

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	<p>"I will say it improved my quality of living because it helped to ease the condition of my rashes."</p> <p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"When it is very itchy and it is causing me a lot of disturbances then I will start applying the steroid."</p> <p>"I apply it [TCS] everyday. It really helps."</p> <p>"Because once when we try the cream...it really works."</p>
Perceived risks	<p>"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."</p> <p>"When I do that [wet wraps with TCS], I noted my skin thinning"</p> <p>"Just the skin getting slightly thinner, at the usual spots that I apply [TCS]...because when I scratch, it's easier to bleed."</p> <p>"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."</p> <p>"Side effects are mainly skin thinning and burning of the skin."</p> <p>"I've noticed this...if you keep applying the steroid creams, the skin surrounding the area will become lighter."</p> <p>"The body is just weaker with all these creams that is being applied."</p> <p>"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."</p> <p>"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"</p> <p>The cream didn't do much because the cream dried up my skin, it became worse, that's where the webbing came in.</p> <p>"I find that that area seems to get dark pigments."</p> <p>"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."</p> <p>"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."</p>

	<p>"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]</p> <p>"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]</p> <p>"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]</p>
Perceived lack of benefit e.g. lack of durability of response	<p>"Benefits [of TCS] are temporary relief, can live a normal life for a few weeks maybe, then it starts to flare up again"</p> <p>"It seems to be that currently steroids is only helping the symptoms... it doesn't solve the root issue, only the symptom".</p> <p>"You have to treat the root cause, if you keep applying creams, there's no use"</p> <p>"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."</p> <p>"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?"</p> <p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"When I stopped the steroids, it's just that my whole skin just became worse."</p> <p>"So when I stopped steroid completely, in 2020, it was like a rebound flare of sorts that got very, very bad."</p>
Attitudes towards TCS: Knowledge of TCS	
Sources of information	<p>"I have relatives that are doctors, I have relatives that are pharmacists, so actually I do get a lot of input from them"</p> <p>"My friend actually told me, eh you shouldn't use steroid cream."</p> <p>"They [dermatologists] said it [TCS] can cause glaucoma and stuff like that."</p> <p>"There are also other doctors who advocate against the use of steroids."</p> <p>"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]</p> <p>"I think the paranoia [towards steroids] came from my own reading and research."</p> <p>"I didn't want to be too reliant on creams and therefore I went online to do some research."</p> <p>"Instagram, online, facebook or whatever, they have a lot of information like on how steroids are bad for you."</p> <p>"There's this website called ITSAN, I think it talks more about topical steroid withdrawal yeah, and through internet, google search..."</p>

	<p>"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."</p> <p>"I base the information I read on what I experience."</p> <p>"Based on so many cases that I've seen and read, and my personal experience, I would suggest that be safe than sorry..."</p> <p>"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."</p> <p>"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."</p> <p>"I have to test it out myself, no choice."</p>
Critical appraisal of information/Information seeking behavior	<p>"Whenever I go to doctors, clinics or whatever, steroids will still be prescribed. So if doctors prescribe steroids, I assume it's good."</p> <p>"I'm more of a follower, so I just follow whatever the doctor says."</p> <p>"Whatever the doctors tell me, i'll just follow."</p> <p>"Honestly, all these things [side effects] we don't know..If they [doctors] say it's okay then it's okay."</p> <p>"I mean they [doctors] are supposed to help me so I trust them completely."</p> <p>"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."</p> <p>"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."</p> <p>"I don't have the bandwidth to read in such detail [on TCS side effects]."</p> <p>"But after a while, my skin still didn't get better then I will start questioning [the treatment with TCS]."</p> <p>"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."</p> <p>"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]</p>
Presence of alternatives	
Presence of alternatives	<p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"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."</p>

	<p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"For myself, sometimes i do look for alternatives, like i mentioned previously, i went to take collagen."</p> <p>"[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."</p>
Treatment inconvenience	
Treatment inconvenience	<p>"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"</p> <p>"I spend half an hour to 1 hour applying creams and moisturiser every time I wake up and it's like for ladies..."</p> <p>"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."</p> <p>"One thing is because I am a bit lazy to apply creams also unless it is very serious."</p> <p>"It is not easy applying creams, it's like every 3 days or 4 days, you have to keep applying."</p>
Personality	
Personality	<p>"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]</p> <p>"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]</p> <p>"If you're sick then receive treatment, that's all." (mindset towards disease)</p> <p>"So I've known about TSW for a couple of years, actually. But something about, some logical fallacy about how invulnerable I am."</p> <p>"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."</p> <p>" 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."</p>
Patient's evaluation of clinical response to TCS	
Patient's evaluation of clinical response to TCS	<p>"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."</p> <p>"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."</p>

	<p>"Any reasons why I stopped the steroids...because I really feel that steroids isn't helping."</p> <p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"So we start using. It's good, we can see like small parts getting better. So I told him ok, keep continue, we see."</p> <p>"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"</p>
Doctor-patient relationship	
Response of doctors to steroid concerns	<p>"So I express my concerns about topical steroid withdrawal, moisturiser addiction... [but] I think they don't accept my opinion."</p> <p>"I was scolded by doctor, he say all creams are steroid, no one got no steroid, he sounded so unfriendly."</p> <p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"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?"</p> <p>"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."</p> <p>"I think many doctors, are always pushing steroids, yeah so no matter what, their answers are always the same."</p> <p>"They [doctors] always tell me to use more [TCS], they give steroids like candy."</p> <p>"[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."</p>
Doctor - patient relationship	<p>"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,"</p> <p>"I think the trust started weaning because there wasn't one particular doctor that I was consistently seeing. It was always different doctors."</p>

	<p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"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."</p>
Healthcare seeking behavior	
<p>Association with standard healthcare or dermatologist (e.g seeing a dermatologist or dropping out of dermatological care)</p>	<p>"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]</p> <p>"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."</p> <p>"[Regarding relationship with dermatologist] Oh, it's non-existent. I do not want to see a dermatologist anymore."</p> <p>"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]</p> <p>"In terms of my decision to withdraw from steroids, it was not discussed with the healthcare professional."</p>
<p>Association with alternative opinions</p>	<p>"Nearing the withdrawal, I sought out TCM [traditional chinese medication]."</p> <p>"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."</p> <p>"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."</p> <p>"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."</p> <p>"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."</p>