use (to understand whether its a knowledge thing, an innate fear that cannot be shaken etc)
    c. Do you worry when using topical steroids?
        i. Why yes and no
        ii. What made you worried about topical steroids (if worried)
        iii. What made you not worried about topical steroids (if not worried)

1. What do you think about when you use topical steroids
2. What do you feel after applying TCS
3. What do you feel if you do not apply TCS
4. How would you describe your mindset towards using topical steroids
5. What has contributed to this mindset
6. Has anyone tried to change your mindset/thoughts towards topical steroids (friends/family/doctors), how did they do it
    a. What is your response to them?

b. If doctors have tried to tell you about s/e topical steroids/safety of use > how did you feel after that
c. How much did your views towards TCS change

Adherence to topical treatment

1. How compliant are you with your topical treatment/TCS
2. (If not compliant) Could you share reasons why you are not able to comply with treatment adequately?
3. (If compliant) What are some factors that motivate you to comply with your treatment?

Closing

Thank you very much for sharing with us your thoughts. Is there anything else that you would like to share?

Interview Guide Version 5 (last version)

**Modifications were made to the interview guide in an iterative fashion to reflect the learnings gained from earlier interviews and to explore new insights.*

Good afternoon and welcome to the session. Thank you for taking the time to share with us about your skin condition.

My name is ____. I am a doctor at the National University Hospital. Assisting me is ____. The purpose of this interview is to gain an understanding of the effects and usage of moisturisers and steroid creams. We are having discussions like this with other patients and groups.

There are no wrong or right answers. We expect that different people will have different opinions. Please feel free to share your point of view, even if it differs from what others have said (if focused group, not relevant if 1:1).

We will be audio recording this session as we do not want to miss any of your comments. This information will be kept confidential, and no names or identifiers will be used in any reports. The information shared by participants in this group should be kept confidential and not disclosed or discussed outside of this group.

Opening

1. Tell me about yourself
2. Tell me about your skin condition
    a. Explore how does it affect their quality of life e.g. occupation, circumstances where it is problematic
    b. How long have you had your condition
    c. How has your condition evolved over time
3. Tell me about your current treatment

Steroid concern/steroid phobia

1. What are your thoughts towards using creams to treat your skin?
2. What has been your experience with using topical steroids?
3. Do you worry when using topical steroids?
    a. Why yes and no
    b. What made you worried about topical steroids (if worried)
    c. What made you not worried about topical steroids (if not worried)

Explore knowledge seeking behaviour (for those who did)

1. Could you share why you started to search for more information
2. Could you share the process by which you obtained information on TCS

Explore founded vs unfounded fears

1. What are some side effects that you know of
    a. Have you experienced any
    b. Why do you say you have skin thinning/how do you know you have skin thinning
    c. Why is skin thinning bad?

2. Exploring addiction/dependence/reliance
    a. Could you share with us your journey with TSW. How did you know that you were going through TSA/TSW (if relevant)
    b. What are your thoughts towards steroid addiction or steroid withdrawal? > do you think its something that everyone gets if they use TCS for long enough period, or only some people get it?
    c. What are some features that might suggest a person is 'addicted' to TCS
    d. Is there a difference between physical reliance vs mental reliance

3. What are your thoughts/mindset towards using topical steroids?
4. Explore the changes in mindset and opinion over time/usage
    a. What factors influenced this change/contributed to this mindset

1. Has anyone tried to change your mindset/thoughts towards topical steroids (friends/family/doctors), how did they do it
    a. What is your response to them?
    b. How did you feel
2. What might change your belief (for those who hold stronger beliefs). Do you think anything can convince you to use steroids again/safety of topical steroids? (for steroid phobic patients)
3. If doctors have tried to tell you about s/e topical steroids/safety of use > how did you feel after that
4. How much did your views towards TCS change
5. Exploring "natural" treatment options (if relevant/raised)
    a. What do you consider natural
    b. Why is natural better

For those who belong to a TSW/TSA community

1. What led you to speak up/share about your journey with TSW?
2. Do you mind sharing with us more about the TSW/TSW community
3. What do you think is the relationship most people with TSW have with their dermatologists
4. How do you think the medical community/dermatologists can support people with TSW/TSA?
5. Why do you think some/many dermatologists/doctors reject the idea of TSW (If raised)

Adherence to topical treatment

1. How frequently do you use your topical treatment/TCS
    a. What influences how much and how often you choose to apply
2. Could you share reasons why you apply your creams (regularly/not regularly)
    a. If adherent > what motivates you to apply your creams regularly
    b. If non adherent > why

Factors associated with steroid concerns

1. Why do you think some people have more/less fear about steroid side effects ?

2. Why do you think some people use steroid creams and seem to be okay?

Where do you get information on TCS from

1. Where is most of your information about TCS/TSA from?
2. How is the message different on these different sources/How is the consistency of information about TCS/TSA/TDW
3. Which source do you trust the most? If there are differing opinions on __ vs ___, which would you choose to believe
4. What determines whether you trust the information
5. What determines whether that information influences your beliefs
6. What determines whether that information/beliefs influence your actions (usage/adherence)

Personality and demographics

1. Can you describe your personality?
    - How do you think your personality influences your acceptance/rejection of topicals steroids
2. How does your personality influence your acceptance of the information given by doctors/information you read on internet
    - How does your personality influence your view towards using TCS
3. How does personality influence decision making
4. Do you think there is a gender, age difference in steroid phobia?
5. Do you think males and females may have different concerns towards steroid concerns? Why
6. Do you think patients who are older/young may have different concerns towards steroids? Why
7. Do you think there's a difference based on how long a person has been using TCS for?
8. Do you think there is a difference based on the severity of disease, impact on quality of life?
    - How does your severity of your condition at a particular point influence your decision to use TCS
    - How does your decision to use TCS affect your severity
    - Which one influences which (do you think your decision affects severity more, or severity affects decision more)

Relationship with dermatologist

1. How is your relationship with the dermatologist?
    - How much do your trust the doctor?
    - Does your relationship and trust influence your view and decision to use TCS?
    - What are some things you hope or expect from the doctor?
    - What kind of information, support would you want

Closing

Thank you very much for sharing with us your thoughts. Is there anything else that you would like to share?

Supplementary file 2: Full table of themes and quotations explaining the factors influencing the attitudes and usage of TCS

Theme	Representative Quote
Attitudes towards TCS	
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." "It seems to work so I just kept applying over and over again.... I started applying very thick layers, thinking that the more I applied, the better it is... I will just apply a very thick layer over it so that I won't wake up in the middle of the night." "I put topical steroids so my skin won't react to anything, because topical steroids are a type of immunosuppressants right, so I wouldn't want my skin to react to anything that my immune system doesn't want it to." "I think at one point I myself was addicted to steroids, when I was still schooling. So of course I don't want to go to school with bad skin, because I don't want my friends to look at me in some way, so I'll put topical steroids, and at some point of time, even after my skin is good, I still put topical steroids to make sure it stays that way." "When it is very itchy and it is causing me a lot of disturbances then I will start applying the steroid." "I apply it [TCS] everyday. It really helps." "Because once when we try the cream...it really works."
Perceived risks	"I think the very fact is that steroids in itself has the very clear side effect of thinning your skin, which I experienced before for my lip and other parts that I tried before." "When I do that [wet wraps with TCS], I noted my skin thinning" "Just the skin getting slightly thinner, at the usual spots that I apply [TCS]...because when I scratch, it's easier to bleed." "Once you apply the stronger 1% [TCS] dose is you will heal faster…[but the] thinning of the skin problem is always there. So I don't want to have that side effect, so I stop [TCS] totally." "Side effects are mainly skin thinning and burning of the skin." "I've noticed this...if you keep applying the steroid creams, the skin surrounding the area will become lighter." "The body is just weaker with all these creams that is being applied." "The doctors gave very strong steroid creams. So I put on my skin and then it went inside. Then it made my immune system very weak, then now, I have both eczema and adrenal insufficiency." "I know that steroid, what in Chinese they say it's poison, so it will be inside my body for a couple of years even the dosage is small" The cream didn't do much because the cream dried up my skin, it became worse, that's where the webbing came in. "I find that that area seems to get dark pigments." "I do see some changes to the skin, it's a lot more dry. And you know, with all the keratinocytes popping up and going off away, there are a few bumps on my skin at this moment...these are the more visible change that I have...applying all this sort of topical steroids." "I believe that if you use steroid creams, the side effects are mainly skin thinning and burning of the skin.... I believe that these are side effects, because I can feel it happening to me."

	"We are so old already, we are not young anymore, almost 70 years! When you are young, you care more about appearance, then when you are old you don't!" [A contrary opinion from an elderly chinese on why he does not fear side effects of TCS] "I see the benefits but nobody told me there is a side effect to it until I started realising that something is not right" [Lack of counselling about TCS side effects] "Sometimes the doctors do not mention that it contain steroids, so people do not know, so they will just take it." [Lack of counselling about TCS side effects]
Perceived lack of benefit e.g. 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 is only helping the symptoms... it doesn't solve the root issue, only the symptom". "You have to treat the root cause, if you keep applying creams, there's no use" "I think steroids are a temporary relief for the skin, it gets better but eventually it'll be a flare up somewhere...then I have to go back to steroids again." "So if me having to apply the cream...means I am dependent on the cream, why would I let myself be dependent on something when I can choose not to?" "The [TCS] creams didn't work anymore.... At most it will go away for a while then like it comes back. And then when it comes back, there might be new spots or like it comes back with vengeance." "I realized like it [skin condition] keeps getting worse… [and I was] using stronger stuff [TCS] to try to suppress the whole condition. So that was when the first red flag occurred]." "I was prescribed with corticosteroid creams...but the area of flare increased and the number of flares in a day also increased, followed by the dosage. Used to be like 0.01…[then] I was told to go for a higher dosage." "When I stopped the steroids, it's just that my whole skin just became worse." "So when I stopped steroid completely, in 2020, it was like a rebound flare of sorts that got very, very bad."
Attitudes towards TCS: Knowledge of TCS	
Sources of information	"I have relatives that are doctors, I have relatives that are pharmacists, so actually I do get a lot of input from them" "My friend actually told me, eh you shouldn't use steroid cream." "They [dermatologists] said it [TCS] can cause glaucoma and stuff like that." "There are also other doctors who advocate against the use of steroids." "Doctors tell me that moisturiser is always good, but I read online that moisturisers may not be so good because it may make my oil glands inactive." [Contradictory information from doctors and online] "I think the paranoia [towards steroids] came from my own reading and research." "I didn't want to be too reliant on creams and therefore I went online to do some research." "Instagram, online, facebook or whatever, they have a lot of information like on how steroids are bad for you." "There's this website called ITSAN, I think it talks more about topical steroid withdrawal yeah, and through internet, google search..."

	"I did go to ITSAN, also looked at YouTube videos that talked about TSA/TSW. Then only recently…[to] Instagram to see how others are coping with their TSA/TSW." "I base the information I read on what I experience." "Based on so many cases that I've seen and read, and my personal experience, I would suggest that be safe than sorry…" "I did a personal experiment, stubborn lah, I want to try if it's really the diet, and I tried and yeah it's showing." "I think the most important is your own experience...the cream might work for someone else with other issues but...doesn't mean that it is a solution for everybody." "I have to test it out myself, no choice."
Critical appraisal of information/Information seeking behavior	"Whenever I go to doctors, clinics or whatever, steroids will still be prescribed. So if doctors prescribe steroids, I assume it's good." "I'm more of a follower, so I just follow whatever the doctor says." "Whatever the doctors tell me, i'll just follow." "Honestly, all these things [side effects] we don't know..If they [doctors] say it's okay then it's okay." "I mean they [doctors] are supposed to help me so I trust them completely." "To some extent, it's easier to check credibility if you know how to think critically, the wealth of information [on the internet] is quite valuable." "It actually only came into my mind [concern about TCS passing into the bloodstream] because of the questionnaire that you actually sent over to me. That was actually one of the points that crossed my mind but I didn't go in depth into reading it." "I don't have the bandwidth to read in such detail [on TCS side effects]." "But after a while, my skin still didn't get better then I will start questioning [the treatment with TCS]." "I sort of realized that I had [TCS] addiction, after I did my own thorough research, and found that there is a very well-established community." "We don't want to challenge the doctor, and we trust what the doctor says, and we assume that they know better in that sense." [Why asked why she did not raise her concerns about TCS to the doctor]
Presence of alternatives	
Presence of alternatives	"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." "My mindset is if there are no other alternatives then i'll use it, but if there are other alternatives, i'll be more than happy to stop the steroid creams and use the other alternatives." "I did a bit of reading that steroid is bad for health…[but] I would still use it because that is the only medication I have." "Whatever the doctors give me, that is my only source of medication i have for my skin, so I've no choice but to use." "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." "I would rather that it naturally heal, if there is natural medicine that can apply on naturally.... I find that natural healing is still the best."

	"I started to go for the more natural products because I want my skin to heal naturally, so I started using coconut oil, cocoa butter, shea butter, to apply on my skin." "So I rather spend the money on maintaining a healthy lifestyle, than to go see doctors and visit and get the steroid creams that ultimately didn't help." "The only good way I can think of eczema [treatment], is maybe setting up the alarm early, to make me change my lifestyle and my eating habits." "For myself, sometimes i do look for alternatives, like i mentioned previously, i went to take collagen." "[Regarding usage of traditional chinese medications] I felt that at least it was a natural thing. Yeah, it's not like a chemical steroid or anything. So I felt that even though there were steroids in the Chinese medication, it was a lot milder."
Treatment inconvenience	
Treatment inconvenience	"So inconvenience is one [reason for non-use]. I mean I could have half an hour more sleep, I mean in a city like Singapore, which is very high time. If you ask me, 30 minutes applying lotion and cream or 30 minutes getting another nap, I would choose a 30 minute nap. So yeah" "I spend half an hour to 1 hour applying creams and moisturiser every time I wake up and it's like for ladies..." "Like very mafan [troublesome]... every day you need to do it, so it's really tiring and thats why sometimes i tend to skip it." "One thing is because I am a bit lazy to apply creams also unless it is very serious." "It is not easy applying creams, it's like every 3 days or 4 days, you have to keep applying."
Personality	
Personality	"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. So I do feel like personality type and sensitivity makes a difference on whether you are likely to become so called addicted or no" [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…. So everyone has their own individual thoughts" [Patient without TCS concerns postulating why some may not be keen to use TCS] "If you're sick then receive treatment, that's all." (mindset towards disease) "So I've known about TSW for a couple of years, actually. But something about, some logical fallacy about how invulnerable I am." "I was hoping that one day the rashes will be gone, my skin is more moisturized, I won't have these rashes again. But till today, 3 years, it hasn't been cured yet." " I do feel very conscious about it and I do feel embarrassed about it [having TSA/TSW]. I really don't need to like… um, air it out [on online forums/social media]. Maybe [it's] personality... I know there are Asians who will...be very open about it but it's just not me."
Patient's evaluation of clinical response to TCS	
Patient's evaluation of clinical response to TCS	"So I was using Betamethasone 0.1%....consistent application…. My skin was constantly flaking, like, my legs got very, very bad.... I just rationalized it in my head...it's supposed to be for localized usage...if the surface is that big, there must be something that's a little bit off, which made me conclude that maybe I should just stop doing this." "I realized like it keeps getting worse and not better then like I keep using stronger stuff to try to suppress the whole condition. So that was when the first red flag occurred."

	"Any reasons why I stopped the steroids...because I really feel that steroids isn't helping." "I was really so tired of using steroids...and I felt that it was just not useful anymore. Yeah. So even though I bought the cream in the end I threw it away." "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." "So yeah, so at that point of time i didn't think it really works on me, so yeah, thats why i end up sometimes not using it and all." "So we start using. It's good, we can see like small parts getting better. So I told him ok, keep continue, we see." "If I have to use it, then I have to use it. I think it's easier, faster to recover than using the non-steroids, so I will still use it"
Doctor-patient relationship	
Response of doctors to steroid concerns	"So I express my concerns about topical steroid withdrawal, moisturiser addiction… [but] I think they don't accept my opinion." "I was scolded by doctor, he say all creams are steroid, no one got no steroid, he sounded so unfriendly." "It felt like they [dermatologists] were rushing for time or something. So the doctor actually just looked at my condition, mentioned that it's GED, then wanted to put me on oral steroids and would prefer for me to be hospitalized...I did mention [concerns towards TCS], but the doctor didn't really agree or disagree. It felt like I was just speaking my piece, but it wasn't a two way conversation." "We had, quite a big quarrel about eczema and steroid creams, because I was telling him that "I didn't want steroids, you know, this is not working…. That was when he said that "you are not going to get any better if you don't continue steroids… So I said like, "okay, you know what, I'll just take it for the last time". I had both oral and cream, and I even had an injection...I was quite desperate at that point. And then... it just came back very badly, it didn't improve at all. So I was very angry at him and I didn't go back." "They maybe lack a bit of empathy. Then most of the doctors there like to rush, no offense lah, so I only spend 5 mins talking to them, then they just say 'okay, steroids steroids, go. Okay steroids. I prescribe you steroids, then okay, go, your life will be better" - that kind of thing." "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?" "There wasn't any medical professional help, or rather doctors weren't really listening to what I was explaining [TCS concerns]. So it's kind of frustrating." "I think many doctors, are always pushing steroids, yeah so no matter what, their answers are always the same." "They [doctors] always tell me to use more [TCS], they give steroids like candy." "[The first doctor] I get the hint of "okay you don't want but you have to suffer longer, that is your choice". The subsequent one [doctor], when I said I don't want steroid creams, he's more accepting, he said he understands why I don't want...So I can feel that the second one is more professional in that sense."
Doctor - patient relationship	"After this episode of my eczema, I sort of lost respect for dermatologists.... I lost confidence and lost trust in doctors and X dermatological centre. So to me, it appears like they are sort of salesmen for these big pharmas selling steroid creams," "I think the trust started weaning because there wasn't one particular doctor that I was consistently seeing. It was always different doctors."

	"But I didn't feel safe enough to share every single thing [concerns with using TCS] with him, every single concern . Yeah, I didn't feel one doctor was patient enough to listen to everything." "After I understood TSW, naturally I felt angry, like how come I was not told that this would be a possible side effect…. So there was a lot of the anger, fear, I guess even to a point of hatred like feeling injustice and I avoided doctors at all cost." "the deteriorating relationship does not necessarily just stem from the refusal to use TCS, Tt is also the distrust that stems from knowing that such a drug was prescribed for long-term use, likely without mention of side effects like TSW." "But we cannot be too critical of doctors, because doctors have their own specialty and training. What's the purpose of so many years of training? It's to become a specialist."
Healthcare seeking behavior	
Association with standard healthcare or dermatologist (e.g seeing a dermatologist or dropping out of dermatological care)	"It just came back very badly [after a course of systemic steroids], it didn't improve at all. So I was very angry at him and I didn't go back." [Patient with TSA/TSW who stopped seeing her GP] "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." "[Regarding relationship with dermatologst] Oh, it's non-existent. I do not want to see a dermatologist anymore." "I don't know, maybe to be validated in some way?" [Patient who recently stopped TCS against his dermatologist's recommendations, explaining why he plans to still attend his dermatology follow up]' "In terms of my decision to withdraw from steroids, it was not discussed with the healthcare professional."
Association with alternative opinions	"Nearing the withdrawal, I sought out TCM [traditional chinese medication]." "But once you stop it [TCS], then it'll come back and then it like defeats the whole purpose. So thats why I go for TCMs." "What I'm undergoing is, it's called no-moisture treatment... It's devised by some doctor, some quite renowned doctor in Japan…. What this involves is restricting your daily moisture intake and daily exercise, sleeping at consistent timing...I'm not allowed to shower daily." "I started this treatment. It is a skin regenerative treatment. They call it a laser but it is not really a laser. It is just a marketing name. So, it helps to regenerate the skin cells or boost the whatever ATP thing in your cells so that it will start regenerating again." "I'm trying to find people who have went through this process or who are able to cope with this condition, especially when my condition is getting more, I mean, to me, it feels more and more severe."

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description		Reported on Page #
Domain 1: Research team and reflexivity			
Personal Characteristics			
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	Two authors	Methods, page 7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	One author – MBBS, MRCP One author – PhD One author is a medical student One author – MBBS, MRCP One author – MBBS, MRCP	Title Page
3. Occupation	What was their occupation at the time of the study?	One author - internal medicine resident One author – professor of medicine at a university hospital One author – medical student One author – dermatology senior resident at a university hospital One author – dermatology senior consultant at a university hospital	N/A
4. Gender	Was the researcher male or female?	Two authors are male, three are female	N/A
5. Experience and training	What experience or training did the researcher have?	One author is an internal medicine resident. He underwent	N/A

		a course on Qualitative Research Methods by University of Amsterdam, offered through Coursera, prior to initiation of the study. One author is a senior resident in dermatology with research interest in health services research. She underwent a course on Qualitative Research Methods by University of Amsterdam, offered through Coursera, prior to initiation of this study. One author obtained his PhD in strategic management. He has published multiple qualitative studies in corporate governance, technology transfer, and innovation and quality in healthcare.	
Relationship with participants			
6. Relationship established	Was a relationship established prior to study commencement?	Two authors work in the division of dermatology and some study participants under their care were recruited. However, care was taken not to unduly influence patient participation. 3 authors had no prior relationship to study participants	N/A

7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	All participants were provided with an informed consent form detailing the purpose of the study as well as relevant contact details. The consent forms were signed and collected for acknowledgement of informed consent. Additionally, the study title, researchers' background, and interests and reasons for conducting the research were verbally explained to participants prior to the interview.	N/A
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	The main interest of the the lead author was grounded in the daily clinical work in the division of dermatology and interaction with patients. No characteristics were reported.	N/A
Domain 2: study design			
Theoretical framework			
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	The study is based on grounded theory.	Methods, page 9
Participant selection			
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Participants were recruited via purposive and snowball sampling. All participants recruited had previously	Methods, page 9

		expressed topical corticosteroid phobia.	
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	All participants were recruited face-to-face or via video conferencing.	Results, page 9
12. Sample size	How many participants were in the study?	26 participants were recruited for the study.	Results, page 9
13. Non-participation	How many people refused to participate or dropped out? Reasons?	1 participant declined to be interviewed. Reason was not sought. None of the participants dropped out of the interview.	Results, page 9
Setting			
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Data was collected in hospital clinics and from home when face-to-face interviews and video-conferencing were used respectively.	Methods, page 8
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	No one else was present besides the participants and researchers.	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	26 participants were recruited. 12 were male, 14 were female. The mean age was 33.8. Interviews were conducted from June 2020 to Mar 2021.	Results, page 9 Table 1
Data collection			
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Semi-structured interview was used to elicit the participants' thoughts on the subject of interest and yet allow pursuit of new ideas that arose during the conversation. The interview guide was not pilot tested, but	Methods, page 3 Supplementary file

		was refined after each round of 5-6 interviews to reflect earlier learnings and to explore emerging themes.	
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No.	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Interviews were audio recorded and transcribed verbatim into text for further analysis.	Methods, page 8
20. Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made during the interviews and were reviewed in addition to the interview transcript.	Methods, page 8
21. Duration	What was the duration of the interviews or focus group?	Interview duration ranged from 8 to 65 minutes. Mean duration 34.9 minutes.	Results, page 9
22. Data saturation	Was data saturation discussed?	Yes	Methods, page 8
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No	N/A
Domain 3: analysis and findings			
Data analysis			
24. Number of data coders	How many data coders coded the data?	2 authors coded the data	Methods, page 8
25. Description of the coding tree	Did authors provide a description of the coding tree?	Yes.	Results, page 9
26. Derivation of themes	Were themes identified in advance or derived from the data?	The themes were derived from data.	Methods, page 8
27. Software	What software, if applicable, was used to manage the data?	ATLAS.ti 8.0 was used to manage the data.	Methods, page 9

28. Participant checking	Did participants provide feedback on the findings?	Yes. The results were shown to 2 participants for feedback to ensure hermeneutic reliability.	Discussion, page 17
Reporting			
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, themes and ideas were supported with direct quotes from anonymized participants	Results and discussion, pages 8-17
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, data presented and findings are consistent from our point of view	Results and discussion, pages 8-17
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes. Major themes are discussed in the manuscript	Results and discussion, pages 8-17
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes. Minor themes are discussed in the manuscript	Results and discussion, pages 8-17

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A Qualitative Analysis of Topical Corticosteroid Concerns, Topical Steroid Addiction and Withdrawal in Dermatological Patients

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Title: A Qualitative Analysis of Topical Corticosteroid Concerns, Topical Steroid Addiction and Withdrawal in Dermatological Patients

Running head: Topical Steroid Concern, Addiction and Withdrawal

Authors: Sean Yilong Tan (MBBS, MRCP)[1], Phillip Phan (PhD)[2,3,4], Je Yin Law[4], Ellie Choi (MBBS, MRCP)[1,4]*, Nisha Suyien Chandran (MBBS, MRCP)[1,4]*

*Co last-authors

Affiliations

[1] Division of Dermatology, Department of Medicine, National University Hospital, Singapore

[2] Johns Hopkins Carey Business School, Baltimore, Maryland

[3] Department of Medicine, Johns Hopkins Medicine, Baltimore, Maryland

[4] Yong Loo Lin School of Medicine, National University of Singapore, Singapore

Corresponding author

Dr Ellie Choi

Division of Dermatology, Department of Medicine, National University Hospital, Singapore

ellie_choi@nuhs.edu.sg

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Abstract

Objective: To explore the phenomenon of topical corticosteroid steroid (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 semi-structured 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 categorized into 7 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.

Article Summary

Strengths and limitations

- 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 TCS 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 diseases characteristics, the results may not be generalizable to the entire population

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Background

Topical corticosteroids (TCS) are prescribed widely in fields like allergy, ophthalmology and dermatology for various inflammatory and allergic conditions. Excessive topical corticosteroid (TCS) concern is recognized as a clinical problem and can lead to suboptimal treatment,[1] use of harmful alternatives[2] or excessive food 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 score (a score designed to measure TCS phobia)[4–6] reporting an average of 40-44%.[7–9] Fears about topical corticosteroid addiction and withdrawal (TSA/TSW) is another reason for TCS concerns. 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 "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 old. 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. The study was approved by the hospital institutional review board.

Data collection

1:1 or 1:2 in-depth semi-structured interviews[16] 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 (supplementary 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 multi-dimensional theory grounded from systematically obtained data. The process started with line-by-line coding followed by analytical focused coding. Team discussions were conducted after 5-6 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 and 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 8.0.[19] The study was designed and reported following Consolidated Criteria for Reporting Qualitative Studies (COREQ) guidelines for qualitative studies.

Patient and public involvement

The themes and framework derived was presented to a random selection of participants to assess face validity of the model and to streamline for theoretical parsimony. Participants were given the opportunity to suggest and propose changes prior to the finalization 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. 17 participants were recruited from the dermatological clinics while 9 were recruited through word of mouth and online social medial platforms. 1 patient declined participation. All participants at some point had been attended to and prescribed topical steroids by a dermatologist.

15 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 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 mins (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.

Table 1. Participant Demographics

Variable		Frequency (total n=26)
Recruitment site	Dermatology clinics Word of mouth/social medial platforms	17 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/ITE	8
	Bachelor's degree	13
	Masters/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)

Analysis showed that the drivers of TCS concerns could be categorized into 7 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, Supplementary file 2 in detail).

Table 2. Abbreviate 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 e.g. 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 e.g. 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."

Attitudes towards TCS

Attitudes towards TCS – Beliefs about TCS (Table 2.1)

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").

More than 2/3 of the patients reported known side effects of TCS such as "the skin surrounding the area will become lighter" and "skin thinning". 2 participants reported systemic side effects such as adrenal insufficiency 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 (Table 2.2)

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 health care professionals, friends and family to online searches and social media groups.

Importantly, while information from the doctor was the most valuable source of information for 10 patients, 8 cited their own experiences as being more important and trustworthy than 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 the 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 (Table 2.3)

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” 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.

A participant with prolonged drug hypersensitivity syndrome described the side effects of TCS as a lesser evil compared to 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 (Table 2.4)

Treatment inconvenience was a minor theme that factored into 2 participants decisions, citing TCS application as “inconvenient” and “troublesome”.

Personality (Table 2.5)

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 Measure (TIPI).[25] Patients who self-reported as having TSA/TSW 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.

Patient's evaluation of clinical response to TCS (Table 2.6)

Beliefs toward TCS evolved over time, driven by the patient's evaluation of their response to TCS, and the benefits and side effects experienced. 22 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.

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 increase 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 suggested 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 felt 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 (Table 2.7)

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 to 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".

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, supplementary table in supplementary 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 (Table 2.8)

The data suggests that patient's healthcare seeking behaviour was influenced by their evaluation of their clinical response to TCS and relationship with their doctors. 9 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 1 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 Traditional Chinese Medicine (TCM) practitioners.

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 and 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 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 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 dermatologic 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 that 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 programs have been trialled with variable improvements in adherence.[7,33–35] However, despite their merits, a sizable 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 upon cessation. They placed great value on their own experiences and seeked confirmation of these experiences online. Standard counselling and reminders are unlikely to work when non-adherence is intentional, arisingfrom 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 emphasize 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 valiation 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] phosphodiasterase inhibitors[40] and 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 co-directing 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 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.

This study's strength 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] authors engaged in the diligent writing of memos, reflexive documentation and kept a high level of sensitivity to the researcher's role as co-constructor 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 to 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 to patients with eczema. By recruiting from a range of demographics, disease severities (from mild to severe erythrodermic disease) and perceptions toward TCS (from no concerns to extreme steroid phobia), we ensured that we accurately captured the spectrum to allow for analytic 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 upon 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.

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Availability of data and materials

The datasets supporting the conclusions of this article are available from the authors on reasonable request

Ethics approval

The study was approved by the National Healthcare Group DSRB, reference number 2020/00243.

Patient consent for publication

Not applicable

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Contributorship statement

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 while ST and LJW observed the discussions. EC, ST and LJY transcribed and coded the data. EC, ST, LJY, 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, LJY, PP and NSC approved the final version of the manuscript and are in agreement to be accountable for all aspects of the work.

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Figure/table legend

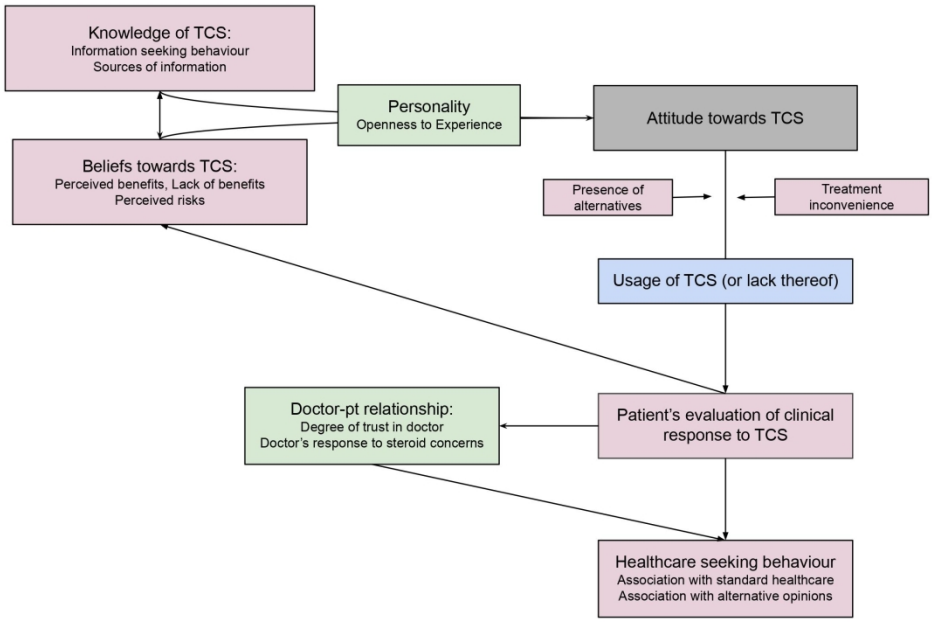
Table 1: Participant Demographics

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

Figure 1: Derived framework explaining the use and non-use of TCS among patients. Pink boxes represent independent variables; Grey boxes represent latent variable and Green boxes are moderating variables. In this framework, knowledge and beliefs make up a patient's attitude towards to 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.

Supplementary file 1. Study questionnaire and interview guide

Supplementary file 2. Full table of themes and quotations explaining the factors influencing the attitudes and usage of TCS



211x158mm (300 x 300 DPI)

Supplementary file 1. Study questionnaire and interview guide

To be filled by patient:

Dear Sir/Madam, thank you for taking time out of your day to fill in this questionnaire. Please feel free to ask us any questions along the way. Your data will be anonymized.

Part 1: General Information

Age:					
Gender:	Male		Female		
Race:	Chinese	Malay	Indian	Caucasian	Others
Highest Education Level:	Primary School	Secondary School	Junior College, polytechnic or ITE	Bachelor Degree	Masters or Doctorate

Usage of topical steroids (TCS)

This part of the questionnaire is for us to understand your progress and the factors that influence the treatment for your skin condition.

Factors affecting Adherence	Strongly disagree	Disagree	Agree	Strongly agree
I use TCS more often than what is prescribed				
I use TCS less often than what is prescribed				
I often miss applying TCS because I forget/too busy/inconvenient				
I often miss applying TCS because I consciously decide not to				
The creams/TCS prescribed for my skin condition is too expensive				
I am too busy to comply with the treatment for my skin condition				

TOPICOP© score

This part of the questionnaire is for us to understand your knowledge and beliefs, fears and behaviour towards the usage of topical steroids (TCS).

Topical Steroids (TCS)	Totally disagree	Not really agree	Almost Agree	Totally Agree
TCS pass into the blood stream				
TCS can lead to infections				
TCS make you fat				
TCS damage your skin				
TCS will affect my future health				
TCS can lead to asthma				
I don't know of any side effects but I'm still afraid of TCS				
Regarding TCS/steroid creams	**Never**	**Sometimes**	**Often**	**Always**
I am afraid of applying too much cream (TCS)				
I am afraid of putting cream (TCS) on certain zones like the eyelids where the skin is thinner				
I wait as long as I can before treating myself with TCS				
I stop treatment as soon as I can				
I need reassurance about TCS				

This section aims to measure how much your skin problem has affected your life OVER THE LAST WEEK.					
	Very much	**A lot**	**A little**	**Not at all**	**NA**
Over the last week, how **itchy, sore, painful** or **stinging** has your skin been?					
Over the last week, how **embarrassed** or **self conscious** have you been because of your skin?					
Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home** or **garden?**					
Over the last week, how much has your skin influenced the **clothes** you wear?					
Over the last week, how much has your skin affected any **social** or **leisure** activities?					
Over the last week, how much has your skin made it difficult for you to do any **sport**?					
Over the last week, has your skin prevented you from **working** or **studying**?	Yes		No		NA

If 'No', over the last week, how much has your skin been a problem at **work** or **studying**?	A lot	A little	Not at all		NA
	Very much	**A lot**	**A little**	**Not at all**	**NA**
Over the last week, how much has your skin created problems with your **partner,** or any of your **close friends** or **relatives?**					
Over the last week, how much as your skin caused any **sexual difficulties**?					
Over the last week, how much of a problem has the **treatmen**t for your skin been, for example by making your home messy, or by taking up time?					

TEN-ITEM PERSONALITY INVENTORY-(TIPI)

Here are a number of personality traits that may or may not apply to you. Please write a number next to each statement to indicate the extent to which you agree or disagree with that statement. You should rate the extent to which the pair of traits applies to you, even if one characteristic applies more strongly than the other.

1 = Disagree strongly
2 = Disagree moderately
3 = Disagree a little
4 = Neither agree nor disagree
5 = Agree a little
6 = Agree moderately
7 = Agree strongly

I see myself as:

1. _____ Extraverted, enthusiastic.

2. _____ Critical, quarrelsome.

3. _____ Dependable, self-disciplined.

4. _____ Anxious, easily upset.

5. _____ Open to new experiences, complex.

6. _____ Reserved, quiet.

7. _____ Sympathetic, warm.

8. _____ Disorganized, careless.

9. _____ Calm, emotionally stable.

10. _____ Conventional, uncreative.

To be filled by doctor or patient:

Disease condition: _____ Duration of disease: _____ years

Highest potency topical steroid: _____ Duration of topical steroid use: _____

Interview Guide Version 1

Interview Guide

Good afternoon and welcome to the session. Thank you for taking the time to share with us about your skin condition.

My name is ____. I am a doctor at the National University Hospital. Assisting me is ____. The purpose of this interview is to gain an understanding into possible factors influencing usage of moisturisers and steroid creams. We are having discussions like this with other patients and groups.

There are no wrong or right answers. We expect that different people will have different opinions. Please feel free to share your point of view, even if it differs from what others have said.

We will be audio recording this session as we do not want to miss any of your comments. This information will be kept confidential, and no names or identifiers will be used in any reports. The information shared by participants in this group should be kept confidential and not disclosed or discussed outside of this group.

<u>Opening</u>

1. Tell me about yourself
2. Tell me about your skin condition
3. Tell me about your current treatment

<u>Steroid concern/steroid phobia</u>

1. What are your thoughts towards using creams to treat your skin?
2. What are your thoughts towards using topical steroids?
    a. Elaborate more
    b. What do you think about the safety of topical steroids
        i. Why do you think it might be ___ (dangerous/thin the skin/cannot use too long/whatever they suggest)
        ii. Describe your worry towards topical steroid use (to understand whether its a knowledge thing, an innate fear that cannot be shaken etc)
    c. Do you worry when using topical steroids?
        i. Why yes and no
        ii. What made you worried about topical steroids (if worried)
        iii. What made you not worried about topical steroids (if not worried)

1. What do you think about when you use topical steroids
2. What do you feel after applying TCS
3. What do you feel if you do not apply TCS
4. How would you describe your mindset towards using topical steroids
5. What has contributed to this mindset
6. Has anyone tried to change your mindset/thoughts towards topical steroids (friends/family/doctors), how did they do it
    a. What is your response to them?

b. If doctors have tried to tell you about s/e topical steroids/safety of use > how did you feel after that
c. How much did your views towards TCS change

Adherence to topical treatment

1. How compliant are you with your topical treatment/TCS
2. (If not compliant) Could you share reasons why you are not able to comply with treatment adequately?
3. (If compliant) What are some factors that motivate you to comply with your treatment?

Closing

Thank you very much for sharing with us your thoughts. Is there anything else that you would like to share?

Interview Guide Version 5 (last version)

**Modifications were made to the interview guide in an iterative fashion to reflect the learnings gained from earlier interviews and to explore new insights.*

Good afternoon and welcome to the session. Thank you for taking the time to share with us about your skin condition.

My name is ____. I am a doctor at the National University Hospital. Assisting me is ____. The purpose of this interview is to gain an understanding of the effects and usage of moisturisers and steroid creams. We are having discussions like this with other patients and groups.

There are no wrong or right answers. We expect that different people will have different opinions. Please feel free to share your point of view, even if it differs from what others have said (if focused group, not relevant if 1:1).

We will be audio recording this session as we do not want to miss any of your comments. This information will be kept confidential, and no names or identifiers will be used in any reports. The information shared by participants in this group should be kept confidential and not disclosed or discussed outside of this group.

<u>Opening</u>

1. Tell me about yourself
2. Tell me about your skin condition
    a. Explore how does it affect their quality of life e.g. occupation, circumstances where it is problematic
    b. How long have you had your condition
    c. How has your condition evolved over time
3. Tell me about your current treatment

<u>Steroid concern/steroid phobia</u>

1. What are your thoughts towards using creams to treat your skin?
2. What has been your experience with using topical steroids?
3. Do you worry when using topical steroids?
    a. Why yes and no
    b. What made you worried about topical steroids (if worried)
    c. What made you not worried about topical steroids (if not worried)

Explore knowledge seeking behaviour (for those who did)

1. Could you share why you started to search for more information
2. Could you share the process by which you obtained information on TCS

Explore founded vs unfounded fears

1. What are some side effects that you know of
    a. Have you experienced any
    b. Why do you say you have skin thinning/how do you know you have skin thinning
    c. Why is skin thinning bad?

2. Exploring addiction/dependence/reliance
    a. Could you share with us your journey with TSW. How did you know that you were going through TSA/TSW (if relevant)
    b. What are your thoughts towards steroid addiction or steroid withdrawal? > do you think its something that everyone gets if they use TCS for long enough period, or only some people get it?
    c. What are some features that might suggest a person is 'addicted' to TCS
    d. Is there a difference between physical reliance vs mental reliance

3. What are your thoughts/mindset towards using topical steroids?
4. Explore the changes in mindset and opinion over time/usage
    a. What factors influenced this change/contributed to this mindset

1. Has anyone tried to change your mindset/thoughts towards topical steroids (friends/family/doctors), how did they do it
    a. What is your response to them?
    b. How did you feel
2. What might change your belief (for those who hold stronger beliefs). Do you think anything can convince you to use steroids again/safety of topical steroids? (for steroid phobic patients)
3. If doctors have tried to tell you about s/e topical steroids/safety of use > how did you feel after that
4. How much did your views towards TCS change
5. Exploring "natural" treatment options (if relevant/raised)
    a. What do you consider natural
    b. Why is natural better

For those who belong to a TSW/TSA community

1. What led you to speak up/share about your journey with TSW?
2. Do you mind sharing with us more about the TSW/TSW community
3. What do you think is the relationship most people with TSW have with their dermatologists
4. How do you think the medical community/dermatologists can support people with TSW/TSA?
5. Why do you think some/many dermatologists/doctors reject the idea of TSW (If raised)

Adherence to topical treatment

1. How frequently do you use your topical treatment/TCS
    a. What influences how much and how often you choose to apply
2. Could you share reasons why you apply your creams (regularly/not regularly)
    a. If adherent > what motivates you to apply your creams regularly
    b. If non adherent > why

Factors associated with steroid concerns

1. Why do you think some people have more/less fear about steroid side effects ?

2. Why do you think some people use steroid creams and seem to be okay?

Where do you get information on TCS from

1. Where is most of your information about TCS/TSA from?
2. How is the message different on these different sources/How is the consistency of information about TCS/TSA/TDW
3. Which source do you trust the most? If there are differing opinions on __ vs ___, which would you choose to believe
4. What determines whether you trust the information
5. What determines whether that information influences your beliefs
6. What determines whether that information/beliefs influence your actions (usage/adherence)

Personality and demographics

1. Can you describe your personality?
    - How do you think your personality influences your acceptance/rejection of topicals steroids
2. How does your personality influence your acceptance of the information given by doctors/information you read on internet
    - How does your personality influence your view towards using TCS
3. How does personality influence decision making
4. Do you think there is a gender, age difference in steroid phobia?
5. Do you think males and females may have different concerns towards steroid concerns? Why
6. Do you think patients who are older/young may have different concerns towards steroids? Why
7. Do you think there's a difference based on how long a person has been using TCS for?
8. Do you think there is a difference based on the severity of disease, impact on quality of life?
    - How does your severity of your condition at a particular point influence your decision to use TCS
    - How does your decision to use TCS affect your severity
    - Which one influences which (do you think your decision affects severity more, or severity affects decision more)

Relationship with dermatologist

1. How is your relationship with the dermatologist? ○ How much do your trust the doctor?
    - ○ Does your relationship and trust influence your view and decision to use TCS?
    - ○ What are some things you hope or expect from the doctor?
    - ○ What kind of information, support would you want

Closing

Thank you very much for sharing with us your thoughts. Is there anything else that you would like to share?

Supplementary file 2: Full table of themes and quotations explaining the factors influencing the attitudes and usage of TCS

Theme	Representative Quote
Attitudes towards TCS	
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." "It seems to work so I just kept applying over and over again.... I started applying very thick layers, thinking that the more I applied, the better it is... I will just apply a very thick layer over it so that I won't wake up in the middle of the night." "I put topical steroids so my skin won't react to anything, because topical steroids are a type of immunosuppressants right, so I wouldn't want my skin to react to anything that my immune system doesn't want it to." "I think at one point I myself was addicted to steroids, when I was still schooling. So of course I don't want to go to school with bad skin, because I don't want my friends to look at me in some way, so I'll put topical steroids, and at some point of time, even after my skin is good, I still put topical steroids to make sure it stays that way." "When it is very itchy and it is causing me a lot of disturbances then I will start applying the steroid." "I apply it [TCS] everyday. It really helps." "Because once when we try the cream...it really works."
Perceived risks	"I think the very fact is that steroids in itself has the very clear side effect of thinning your skin, which I experienced before for my lip and other parts that I tried before." "When I do that [wet wraps with TCS], I noted my skin thinning" "Just the skin getting slightly thinner, at the usual spots that I apply [TCS]...because when I scratch, it's easier to bleed." "Once you apply the stronger 1% [TCS] dose is you will heal faster…[but the] thinning of the skin problem is always there. So I don't want to have that side effect, so I stop [TCS] totally." "Side effects are mainly skin thinning and burning of the skin." "I've noticed this...if you keep applying the steroid creams, the skin surrounding the area will become lighter." "The body is just weaker with all these creams that is being applied." "The doctors gave very strong steroid creams. So I put on my skin and then it went inside. Then it made my immune system very weak, then now, I have both eczema and adrenal insufficiency." "I know that steroid, what in Chinese they say it's poison, so it will be inside my body for a couple of years even the dosage is small" The cream didn't do much because the cream dried up my skin, it became worse, that's where the webbing came in. "I find that that area seems to get dark pigments." "I do see some changes to the skin, it's a lot more dry. And you know, with all the keratinocytes popping up and going off away, there are a few bumps on my skin at this moment...these are the more visible change that I have...applying all this sort of topical steroids." "I believe that if you use steroid creams, the side effects are mainly skin thinning and burning of the skin.... I believe that these are side effects, because I can feel it happening to me."

	"We are so old already, we are not young anymore, almost 70 years! When you are young, you care more about appearance, then when you are old you don't!" [A contrary opinion from an elderly chinese on why he does not fear side effects of TCS] "I see the benefits but nobody told me there is a side effect to it until I started realising that something is not right" [Lack of counselling about TCS side effects] "Sometimes the doctors do not mention that it contain steroids, so people do not know, so they will just take it." [Lack of counselling about TCS side effects]
Perceived lack of benefit e.g. 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 is only helping the symptoms... it doesn't solve the root issue, only the symptom". "You have to treat the root cause, if you keep applying creams, there's no use" "I think steroids are a temporary relief for the skin, it gets better but eventually it'll be a flare up somewhere...then I have to go back to steroids again." "So if me having to apply the cream...means I am dependent on the cream, why would I let myself be dependent on something when I can choose not to?" "The [TCS] creams didn't work anymore.... At most it will go away for a while then like it comes back. And then when it comes back, there might be new spots or like it comes back with vengeance." "I realized like it [skin condition] keeps getting worse… [and I was] using stronger stuff [TCS] to try to suppress the whole condition. So that was when the first red flag occurred]." "I was prescribed with corticosteroid creams...but the area of flare increased and the number of flares in a day also increased, followed by the dosage. Used to be like 0.01…[then] I was told to go for a higher dosage." "When I stopped the steroids, it's just that my whole skin just became worse." "So when I stopped steroid completely, in 2020, it was like a rebound flare of sorts that got very, very bad."
Attitudes towards TCS: Knowledge of TCS	
Sources of information	"I have relatives that are doctors, I have relatives that are pharmacists, so actually I do get a lot of input from them" "My friend actually told me, eh you shouldn't use steroid cream." "They [dermatologists] said it [TCS] can cause glaucoma and stuff like that." "There are also other doctors who advocate against the use of steroids." "Doctors tell me that moisturiser is always good, but I read online that moisturisers may not be so good because it may make my oil glands inactive." [Contradictory information from doctors and online] "I think the paranoia [towards steroids] came from my own reading and research." "I didn't want to be too reliant on creams and therefore I went online to do some research." "Instagram, online, facebook or whatever, they have a lot of information like on how steroids are bad for you." "There's this website called ITSAN, I think it talks more about topical steroid withdrawal yeah, and through internet, google search..."

	"I did go to ITSAN, also looked at YouTube videos that talked about TSA/TSW. Then only recently…[to] Instagram to see how others are coping with their TSA/TSW." "I base the information I read on what I experience." "Based on so many cases that I've seen and read, and my personal experience, I would suggest that be safe than sorry…" "I did a personal experiment, stubborn lah, I want to try if it's really the diet, and I tried and yeah it's showing." "I think the most important is your own experience...the cream might work for someone else with other issues but...doesn't mean that it is a solution for everybody." "I have to test it out myself, no choice."
Critical appraisal of information/Information seeking behavior	"Whenever I go to doctors, clinics or whatever, steroids will still be prescribed. So if doctors prescribe steroids, I assume it's good." "I'm more of a follower, so I just follow whatever the doctor says." "Whatever the doctors tell me, i'll just follow." "Honestly, all these things [side effects] we don't know..If they [doctors] say it's okay then it's okay." "I mean they [doctors] are supposed to help me so I trust them completely." "To some extent, it's easier to check credibility if you know how to think critically, the wealth of information [on the internet] is quite valuable." "It actually only came into my mind [concern about TCS passing into the bloodstream] because of the questionnaire that you actually sent over to me. That was actually one of the points that crossed my mind but I didn't go in depth into reading it." "I don't have the bandwidth to read in such detail [on TCS side effects]." "But after a while, my skin still didn't get better then I will start questioning [the treatment with TCS]." "I sort of realized that I had [TCS] addiction, after I did my own thorough research, and found that there is a very well-established community." "We don't want to challenge the doctor, and we trust what the doctor says, and we assume that they know better in that sense." [Why asked why she did not raise her concerns about TCS to the doctor]
Presence of alternatives	
Presence of alternatives	"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." "My mindset is if there are no other alternatives then i'll use it, but if there are other alternatives, i'll be more than happy to stop the steroid creams and use the other alternatives." "I did a bit of reading that steroid is bad for health…[but] I would still use it because that is the only medication I have." "Whatever the doctors give me, that is my only source of medication i have for my skin, so I've no choice but to use." "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." "I would rather that it naturally heal, if there is natural medicine that can apply on naturally.... I find that natural healing is still the best."

	"I started to go for the more natural products because I want my skin to heal naturally, so I started using coconut oil, cocoa butter, shea butter, to apply on my skin." "So I rather spend the money on maintaining a healthy lifestyle, than to go see doctors and visit and get the steroid creams that ultimately didn't help." "The only good way I can think of eczema [treatment], is maybe setting up the alarm early, to make me change my lifestyle and my eating habits." "For myself, sometimes i do look for alternatives, like i mentioned previously, i went to take collagen." "[Regarding usage of traditional chinese medications] I felt that at least it was a natural thing. Yeah, it's not like a chemical steroid or anything. So I felt that even though there were steroids in the Chinese medication, it was a lot milder."
Treatment inconvenience	
Treatment inconvenience	"So inconvenience is one [reason for non-use]. I mean I could have half an hour more sleep, I mean in a city like Singapore, which is very high time. If you ask me, 30 minutes applying lotion and cream or 30 minutes getting another nap, I would choose a 30 minute nap. So yeah" "I spend half an hour to 1 hour applying creams and moisturiser every time I wake up and it's like for ladies..." "Like very mafan [troublesome]... every day you need to do it, so it's really tiring and thats why sometimes i tend to skip it." "One thing is because I am a bit lazy to apply creams also unless it is very serious." "It is not easy applying creams, it's like every 3 days or 4 days, you have to keep applying."
Personality	
Personality	"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. So I do feel like personality type and sensitivity makes a difference on whether you are likely to become so called addicted or no" [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…. So everyone has their own individual thoughts" [Patient without TCS concerns postulating why some may not be keen to use TCS] "If you're sick then receive treatment, that's all." (mindset towards disease) "So I've known about TSW for a couple of years, actually. But something about, some logical fallacy about how invulnerable I am." "I was hoping that one day the rashes will be gone, my skin is more moisturized, I won't have these rashes again. But till today, 3 years, it hasn't been cured yet." " I do feel very conscious about it and I do feel embarrassed about it [having TSA/TSW]. I really don't need to like… um, air it out [on online forums/social media]. Maybe [it's] personality... I know there are Asians who will...be very open about it but it's just not me."
Patient's evaluation of clinical response to TCS	
Patient's evaluation of clinical response to TCS	"So I was using Betamethasone 0.1%....consistent application…. My skin was constantly flaking, like, my legs got very, very bad.... I just rationalized it in my head...it's supposed to be for localized usage...if the surface is that big, there must be something that's a little bit off, which made me conclude that maybe I should just stop doing this." "I realized like it keeps getting worse and not better then like I keep using stronger stuff to try to suppress the whole condition. So that was when the first red flag occurred."

	"Any reasons why I stopped the steroids...because I really feel that steroids isn't helping." "I was really so tired of using steroids...and I felt that it was just not useful anymore. Yeah. So even though I bought the cream in the end I threw it away." "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." "So yeah, so at that point of time i didn't think it really works on me, so yeah, thats why i end up sometimes not using it and all." "So we start using. It's good, we can see like small parts getting better. So I told him ok, keep continue, we see." "If I have to use it, then I have to use it. I think it's easier, faster to recover than using the non-steroids, so I will still use it"
Doctor-patient relationship	
Response of doctors to steroid concerns	"So I express my concerns about topical steroid withdrawal, moisturiser addiction… [but] I think they don't accept my opinion." "I was scolded by doctor, he say all creams are steroid, no one got no steroid, he sounded so unfriendly." "It felt like they [dermatologists] were rushing for time or something. So the doctor actually just looked at my condition, mentioned that it's GED, then wanted to put me on oral steroids and would prefer for me to be hospitalized...I did mention [concerns towards TCS], but the doctor didn't really agree or disagree. It felt like I was just speaking my piece, but it wasn't a two way conversation." "We had, quite a big quarrel about eczema and steroid creams, because I was telling him that "I didn't want steroids, you know, this is not working…. That was when he said that "you are not going to get any better if you don't continue steroids… So I said like, "okay, you know what, I'll just take it for the last time". I had both oral and cream, and I even had an injection...I was quite desperate at that point. And then... it just came back very badly, it didn't improve at all. So I was very angry at him and I didn't go back." "They maybe lack a bit of empathy. Then most of the doctors there like to rush, no offense lah, so I only spend 5 mins talking to them, then they just say 'okay, steroids steroids, go. Okay steroids. I prescribe you steroids, then okay, go, your life will be better" - that kind of thing." "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?" "There wasn't any medical professional help, or rather doctors weren't really listening to what I was explaining [TCS concerns]. So it's kind of frustrating." "I think many doctors, are always pushing steroids, yeah so no matter what, their answers are always the same." "They [doctors] always tell me to use more [TCS], they give steroids like candy." "[The first doctor] I get the hint of "okay you don't want but you have to suffer longer, that is your choice". The subsequent one [doctor], when I said I don't want steroid creams, he's more accepting, he said he understands why I don't want...So I can feel that the second one is more professional in that sense."
Doctor - patient relationship	"After this episode of my eczema, I sort of lost respect for dermatologists.... I lost confidence and lost trust in doctors and X dermatological centre. So to me, it appears like they are sort of salesmen for these big pharmas selling steroid creams," "I think the trust started weaning because there wasn't one particular doctor that I was consistently seeing. It was always different doctors."

	"But I didn't feel safe enough to share every single thing [concerns with using TCS] with him, every single concern . Yeah, I didn't feel one doctor was patient enough to listen to everything." "After I understood TSW, naturally I felt angry, like how come I was not told that this would be a possible side effect…. So there was a lot of the anger, fear, I guess even to a point of hatred like feeling injustice and I avoided doctors at all cost." "the deteriorating relationship does not necessarily just stem from the refusal to use TCS, Tt is also the distrust that stems from knowing that such a drug was prescribed for long-term use, likely without mention of side effects like TSW." "But we cannot be too critical of doctors, because doctors have their own specialty and training. What's the purpose of so many years of training? It's to become a specialist."
Healthcare seeking behavior	
Association with standard healthcare or dermatologist (e.g seeing a dermatologist or dropping out of dermatological care)	"It just came back very badly [after a course of systemic steroids], it didn't improve at all. So I was very angry at him and I didn't go back." [Patient with TSA/TSW who stopped seeing her GP] "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." "[Regarding relationship with dermatologst] Oh, it's non-existent. I do not want to see a dermatologist anymore." "I don't know, maybe to be validated in some way?" [Patient who recently stopped TCS against his dermatologist's recommendations, explaining why he plans to still attend his dermatology follow up]' "In terms of my decision to withdraw from steroids, it was not discussed with the healthcare professional."
Association with alternative opinions	"Nearing the withdrawal, I sought out TCM [traditional chinese medication]." "But once you stop it [TCS], then it'll come back and then it like defeats the whole purpose. So thats why I go for TCMs." "What I'm undergoing is, it's called no-moisture treatment... It's devised by some doctor, some quite renowned doctor in Japan…. What this involves is restricting your daily moisture intake and daily exercise, sleeping at consistent timing...I'm not allowed to shower daily." "I started this treatment. It is a skin regenerative treatment. They call it a laser but it is not really a laser. It is just a marketing name. So, it helps to regenerate the skin cells or boost the whatever ATP thing in your cells so that it will start regenerating again." "I'm trying to find people who have went through this process or who are able to cope with this condition, especially when my condition is getting more, I mean, to me, it feels more and more severe."

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description		Reported on Page #
Domain 1: Research team and reflexivity			
Personal Characteristics			
1. Inter viewer/facilitator	Which author/s conducted the inter view or focus group?	Two authors	Methods, page 7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	One author – MBBS, MRCP One author – PhD One author is a medical student One author – MBBS, MRCP One author – MBBS, MRCP	Title Page
3. Occupation	What was their occupation at the time of the study?	One author - internal medicine resident One author – professor of medicine at a university hospital One author – medical student One author – dermatology senior resident at a university hospital One author – dermatology senior consultant at a university hospital	N/A
4. Gender	Was the researcher male or female?	Two authors are male, three are female	N/A
5. Experience and training	What experience or training did the researcher have?	One author is an internal medicine resident. He underwent	N/A

		a course on Qualitative Research Methods by University of Amsterdam, offered through Coursera, prior to initiation of the study. One author is a senior resident in dermatology with research interest in health services research. She underwent a course on Qualitative Research Methods by University of Amsterdam, offered through Coursera, prior to initiation of this study. One author obtained his PhD in strategic management. He has published multiple qualitative studies in corporate governance, technology transfer, and innovation and quality in healthcare.	
Relationship with participants			
6. Relationship established	Was a relationship established prior to study commencement?	Two authors work in the division of dermatology and some study participants under their care were recruited. However, care was taken not to unduly influence patient participation. 3 authors had no prior relationship to study participants	N/A

7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	All participants were provided with an informed consent form detailing the purpose of the study as well as relevant contact details. The consent forms were signed and collected for acknowledgement of informed consent. Additionally, the study title, researchers' background, and interests and reasons for conducting the research were verbally explained to participants prior to the interview.	N/A
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	The main interest of the the lead author was grounded in the daily clinical work in the division of dermatology and interaction with patients. No characteristics were reported.	N/A
Domain 2: study design			
Theoretical framework			
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	The study is based on grounded theory.	Methods, page 9
Participant selection			
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Participants were recruited via purposive and snowball sampling. All participants recruited had previously	Methods, page 9

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		expressed topical corticosteroid phobia.	
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	All participants were recruited face-to-face or via video conferencing.	Results, page 9
12. Sample size	How many participants were in the study?	26 participants were recruited for the study.	Results, page 9
13. Non-participation	How many people refused to participate or dropped out? Reasons?	1 participant declined to be interviewed. Reason was not sought. None of the participants dropped out of the interview.	Results, page 9
Setting			
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Data was collected in hospital clinics and from home when face-to-face interviews and video-conferencing were used respectively.	Methods, page 8
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	No one else was present besides the participants and researchers.	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	26 participants were recruited. 12 were male, 14 were female. The mean age was 33.8. Interviews were conducted from June 2020 to Mar 2021.	Results, page 9 Table 1
Data collection			
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Semi-structured interview was used to elicit the participants' thoughts on the subject of interest and yet allow pursuit of new ideas that arose during the conversation. The interview guide was not pilot tested, but	Methods, page 3 Supplementary file

		was refined after each round of 5-6 interviews to reflect earlier learnings and to explore emerging themes.	
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No.	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Interviews were audio recorded and transcribed verbatim into text for further analysis.	Methods, page 8
20. Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made during the interviews and were reviewed in addition to the interview transcript.	Methods, page 8
21. Duration	What was the duration of the interviews or focus group?	Interview duration ranged from 8 to 65 minutes. Mean duration 34.9 minutes.	Results, page 9
22. Data saturation	Was data saturation discussed?	Yes	Methods, page 8
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No	N/A
Domain 3: analysis and findings			
Data analysis			
24. Number of data coders	How many data coders coded the data?	2 authors coded the data	Methods, page 8
25. Description of the coding tree	Did authors provide a description of the coding tree?	Yes.	Results, page 9
26. Derivation of themes	Were themes identified in advance or derived from the data?	The themes were derived from data.	Methods, page 8
27. Software	What software, if applicable, was used to manage the data?	ATLAS.ti 8.0 was used to manage the data.	Methods, page 9

28. Participant checking	Did participants provide feedback on the findings?	Yes. The results were shown to 2 participants for feedback to ensure hermeneutic reliability.	Discussion, page 17
Reporting			
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, themes and ideas were supported with direct quotes from anonymized participants	Results and discussion, pages 8-17
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, data presented and findings are consistent from our point of view	Results and discussion, pages 8-17
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes. Major themes are discussed in the manuscript	Results and discussion, pages 8-17
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes. Minor themes are discussed in the manuscript	Results and discussion, pages 8-17