# Breaking through the steroid stigma: a single-centre study on topical corticosteroid perception and adherence in dermatology patients and caregivers

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# ABSTRACT

Introduction: Topical corticosteroid phobia is a common phenomenon that can result in poor treatment adherence and therapeutic failure. Objectives: This study aims to evaluate the prevalence and degree of topical corticosteroid phobia and its impact on treatment adherence in various dermatological conditions. Additionally, we explored the sources of information regarding topical corticosteroids.

Materials and Methods: A cross-sectional study was conducted among 300 participants with topical corticosteroid usage experience. Topical corticosteroid phobia was assessed with the topical corticosteroid phobia (TOPICOP) scale, and treatment adherence was measured with the Elaboration d'un outil d'evaluation de l'observance des traitements medicamenteux (ECOB) score. Information sources regarding topical corticosteroids were identified, and their level of trust was assessed. The data were collected via questionnaires in three languages, namely English, Malay and Mandarin.

Results: The study found that topical corticosteroid phobia was prevalent, with 98% of participants expressing a certain degree of phobia. The mean global TOPICOP score was 32.7  $\pm$  6.7%. The mean score of each domain was 27.1  $\pm$  17.2% for knowledge and belief, 35.7  $\pm$  23.8% for fears and 40.8  $\pm$  25.8% for behaviour. Patients/caregivers who have eczema, highly educated, severe disease, low tolerability to symptoms, previous adverse effects with topical corticosteroids and tend to traditional/non-steroidal alternative therapy usage had a significant association with topical corticosteroid phobia (p<0.05). Dermatologists were the most common and trusted source of information on topical corticosteroids.

Conclusions: This study highlights the widespread topical corticosteroid phobia in dermatological practice. Dermatologists should take the lead in combating steroid phobia and provide patients with public awareness regarding topical corticosteroids to improve treatment adherence and therapeutic outcomes.

**KEYWORDS**:

Topical corticosteroids, steroid phobia, TOPICOP, treatment adherence

## INTRODUCTION

Topical corticosteroids have been a cornerstone of dermatological practice for over 70 years, effectively treating a wide range of skin conditions from inflammatory diseases to autoimmune disorders.<sup>1-3</sup> Although the adverse effects of topical corticosteroids have been well documented, their efficacy and safety, if used appropriately, are equally well recognised.<sup>1-2</sup> Nevertheless, topical corticosteroid phobia remains a prevalent issue encountered in everyday clinical practice, where patients or caregivers experience excessive fear and anxiety about using topical corticosteroids.<sup>4-8</sup> Systematic reviews from 2017 to 2021 reported that the prevalence of topical corticosteroid phobia ranged from 21.0% to 95.7%.<sup>9-10</sup>

Topical corticosteroid phobia posed a significant obstacle to therapy adherence, resulting in poor treatment outcomes and reduced quality of life.<sup>5,7,10-15</sup> Kojima et al. found a higher nonadherence rate of 57.7% among patients with topical corticosteroid phobia than patients without topical corticosteroid phobia who reported non-adherence (25.0%).<sup>12</sup> Factors contributing to topical corticosteroid phobia may include misinformation from various sources, such as the internet, friends, relatives and even healthcare professionals.<sup>3,6,8,10,12-13,16-19</sup>

As a diverse and multi-ethnic nation, Malaysia is home to various disease backgrounds. Despite the prevalence of steroid phobia, there has been a lack of studies on this issue in our country, until now.<sup>14,25</sup> Previous studies also often used the term "phobia" empirically without properly quantifying the studied parameters.<sup>5,7,9,12</sup> Our primary objective is to assess the prevalence and define the degree of topical corticosteroid phobia in the local setting. The secondary objectives are to study the correlation of topical corticosteroid phobia with treatment adherence and identify the sources of topical corticosteroid-related information. This study aims to provide a better understanding of the phenomenon of topical corticosteroid phobia and inform future educational and counselling efforts to improve adherence to topical corticosteroid therapy.

#### MATERIALS AND METHODS

The present cross-sectional study was carried out at the

This article was accepted: 07 June 2023 Corresponding Author: Dr. Kew Chen Hui Email: drkewchenhui@gmail.com dermatology clinic of Hospital Sultanah Bahiyah, Alor Setar, Kedah between July 2021 and February 2022. Participants with a history of topical corticosteroid usage, including patients or caregivers, were invited to participate in the survey irrespective of their primary dermatological conditions. In the case of participants under the age of 18, their parents or guardians assisted with the questionnaire.

Data were collected through a comprehensive questionnaire that was divided into four parts. The first part gathered information on participant demographics, skin conditions, and past experiences with topical corticosteroids. The second part involved the use of the validated Elaboration d'un outil d'evaluation de l'observance des traitements medicamenteux (ECOB) topical treatment mini questionnaire consisting of four questions to assess treatment compliance.<sup>21</sup> The third part evaluated the level of topical corticosteroid phobia using the validated Topical Corticosteroid Phobia Scale (TOPICOP), which measured 12 items across three domains of topical corticosteroid phobia (knowledge and beliefs, fears and behaviour) in atopic dermatitis. The responses were scored on a four-point Likert scale (score range 0-3: 0=never, 1=sometimes, 2=often and 3=always; or 0= totally disagree, 1=do not really agree, 2=almost agree and 3=totally agree) to a maximum of 36 points. The higher the score, the higher the degree of steroid phobia.<sup>5</sup> Additional questions were included to assess traditional/herbal medicine usage and willingness to use a non-steroidal agent. The last part of the questionnaire investigated the sources of information on topical corticosteroids and assessed the level of trust in each of these sources. Permission to use the questionnaires and translate them into other languages was obtained from the authors.

The questionnaire was translated into Malay and Mandarin languages using forward and backward translations. A pilot study involving 15 participants for each language was conducted to assess the test-retest and intra-rater reliabilities using Cohen's unweighted kappa statistic for nominal scale (ECOB) and intraclass correlation coefficient (ICC) for interval scale (TOPICOP).<sup>20-22</sup> The k values for questions ECOB1 and ECOB4 in Malay and Mandarin questionnaires ranged from 0.71 to 0.74 (p<0.05) and 0.76 to 1.00 (p<0.05), indicating a substantial to almost perfect strength of agreement between the test and retest. However, Cohen's kappa was inconclusive for questions EOB2 and EOB3 in the Malay questionnaire because three out of four subcategorical values were ≤1. Nevertheless, both EOB2 and EOB3 showed high concordance pairs during comparison with EOB2 having 13/15 concordance pairs and EOB3 having 14/15. The ICC revealed moderate to almost perfect reliability in Malay (0.54–0.88, p<0.05) and Mandarin (0.54–0.94, p<0.05) questionnaires.

The calculated sample size was 279 including an additional 10% potential dropout from the survey.<sup>23</sup> Descriptive statistics were used to analyse the final responses, which were presented as frequencies and percentages for categorical variables. Independent t-test was used to identify binary variables, while one-way ANOVA was used to assess variables with multiple groups associated with greater TOPICOP scores. Fisher's exact test and Pearson Chi-square

test were applied to determine the association between categorical variables. Statistical significance was set at pvalue <0.05. The data analysis was performed using SPSS statistics for Windows, version 26.

This study was approved by the Medical Research and Ethics Committee, Ministry of Health, Malaysia, and was registered with the National Medical Research Registry (NMRR-21-1312-5999). All ethical considerations were taken into account to ensure the confidentiality of the participants' data.

# RESULTS

This study recruited a sizable cohort of 300 participants, and their socio-demographic and clinical characteristics were summarised in Table I. Of these participants, 41.7% were male and 58.3% were female, with a median age of 46 years. The most prevalent skin conditions reported were eczema (61.5%), psoriasis (31.3%), vitiligo (3.2%), connective tissue disease (3.2%) and seborrheic dermatitis (1.1%). Notably, non-drug adherence (54%) slightly outstripped the adherence group (46%).

The responses of participants to the TOPICOP scale were analysed based on the various domains assessed, as depicted in Table II. 98% (n=294) of the participants indicated some level of steroid phobia in the present study. The mean global TOPICOP score was  $32.7\pm16.7\%$ . Further, the mean score of each domain was  $27.1\pm17.2\%$  for knowledge and belief,  $35.7\pm23.8\%$  for fears and  $40.8\pm25.8\%$  for behaviour.

Our research findings highlight the fact that patients with eczema are more prone to steroid phobia compared to those without this condition. This disparity was significant in the behaviour domain (t=2.12, p=0.03). Our results also revealed that patients who showed non-adherence tendencies scored higher on the TOPICOP scale. This relationship was statistically significant in the behaviour domain (t=2.15, p=0.03).

The results of the study indicate a statistically significant relationship between education levels and mean scores in the TOPICOP domains of global (F(2, 297)=7.5, p=0.00), knowledge and belief (F(2, 297)=3.5, p=0.03) and fear (F(2, 297)=12.1, p=0.00). Specifically, the mean scores were significantly higher in participants with university-level education compared to those with secondary or non-formal education-primary education levels in all three domains. In the global domain, the mean scores for the university group were 36±16.6%, significantly higher than the scores for the secondary education group ( $30.8 \pm 15.6\%$ , p=0.03) and the non-formal education-primary education group (24.2 ± 19.0%, p=0.00). In the knowledge and belief domain, the university group had a mean score of 29±16.2%, which was significantly higher than the score for the non-formal education-primary education group (19.5  $\pm$  20.7%, p=0.03). In the fear domain, the university group had a mean score of 41.6  $\pm$  23.9%, which was significantly higher than the score for the secondary education group  $(32.2 \pm 21.4\%, p=0.00)$ and the non-formal education-primary education group  $(20.6 \pm 25.4\%, p=0.00)$  (Table III). Furthermore, the data revealed a significant association between non-adherence

Variable	No. (%)
Gender (n=300)	
Male	125 (41.7)
Female	175 (58.3)
Age range (vears: n=300)	
< 20	12 (4)
21_30	61 (20 3)
31-40	62 (20.7)
41_50	50 (10 7)
50 51_60	/3 (1/ 3)
S1=00 ≤ 61	43 (14.3) 62 (21)
$\leq 01$ Ethnicity (n-200)	05 (21)
Malay	221 (72 7)
Chinese	(75.7)
Chinese	62 (20.7)
Indian	10 (3.3)
Other	7 (2.3)
Education level (n=300)	2 (1)
Non-tormal education	3 (1)
Primary school	24 (8)
Secondary school	129 (43)
Pre-university education	88 (29.3)
Undergraduate degree	50 (16.7)
Master's degree/Doctorate	6 (2)
Top five reported skin conditions (n=283)	
Eczema	174 (61.5)
Psoriasis	88 (31.1)
Vitiligo	9 (3.2)
Connective tissue diseases	9 (3.2)
Seborrheic dermatitis	3 (1.1)
Duration of skin condition (n=300)	
< 6 weeks	2 (0.7)
6 weeks–3 months	15 (5)
3 months–1 year	32 (10.7)
1 year–2 years	41 (13.7)
> 2 years	210 (70)
Perceived severity of skin condition (n=300)	
Lowest severity	37 (12.3)
Low severity	82 (27.3)
Moderate severity	137 (45.7)
High severity	44 (14.7)
Perceived tolerance to skin condition (n=300)	
Lowest tolerance	14 (4.7)
Low tolerance	48 (16)
Moderate tolerance	183 (61)
High tolerance	55 (18 3)
Period of steroid use $(n=300)$	55 (10.5)
< 2 weeks	8 (2 7)
2 weeks-3 months	A2 (14)
3 months=1 year	38 (12 7)
1  voar - 2  voar	37 (12 3)
> 1 years	175 (58 3)
2  ycdls	
Adhoropical steroius "ECOD store (II=500)	128 (16)
Autorence Non adherence	150 (40)
	102 (34)

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and non-formal education-primary education levels, with 81.5% of non-adherence participants belonging to this group (Table IV).

The present study investigates the relationship between disease severity, tolerability of skin symptoms, and fear of using topical corticosteroids in the management of skin conditions. The results revealed that participants who perceived high disease severity had significantly higher knowledge and belief domain scores than those who perceived low disease severity (F(3, 296)=2.9, p=0.04; post hoc analysis: high severity,  $33\pm22.2\%$  vs low severity,  $23.6\pm16.9\%$ , p=0.02). The study also found that participants with high tolerability to skin symptoms had lower fear domain scores than those with moderate tolerability (F(3, 296)=1.7, p=0.02; post hoc analysis: high tolerability,  $27.7\pm24.5\%$  vs moderate tolerability,  $37.7\pm23.4\%$ , p=0.04). There was no significant difference observed between the high tolerability group and the other groups (Table III).

Dimension	Domain subscore Mean ± SD (%)	Question	%			
			Totally disagree/ never	Not really agree/ sometimes	Almost agree/ often	Totally agree/ always
Knowledge and belief	27.1 ± 17.2%	Topical corticosteroids pass into the	15.3	43.0	38.0	3.7
		bloodstream Topical corticosteroids can lead to infections	41.3	50.7	6.7	1.3
		Topical corticosteroids make you fat	54.0	37.3	6.7	2.0
		Topical corticosteroids damage your skin	35.7	43.3	17.0	4.0
		Topical corticosteroids will affect my future health	33.0	47.7	16.7	2.7
		Topical corticosteroids can lead to asthma	50.0	45.3	3.7	1.0
Fears	35.7 ±23.8%	I am afraid of putting cream (topical corticosteroids) on certain zones like the evelids where the skin is thinner	32.3	33.0	18.7	16.0
		I don't know of any side effects but I'm still afraid of topical corticosteroids	28.0	36.0	28.0	8.0
		I am afraid of applying too much cream (topical corticosteroids)	34.0	50.3	10.7	5.0
Behaviour	40.8 ±25.8%	I wait as long as I can before treating myself with topical corticosteroids	41.7	35.3	19.0	4.0
		I stop treatment as soon as I can	41.0	32.3	20.3	6.3
		I need reassurance about topical corticosteroids	15.7	17.7	27.7	39
Global TOPICOP score	32.7 ±16.7%					
Additional questions		I would rather try TCMs/herbal medications before using topical corticosteroids	66.7	23.0	7.3	3.0
		I would rather use something that does not contain steroids	43	31.7	16	9.3
		I have benefited from topical corticosteroid use	4	11.7	66	18.3
		I have experienced side effects from topical corticosteroid use	37.3	44	16.3	2.3

SD: standard deviation; TCM: traditional Chinese medicine; TOPICOP: topical corticosteroid phobia

According to the findings presented in the study, there is a significant relationship between higher TOPICOP scores and the likelihood of trying traditional medicine (p=0.00) and non-steroidal alternatives (p=0.00), respectively (Table III). Moreover, the results indicate that a considerable proportion of participants who portrayed a preference for traditional medicine (p=0.01) and non-steroidal alternatives (p=0.04) did not comply with topical corticosteroids (Table IV).

The study results demonstrated a significant difference in TOPICOP scores between participants who experienced a positive outcome from topical corticosteroid therapy and those who did not. Participants who benefited from topical corticosteroid therapy showed a lower TOPICOP score (p=0.00), whereas those who suffered from adverse effects of topical corticosteroids had a higher TOPICOP score (p=0.00) (Table III). The findings also suggest that poor adherence to treatment was associated with participants who did not benefit from topical corticosteroid therapy (p=0.01) and experienced negative effects (p=0.09) (Table IV).

Our study results indicated that various socio-demographic variables, such as gender, age, ethnicity, marital status, income, duration of skin conditions and steroid usage did not show any significant association with the global TOPICOP score and other domains.

A substantial proportion of the study participants obtained knowledge about topical corticosteroids from multiple sources, including dermatologists (76.3%), other doctors (28.3%), the internet and media (26.6%) and friends and family (16%). Of these, the majority of participants (99.3%) trusted the expertise of dermatologists, while 82.3% had confidence in other doctors' knowledge. The internet and media were a source of information for just over half of the participants (54.3%), with 46.7% expressing trust in friends and family as a source of information (Table V).

# DISCUSSION

The debilitating condition of atopic dermatitis affects many individuals, but the presence of steroid phobia has made effective management of symptoms a challenging task.<sup>3,9,10,11,13</sup> The emergence of TOPICOP has facilitated the assessment and comparison of steroid phobia, making treatment more accessible. With its demonstrated efficacy in evaluating patients with a range of dermatological conditions, TOPICOP has proven to be an indispensable tool.<sup>16,24</sup> Our study is the

	Knowledge and Belief Fears			Behaviour		Global			
Education level	Mean±S				SD (%)				
Non-formal education-primary education	19.5±20.7 °		20.6±25.4°		37.0±22.0		24.2±19.0 °		
Secondary education	26.7±17.2 32.2		32.2±2	21.4 <sup>b</sup>	37.5	37.5±25.7		30.8±15.6 <sup>b</sup>	
University	29.0±	:16.2 °	41.6±23.9 <sup>a, b</sup>		44.5±26.2		36.0±16.6 <sup>a, b</sup>		
F p	3.5	0.03	12.1	0.00	2.9	0.06	7.5	0.00	
Disease severity									
Lowest	27.1:	±16.8	30.9±	22.7	40.8	±28.7	31.5±17.9		
Low	23.6±	:16.9°	33.7±	23.4	40.2	40.2±24.4		±16.9	
Moderate	27.4:	±15.3	35.9±	23.7	41.1±25.2		32.9±15.4		
High	33.0±	:22.2 °	42.4±	25.2	40.9±28.5		37.3±19.0		
F р	2.9	0.04	1.7	0.14	0.0	1.00	1.7 0.16		
Disease tolerability									
Lowest	26.6	±19.3	29.4±	26.0	29.4	±29.1	28.0	28.0±19.5	
Low	27.4:	±16.1	38.9±	22.2	44.7±28.8		34.6±16.5		
Moderate	28.5	±16.8	37.7±2	23.4°	40.9±24.9		33.9±15.7		
High	22.5:	±18.8	27.7±2	24.5°	40.0±24.9		28.2±19.0		
Fр	1.7	0.16	3.2	0.02	1.3 0.27		2.3 0.08		
Traditional medicine									
Never	23.5±16.2 <sup>a, b, c</sup>		31.1±23.1 <sup>a, b, c</sup>		36.1±24.6 <sup>a, b, c</sup>		28.5±15.4 <sup>a, b, c</sup>		
Sometimes	31.7±15.5°		40.6±22.5 <sup>a, d</sup>		45.9±23.8°		37.5±14.8 <sup>a, d, e</sup>		
Often	40.9±16.0 <sup>b</sup>		48.5±17.0 <sup>♭</sup>		60.1±29.4 <sup>b</sup>		47.6±15.6 <sup>b, d</sup>		
Always	40.1±24.8°		67.9±23.9 <sup>c, d</sup>		60.5±23.0 °		52.2±20.0 <sup>c, e</sup>		
F р	12.3	0.00	12.3	0.00	9.8 0.00		18.7	0.00	
Non-steroidal alternatives									
Never	20.6±1	6.9 <sup>a, b, c</sup>	25.8±21.7 <sup>a, b, c</sup>		30.4±23.3 <sup>a, b, c</sup>		24.4±15.2 <sup>a, b, c</sup>		
Sometimes	30.3±	:14.3 °	40.8±17.5°		44.1±20.6 <sup>a, d</sup>		36.4±12.7 <sup>a, d</sup>		
Often	34.4±	:17.1 <sup>b</sup>	42.8±24.4 <sup>b</sup>		49.1±27.1°		40.2±16.0 <sup>b</sup>		
Always	34.1±	:18.5°	51.6±32.2°		63.5±29.0 <sup>c, a</sup>		45.8±18.7 <sup>c, d</sup>		
F p	12.9	0.00	16.7	0.00	19.4 0.00		26.5 0.00		
Benefited from topical corticosteroids				~		12 5, 24 0			
I otally disagree	25.0:	±17.8	33.3±	21.7	43.5±34.0		31./±18.3		
Not really agree	31./±	:14.4 ª	44.4±24.4 °		47.6±24.0°		38.9±14.6°		
Almost agree	29.9±	:16.1 °	38.4±22.4		42.4±25.2°		35.1±15.7		
lotally agree	14./±	17.5 ª, º	20.8±2	20.8±23.1 <sup>a</sup> 30.3±24.8 <sup>a, b</sup>		20.2±15.5°			
F p	13.6	0.00	10.5	0.00	4.3	0.01	15.2 0.00		
Adverse effects from topical corticosteroids	467	45.2			29 5 . 24 1		211, 14 5		
i otaliy disagree	16.7±15.3		22.4±23.2		28.5±24.1		21.1±14.5		
Not really agree	31.0±	:13./*	39.1±18.2°		44.8±23.2°		36.5± 12.3°		
Almost agree	40.6±	:17.5°	53.1±22.1°		53./±22.0°		4/.0± 10.4°		
lotally agree	27.0±	12.2 <sup>a, D</sup>	61.9±2	0.1 <sup>a, b</sup>	73.0±32.0 <sup> a, b</sup>		4/.2±	14.4 <sup>ª, p</sup>	
F p	34.5	0.00	31.3	0.00	20.8 0.00		50.8	0.00	

a-e: groups with significant differences in post hoc analysis

SD: standard deviation

first to explore the phenomenon of steroid phobia in the local population and its impact on atopic dermatitis, as well as other dermatological conditions.

Our study results revealed that an overwhelming majority of participants (98%, n=294) experienced a sense of fear when it came to using topical corticosteroids. Interestingly, previous studies reported a relatively lower percentage of individuals (39-59.6%) expressing similar concerns about topical corticosteroid usage in atopic dermatitis.<sup>14,25</sup> Our study also showed that our mean global TOPICOP score was 32.7%, falling below the average range reported in other countries (20.7–58.4%).<sup>3,16,26</sup> This disparity in scores reflects the significant cultural diversity between different regions worldwide. Additionally, our study population consisted of patients with varying dermatological conditions, making it challenging to compare the results directly with existing literature.

Steroid phobia originated from confusion and

misunderstanding about topical corticosteroids.<sup>6,10,12-13,16-18</sup> In our study, nearly half (41.7%) of the participants believed that topical corticosteroids could pass into their bloodstream, but the truth is that systemic absorption is minimal when used correctly.<sup>2,8,28</sup> Surprisingly, over a third of the cohort (36%) did not know of any side effects associated with topical corticosteroids, and two-thirds (66.7%) needed reassurance about steroid therapy. It is clear that a lack of knowledge and conflicting information only perpetuates fear and anxiety among steroid users.<sup>6,11</sup> That is why it is crucial to empower patients and caregivers with accurate information, so they can feel confident in the safety of steroid therapy and have guidance in recognising the varying potency of topical corticosteroid formulations.<sup>10,11,13</sup>

Our study has uncovered an interesting correlation that participants with eczema expressed a higher degree of steroid phobia than those without the condition, particularly in the behaviour domain (p=0.03). This may be because eczema is more common among the young population and patients or caregivers worry about prolonged steroid usage.<sup>24</sup>

		Treatment adherence No (%)		
		Adherence	Non-adherence	р
Education level	Non-formal education-primary education	5 (18.5%)	22 (81.5%)	0.01ª
	Secondary education	62 (48.1%)	67 (51.9%)	
	University	71 (49.3%)	73 (50.7%)	
Duration of skin condition	<1 year	16 (32.7%)	33 (67.3%)	0.04ª
	>1 year	122 (48.6%)	129 (51.4%)	
Traditional medicine use	Never	94 (47%)	106 (53%)	0.01 <sup>b</sup>
	Sometimes	38 (55.1%)	31 (44.9%)	
	Often	4 (18.2%)	18 (81.8%)	
	Always	2 (22.2%)	7 (77.8%)	
Non-steroidal alternative	Never	69 (53.5%)	60 (46.5%)	0.04ª
treatment use	Sometimes	44 (46.3%)	51 (53.7%)	
	Often	15 (31.3%)	33 (68.8%)	
	Always	10 (35.7%)	18 (64.3%)	
Benefited from topical	Totally disagree	4 (33.3%)	8 (66.7%)	0.01ª
corticosteroids	Not really agree	7 (20%)	28 (80%)	
	Almost agree	100 (50.5%)	98 (49.5%)	
	Totally agree	27 (49.1%)	28 (50.9%)	
Experienced adverse effects	Totally disagree	57 (41.3%)	55 (34%)	0.09 <sup>b</sup>
from topical corticosteroids	Not really agree	63 (47.7%)	69 (52.3%)	
	Almost agree	17 (34.7%)	32 (65.3%)	
	Totally agree	1 (14.3%)	6 (85.7%)	

#### Table IV: The association of treatment adherence with sociodemographic and clinical characteristics of participants

<sup>a</sup>: Pearson Chi-square; <sup>b</sup>: Fisher's exact test

Table V: Sources of information regarding topical steroids and level of trus
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		%					
. Where do you get information on topical corticosteroids?							
	Never	Sometimes	Often	Always			
Dermatologists	0.3	23.3	23.0	53.3			
Other doctors	37.0	34.7	18.3	10.0			
Friends and family	50.0	34.0	8.3	7.7			
Internet and the media	37	36.3	14.3	12.3			
2. How much do you trust the foll	owing sources for informatio	n on topical corticosteroid	s?				
	Always distrust	Sometimes distrust	Sometimes trust	Always trust			
Dermatologists	0.0	0.7	16.3	83.0			
Other doctors	10.7	7.0	37.0	45.3			
Friends and family	27.7	25.7	35.7	11.0			
Internet and the media	24.0	21.7	41.0	13.3			
		•		•			

Sadly, the greater the fear of topical corticosteroids, the less likely patients are to comply with their prescribed therapy, leading to treatment failure.<sup>13</sup> This issue has been emphasised by many parties and supported by previous studies, including our own.<sup>9-12,15</sup> In fact, we found that the non-adherence cohort scored higher on the TOPICOP scale, reinforcing the critical role of addressing steroid phobia in improving patient outcomes.

According to Noorlaily et al., there is a strong link between education level and steroid phobia, with those who have attained higher education levels being more prone to this fear (p=0.01).<sup>14</sup> Similarly, in the same study, individuals with advanced education also had significantly higher scores on the TOPICOP scale (p<0.05), indicating a greater knowledge of steroids and their potential effects. This suggests that individuals with higher education levels are more likely to seek information from various sources, such as doctors, the internet and the media, and as a result, have a more in-depth understanding of steroid usage and side effects. Although this correlation between education and steroid phobia is not

commonly reported in other literature, it sheds light on the various factors that may contribute to this phenomenon.<sup>16</sup>

A recent systemic review of 37 studies revealed that caretakers of patients with severe atopic dermatitis were more likely to exhibit steroid phobia.<sup>10</sup> Our study also found a significant correlation between high disease severity and a greater knowledge and belief domain score (p=0.04), while participants who had a higher tolerance for their skin symptoms demonstrated less fear of topical corticosteroids. (p=0.02). This suggests that the presumed cause-and-effect relationship between disease severity and tolerability with steroid phobia may be reversed. In other words, steroid phobia may be responsible for the improper use of topical corticosteroids, leading to uncontrolled disease and low tolerance levels. However, it should be noted that some studies have found no connection between steroid phobia and the severity of illness or tolerance.<sup>12-13</sup>

This study offers a fascinating insight into the potential link between a fear of using topical corticosteroids and a preference for traditional medicine and non-steroidal alternatives. We found that participants with higher TOPICOP scores were more inclined to try traditional medicine (p=0.00) and non-steroidal alternatives (p=0.00) and demonstrated low adherence to steroid therapy (p<0.05). While traditional and alternative therapies remain unproven in efficacy, they are highly acceptable in many Asian cities and gaining popularity in the Western world.<sup>3,7,13,16,20</sup> In fact, parents in an Australian focus-group study expressed a preference for "natural" therapies they believed to be safer than medical treatment with topical steroids.<sup>18</sup> Similarly, approximately 50% of participants in a study by Choi et al. would opt for a non-steroidal agent, even if it were more expensive.<sup>16</sup> Ironically, some of these alternative treatments may contain potent corticosteroids, which can be inadvertently used by steroid-phobic patients.<sup>20</sup> To address this issue, steroid-sparing agents such as calcineurin inhibitors and phosphodiesterase inhibitors may provide a viable alternative for patients and caregivers who are wary of using topical steroids.

It comes as no surprise that individuals who do not experience the desired effects of topical corticosteroids or suffer from adverse reactions are more prone to steroid phobia (p<0.05). Such fear may result in unfavourable clinical outcomes, such as early discontinuation of therapy and limited use of topical corticosteroids. Consequently, this may lead to inadequate anti-inflammatory action, resulting in a chronic disease course and frequent relapses.8,10 Therefore, it is essential for treating physicians to closely monitor treatment response and disease progression. Encouraging patients and their caretakers to share their experiences can facilitate the establishment of a quality patient-physician relationship. This connection offers an opportunity for early intervention, promotes patients' adherence to therapy, and ultimately leads to better disease control.

The findings of this survey highlighted the critical role of dermatologists as primary sources of information on corticosteroids, as they are the most trusted by patients and caregivers.<sup>3,6,16</sup> However, conflicting and incorrect messages may still permeate the public sphere, making it crucial for dermatologists to educate their patients on the proper use of topical steroids, including the concept of a fingertip unit.<sup>3,10</sup> Such education may help alleviate fears of overapplication and improve adherence to therapy. In fact, a study demonstrated that a short educational session led by a dermatologist resulted in a significant improvement in the phobia index score.<sup>19</sup> As such, there is a need to further enhance the role of dermatologists as content providers, with potential avenues for improvement including educational videos targeted towards specific fear and behaviour components.<sup>29</sup> Future studies should focus on optimising such approaches to maximise their impact on reducing steroid phobia.

Despite the crucial role of healthcare providers in educating patients about corticosteroid use, recent studies have revealed concerning inaccuracies in the information provided by general practitioners and pharmacists.<sup>6,8,10,17</sup> Such misinformation can lead to confusion and undermine patient trust in the treatment. It is imperative for healthcare

providers to stay up-to-date with accurate knowledge and information, to ensure patients receive correct messages and promote treatment adherence.

While our study provides valuable insights, it is important to acknowledge its limitations. One such limitation is that it was a single-centre, hospital-based study, which may restrict the generalisability of our findings to the broader population. Moreover, our use of a self-administered questionnaire is subject to certain inherent limitations, such as missing data and potential misinterpretation of questions by participants. Additionally, we were unable to objectively assess the severity of the participants' skin conditions and their tolerance levels. Future studies could investigate the relationship between corticosteroid formulations, potency and the degree of steroid phobia. These studies would be invaluable in identifying effective interventions to overcome steroid phobia and enhance treatment outcomes.

### CONCLUSION

The pervasive phenomenon of topical corticosteroid phobia has taken hold in diverse dermatological ailments. Alarming apprehensions were significantly found to be associated with patients/caregivers afflicted with eczema, those with a high level of education, those burdened with severe symptoms, those with low tolerance towards symptoms, those who experienced adverse effects with topical corticosteroids previously, and those who exhibit a tendency towards traditional/alternative therapy usage. Understanding the widespread prevalence of topical corticosteroid phobia provides a comprehensive framework to conduct wellcontrolled studies that would assess interventions aimed at mitigating the fears and improving treatment outcomes. In this regard, dermatologists are urged to take a proactive stance in overcoming steroid phobia and actively providing their patients with public awareness and education regarding the efficacy and safety of topical corticosteroids.

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