

Original Research Article

The effects of topical steroid fears and concerns on patients with eczema: first TOPICOP® scale-based study in Saudi Arabia

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ABSTRACT

Background: Topical corticosteroids (TCS) are the main treatment for eczema, which are often required for months (or years) to control the disease. Despite the well-known side effects of TCS, their efficacy and safety are well established when used appropriately. This study was conducted to assess the fears, concerns, and various practices of patients with eczema toward TCS in the Qassim region of Saudi Arabia.

Methods: A cross-sectional survey-based study was conducted that targeted patients with eczema among all age groups and genders attending the dermatology outpatient clinics. There were no exclusions based on the type, severity, or duration of the disease.

Results: A total of 105 patients with eczema were recruited for this study. It was revealed that 46.8% of participants stopped their treatment as soon as possible, which indicates immediate discontinuation of steroids after their eczema flares had subsided and improved. An interesting finding was that 38.3% of participants did not start their TCS treatment until the disease deteriorated rather than when flare-ups occurred.

Conclusions: Exaggerated fears about TCS exist among patients with eczema and their care givers. This can result in non-adherence or wasting of many prescribed TCS preparations TCS. It is very important to understand and emphasize on the nature and extent of the prevalence of TCS fears to ensure that prompt, correct advice can be offered. Since dermatologists remain the most trusted source of information, there should be an emphasis on individual patient counseling and increased engagement in social media with pre-planned content.

Keywords: Eczema, Atopic eczema, Topical corticosteroids, Fears, Steroid phobia, Concerns, TOPICOP® scale

INTRODUCTION

Eczema is defined by the UK working party's diagnostic criteria as a chronic, relapsing, inflammatory, and cutaneous disorder that affects 10-20% of children. It commonly starts in childhood and can continue into adulthood. While the disease can affect all age groups, it is most commonly diagnosed before the age of 5 years.¹⁻³ Due to its high prevalence, burden on quality of life, and

high cost, it is considered a public health concern that prompts optimal and effective support and education services.^{4,5} TCS are the mainstay treatment of eczema and are often indicted for long durations (months or even years) to control the disease. Despite the well-known side effects of TCS, their safety profile and efficacy are well established.^{6,7} Some patients with atopic eczema do not respond to the treatment, which is not well-understood.⁸ However, poor patient compliance to the given regimen

may be the reason for treatment failure, with research indicating that compliance with the treatment of atopic eczema is as low as 30% (along with other chronic diseases).^{9,10}

Since the introduction of hydrocortisone in 1951, fast evolution in pharmacology has resulted in the production of a significant number of topical corticosteroids with varying potencies.¹¹ Over the ensuing years, most patients with chronic diseases (such as atopic eczema) have received many TCS preparations. This has resulted in a high possibility of confusion about the different available preparations and the exact indications. Hence, it is common for patients to have inconsequential fears and anxieties toward using TCS, which is referred to as steroid phobia. This condition has probably increased through media exposure and the widespread misunderstandings and certain beliefs that TCS have same effects as systemic steroids.¹¹

Topical corticosteroids phobia remains common among patients, with a systemic review of 16 studies in 2017 reporting it has a prevalence of between 21.0 and 83.7%.¹² Further, TCS phobia has been found to increase the prevalence of treatment non-adherence.¹² The new development of the TOPICOP© scale to assess steroid phobia and concerns in patients with atopic eczema (and their care) has made it easier to compare and quantify steroid phobia.^{13,14} Recently, this scale has also been used to assess steroid phobia associated with psoriasis.¹⁵

Steroid phobia can be partially attributed to the significant (or overstated) risks presented by the Internet, friends or family, and even medical professionals. The questionnaire-based study by Smith et al reported that 33% of participants had received false information in the form of overstated risks conveyed by friends, family, and the Internet.¹⁶ Another study by the same group found that 76% of participants reported receiving regular messages from their primary health care providers or pharmacists regarding TCS risks.^{17,18}

Outpatient dermatology clinics have encountered many patients that are hesitant to use TCS, even those with mild potency.¹¹ This inversely affects the patient's adherence to the treatment plan, which could threaten disease control. Patient adherence to the treatment can also be affected by confusion regarding variations in TCS potency and by received mal-information.¹¹ Hence, it is important to identify the prevalence of fears and concerns expressed by patients (or their care givers) about topical steroids. This issue has not yet been addressed in Saudi Arabia. Patients with eczema need to be aware of the various potencies and forms of TCS. This would allow them to make appropriate decisions with their physicians regarding their treatment, including how much they should apply per single application. Therefore, this study was conducted to assess the fears, concerns, and various practices of patients with eczema toward TCS in the Qassim region of Saudi Arabia.

METHODS

Setting

This cross-sectional survey-based study targeted patients of eczema among all age groups and genders who attended the dermatology outpatient clinics at King Saud hospital between October 2019 and January 2020. Ethical approval was obtained from the medical research ethics committee at the college of medicine at Qassim university.

Data collection and recruitment

The questionnaire was generated by the investigators, including questions about participant demographics and TCS fears. All consecutive patients with an established diagnosis of eczema (including atopic eczema) who attended dermatology outpatient clinics during the study period were invited to participate. The study objectives were explained to the participants and their completion of the questionnaire was considered consent. For participants under the age of 16, their parents or guardians were asked to complete the questionnaire.

There were no exclusions based on the type, severity, or duration of the disease. The steroid-phobia questionnaire involved three main domains: knowledge and beliefs (including six elements concerned with possible side effects), fears (consisting of three elements), and behavior (also consisting of three elements). Responses were scored on a four-point Likert scale (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). The maximum score was 36 points, and the higher the score, the higher the degree of steroid phobia. A further five questions were added that assessed fear of steroid addiction, fear of side effects, usage of traditional herbal medications, and the willingness to use an expensive non-steroidal agent.

Statistical analysis

The descriptive statistics were presented using numbers, percentages, and mean and standard deviations (whenever appropriate). The comparison between degree of steroid phobia and the socio-demographic characteristics of participants was conducted using the Mann-Whitney U test. A correlational procedure was conducted using a Spearman correlation, where a p value of <0.05 was considered statistically significant and a p<0.01 was considered highly statistically significant. Normality of data were conducted using the Shapiro Wilk-test, with a p<0.05 being considered skewed data. Missing values were handled carefully by excluding them from the analyses, which was applied to maintain the consistency and accuracy of the study results. All data analysis were performed using IBM SPSS statistics for windows, version 21 (IBM Corp., Armonk, N.Y., USA) on a password-secured laptop.

RESULTS

A total of 105 patients with Eczema were recruited in this study, and their sociodemographic characteristics are shown in (Table 1). There were slightly more participants in the 21-30 year age group (37.4%), followed by the <20 and 31-40 year age groups (both 20.2%). The number of female respondents was significantly higher than the number of males (72.4 and 27.6%, respectively). With regards to educational level, 42.3% had a bachelor’s degree, 32% were at high school level, and 12.4% had a diploma. In terms of the duration of steroid use, 44.6% of respondents had been self-administering for <2 weeks, 22.9% for 2-3 weeks, and 21.7% for >1 year.

Table 1: Socio demographics characteristics of participants.

Study Data	N (%)
Age group (n=99) (year)	
<20	20 (20.2)
21-30	37 (37.4)
31-40	20 (20.2)
41-50	16 (16.2)
>50	06 (06.1)
Gender (n=105)	
Male	29 (27.6)
Female	76 (72.4)
Educational level (n=97)	
Primary or intermediate level	10 (10.3)
High school	31 (32.0)
Diploma	12 (12.4)
Bachelor’s degree	41 (42.3)
Duration of steroid used (n=83)	
<2 weeks	37 (44.6)
2 weeks to 3 months	19 (22.9)
>3 months to 1 year	09 (10.8)
>1 year	18 (21.7)

Note: Note: Variables with missing data were due to incomplete responses and were excluded from the analysis.

When participants were asked about the sources of information about TCS, they could choose between dermatologists, other doctors, friends or family, and internet or media using a 4-point Likert scale. The options were never, sometimes, often, and always. Based on the participant choices, it was revealed that the most frequently accessed source of information was dermatologists (58.6%), where participants always asked for information about TCS. This was followed by Internet and media (always, 36.1%), while 26.2% never asked other doctors for TCS information (Figure 1).

When asked “How much do you trust the following sources for information on TCS?”, participants had to choose between dermatologists, other doctors, friends or family, and internet or media. This was achieved through a 4-point Likert scale with answer options of always distrust, sometimes distrust, sometimes trust, and always

trust. Based on the results, nearly all participants (81.3%) “always trust” dermatologists, followed by both internet and social media (18.9%) and other doctors (18.8%) (Figure 2).

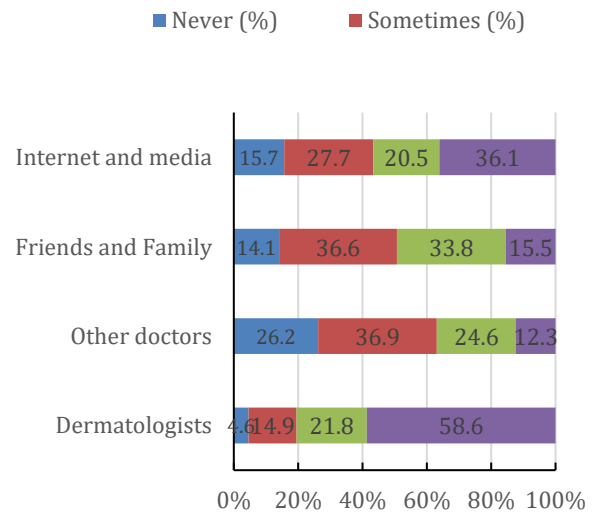


Figure 1: Sources of information on TCS/steroid cream.

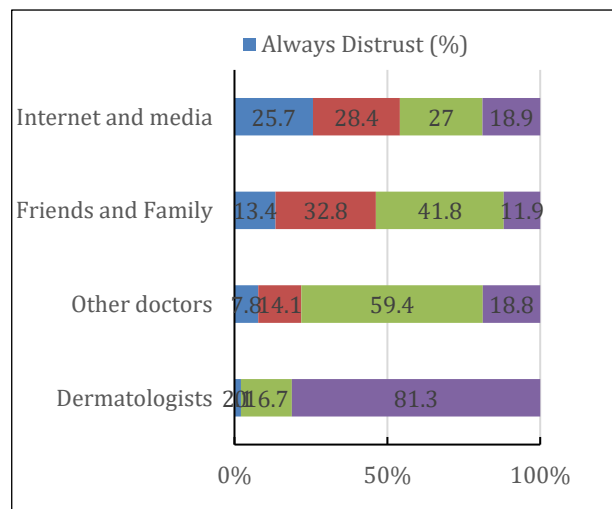


Figure 2: How much do you trust the following sources for information on TCS?

When asked “How do you feel each source of information describe the risks of TCS?”, participants had to choose between dermatologists, other doctors, friends or family, and internet or media using a 4-point Likert scale. This had answer options of strongly underplayed risk, occasionally underplayed risk, occasionally exaggerated risk, and strongly exaggerated risk. It was revealed that friends and family was perceived as the most strongly exaggerated risk (43.1%), followed by internet and media (42%), dermatologists (35.2%) and other doctors (24.6%) (Figure 3).

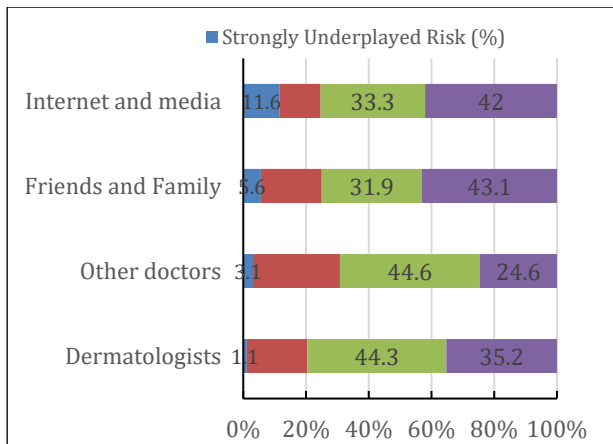


Figure 3: How do you feel each source of information describe the risks of TCS?

The detailed questions concerning the degree of steroid phobia towards topical corticosteroid phobia (TOPICOP) is presented in (Table 2). In the knowledge and belief domain (which included six questions), participants answered almost agree/often to the statement “TCS pass into the blood stream” with the highest mean score among the six questions (1.84). The majority of participants answered not really agree/sometimes to the statement “TCS can lead to infections” (61.2%), while 50.6% answered not really agree/sometimes to “TCS can lead to asthma.” On the other hand, very few participants answered totally disagree/never to the statements “TCS damage your skin” (5.4%) and “TCS will affect my future health” (3.3%). The overall mean score of the knowledge and belief domain after obtaining the sum of the six questions was 8.81 (SD 4.12) out of 18. In the fear domain (with three questions) it was found that a high proportion of the participants (69.8%) answered total agree/always to the statement “I am afraid of putting TCS cream on certain areas like the eyelids where the skin is thinner” (mean score 2.29) while few participants (11.8%) answered totally disagree/never to the statement “I don’t know any side effects but still concern of using TCS” (mean score 1.62). Moreover, 51.1% of participants answered totally agree/always to the statement “I am afraid of applying too much cream” (mean score 2.04). After summing the three questions,

the mean score of the fear domain was 5.94 (SD 2.68) out of 9. In the behavioral domain (with 3 questions), 52.1% of participants answered total agree/always to the statement “I need reassurance about TCS” (mean score: 2.05). On the other hand, few participants (04.3%) answered totally disagree/never to both “I wait as long as I can before treating myself with TCS” and “I stop treatment as soon as I can” (mean scores 1.92 and 1.97, respectively). After obtaining the total score of the three questions, the mean score of the behavior domain was 5.94 (SD 2.59). After summation of the 12 questions to calculate the global TOPICOP, the mean score generated was 20.7 (SD 7.83) out of 39.

As shown in (Table 3), a correlation calculation was conducted to evaluate the relationship between steroid-phobia and its domains. It was observed that a highly positive correlation was found between the global TOPICOPs among each domain (p<0.01).

In Table 4, many participants reported being worried about how to use TCS correctly. The results revealed that 43.3% of participants always ask doctor about “duration of a treatment” and 40.4% always speak with the doctor about the “amount of cream to apply”. Further, 39.6% of participants would speak to a doctor about the “way to apply cream” while 14.9% often discussed the health consequences of TCS with their doctor. Participants were also asked whether information had been consistent if the consultation was introduced to a several doctors. More participants indicated that the information was always same for following points: “to which areas you should apply cream” (always: 43.3%); “the amount of cream to apply” (always: 42.9%); “ways to stop treatment” (always: 34.5%); “If received clear information from doctor about TCS” (always: 48.9%); and “do you trust your doctor?” (always: 68.2%). Conversely, few participants often received constant information about “possible side-effect” (often: 15%) and a few participants never received same info about TCS from doctors and pharmacists (never: 12.2%). When asked which group provided warnings about using TCS, participants had rated groups in following order: friends and family (42.4%), doctors (38.0%), and media (31.3%), whereas pharmacists seldom warned participants (19.5%).

Table 2: Questions concerning the degree of steroid phobia.

Question	Totally disagree/never N (%)	Not really agree/Sometimes N (%)	Almost agree/often N (%)	Totally agree/always N (%)	Mean score±SD
Knowledge and belief domain*					
TCS can pass into the blood	05 (05.3)	15 (16.0)	44 (46.8)	30 (31.9)	1.84±1.01
TCS can lead to infections	12 (14.1)	52 (61.2)	16 (18.8)	05 (05.9)	0.94±0.81
TCS make you obese	09 (10.5)	40 (46.5)	19 (22.1)	18 (20.9)	1.26±1.04
TCS damage your skin	05 (05.4)	25 (27.2)	34 (37.0)	28 (30.4)	1.69±1.05
TCS will affect my future health	03 (03.3)	23 (25.0)	32 (34.8)	34 (37.0)	1.80±1.06
TCS can lead to bronchial asthma	06 (06.7)	45 (50.6)	24 (27.0)	14 (15.7)	1.29±0.95
Knowledge and belief score					8.81±4.12

Continued.

Question	Totally disagree/never N (%)	Not really agree/Sometimes N (%)	Almost agree/often N (%)	Totally agree/always N (%)	Mean score±SD
Fear domain*					
I am afraid of applying cream (TCS) on certain area like the eyelids where the skin is thinner	04 (04.2)	11 (11.5)	14 (14.6)	67 (69.8)	2.29±1.08
I don't know of any side effects but I still concern about using TCS	11 (11.8)	21 (22.6)	34 (36.6)	27 (29.0)	1.62±1.09
I am afraid of applying too much cream (TCS)	05 (05.4)	07 (07.6)	33 (35.9)	47 (51.1)	2.04±1.10
Fear score					5.94±2.68
Behavior domain*					
I wait as long as I can before treating myself with TCS	04 (04.3)	14 (14.9)	40 (42.6)	36 (38.3)	1.92±1.03
I stop treatment as soon as I can	04 (04.3)	17 (18.1)	29 (30.9)	44 (46.8)	1.97±1.08
I need reassurance about TCS	05 (05.2)	17 (17.7)	24 (25.0)	50 (52.1)	2.05±1.09
Behavior score					5.94±2.59
Global TOPICOP score					20.7±7.83
Additional questions*					
There is a discrepancy risk	11 (11.8)	38 (40.9)	24 (25.8)	20 (21.5)	1.39±1.03
I prefer traditional treatment before TCS	15 (16.1)	26 (28.0)	27 (29.0)	25 (26.9)	1.48±1.12
I prefer other medications that do not contain steroid	07 (07.4)	18 (18.9)	27 (28.4)	43 (45.3)	1.91±1.11
If I used TCS, was it beneficial?	05 (05.7)	12 (13.8)	35 (40.2)	35 (40.2)	1.78±1.13
if I used TSC, were there any side effects?	04 (04.7)	51 (60.0)	19 (22.4)	11 (12.9)	1.16±0.90

TCS-topical corticosteroids.* Note: Variables with missing data were due to incomplete responses and were excluded from the analysis.

Table 3: Spearman correlation between the degree of steroid phobia and its components.

Domain	Knowledge and Belief	Fear	Behavior	Global TOPICOP
Knowledge and belief	1			
Fear	0.407**	1		
Behavior	0.270**	0.531**	1	
Global TOPICOP	0.811**	0.755**	0.656**	1

** Correlation was statistically significant at p<0.01 level (2-tailed).

Table 4: Given information and coherence of messages.

Item	Never (%)	Sometimes (%)	Often (%)	Always (%)
Have you talked with your doctor about the following points related to TCS?				
Health consequences	27.7	29.8	14.9	27.7
The way to apply cream	14.3	27.5	18.7	39.6
The amount of cream to apply	23.6	19.1	16.9	40.4
The length time of a treatment	10.9	23.9	14.1	43.3
If you have visited several doctors, has information been the same concerning the following points?				
To which areas you should apply cream	08.9	20.0	27.8	43.3
The amount of cream to apply	11.9	20.2	25.0	42.9
How to stop treatment?	17.9	29.8	17.9	34.5
Possible side-effects	23.8	28.8	15.0	32.5
Have you received clear information from your doctor about TCS?	05.6	28.9	16.7	48.9
Do you trust your doctor?	01.1	10.2	20.5	68.2
I received the same information from doctors and pharmacists	12.2	32.2	23.3	32.2

Continued.

Item	Never (%)	Sometimes (%)	Often (%)	Always (%)
One of these groups has already warned me about using TCS				
Doctors	27.8	26.6	07.6	38.0
Pharmacists	22.1	36.4	22.1	19.5
Friends or family	18.8	24.7	14.1	42.4
The media	25.3	21.7	21.7	31.3

Table 5: Effects of Steroid phobia among the socio demographic characteristics of patients with eczema.

Factor	Knowledge and Belief, total score (18), Mean±SD	Fear Total score (9) Mean±SD	Behavior total score (9) Mean±SD	Global TOPICOP total score (36) Mean±SD
Age group (n=99) (year)				
≤30	9.02±3.98	6.00±2.44	6.21±2.51	21.2±6.96
>30	8.40±4.09	5.69±2.88	5.48±2.53	19.6±8.23
T test, p value	0.748; 0.493	0.578; 0.872	1.435; 0.105	1.086; 0.525
Gender (n=105)				
Male	8.89±4.32	5.52±2.82	6.14±2.34	20.6±8.15
Female	8.78±4.07	6.11±2.63	5.87±2.68	20.7±7.76
T test, p value	0.133; 0.824	-1.003; 0.344	0.476; 0.825	-0.115; 0.796
Educational level (n=97)				
High school or below	7.80±4.17	4.98±2.94	5.49±2.68	18.3±8.36
Diploma or bachelor	9.16±3.70	6.39±2.17	6.09±2.39	21.6±6.25
T test, p value	-1.687; 10.7	-2.734; 0.024**	-1.160; 0.257	-2.276; 0.042**
Duration of steroid used (n=83)				
≤3 months	8.82±3.83	6.27±2.46	6.11±2.45	21.2±6.96
>3 months	8.96±4.43	5.52±2.94	5.89±2.65	20.4±8.27
T test, p value	-0.150; 0.615	1.219; 0.317	0.371; 0.791	0.476; 0.973

Note: Variables with missing data were due to incomplete responses and were excluded from the analysis. The p values were calculated using the Mann Whitney U test. ** Significant at p<0.05 level.

When comparing the mean score of global TOPICOP and its domain, we found that those with a diploma or bachelor's degree were significantly more associated with having a higher fear domain score ($T=-2.734$, $p=0.024$). This was also demonstrated in the global TOPICOP, where those with higher levels of education were significantly higher in the global mean score compared to those with lower levels of education ($T=-2.276$, $p=0.042$). Other variables such as age group, gender, and duration of steroid usage were not statistically significant when compared to global TOPICOP and its domain (Table 5).

DISCUSSION

The current study addresses the issues of knowledge, belief, fear, and behavior among patients with eczema towards TCS use. Irrespective of gender, the results of the study prove that the fears about TCS side effects in our participants were exaggerated. It has been shown that TCS phobia is common and can potentially limit the efficacy of medical care due to patients adhering inadequately to the treatment. To the best of our knowledge, this is the first study from Saudi Arabia to assess and quantify TCS phobia based on the TOPICOP® scaling system in a local population. An important outcome of this study was being able to confirm the high

percentage of TCS phobia among patients with eczema, with 67% reporting being afraid of using TCS. This compares with the study by Fischer et al who found that 40% of patients thought TCS were dangerous.¹⁹ In a survey study that included 200 patients with AD, Charman et al found that 73% of the patients (or their carers) were concerned about using TCS.¹¹ In 2006, using same questionnaire, Hon et al found that 60% of the studied 233 patients had worries about TCS.⁸ Notably, TCS phobia rates differ between China, the United Kingdom, and France, emphasizing influence of cultural variety in how general population realize corticosteroids.¹

Although 67% of our participants had a fear of using TCS, 81.3% “always trust” dermatologists with regard to information about TCS. While these two results may seem contradictory, this could be explained by the study of Smith where the impact of family, friends, and the Internet on patients with long-term topical corticosteroid use was evaluated. It was concluded that high rates of messages about TCS risks from family and friends and the Internet may affect patient/carer understanding about TCS safety and this may contribute to treatment non-adherence.¹⁶ This further supports our finding that 42% of our participants reported that friends and family had warned them about using TCS. In addition, 38% reported

that doctors other than dermatologists had warned them about TCS, which can have more impact on patient compliance. Unfortunately, most of these figures are exaggerated, as demonstrated by 43.1% of participants reporting that friends and family strongly exaggerated risks, followed by internet and media (42%) and doctors (24.6%). This result highlights role of dermatologists as being most trusted source of information, which suggests they should engage more effectively in media and campaigns targeting general population.

Furthermore, our results emphasize the role of dermatologists in limiting steroid phobias, as 52.1% of participants always need reassurance regarding TCS usage. For a better treatment outcome, we recommend addressing patient needs and stressing more about compliance in every visit to overcome the exaggerated risks conveyed by friends, media, and other doctors.

An interesting study by Huynh et al found that the percentage of patients who stopped applying TCS was higher among those with higher educational qualifications, because they are more aware of TCS side effects.¹⁹ Our study indicated that those educated to diploma or bachelor's degree levels were significantly more associated with having a higher fear domain score ($T=-2.734$, $p=0.024$) compared to those with lower levels of education. We considered this finding predictable, because this group actively engages more similarly educated colleagues, where having a conversation about TCS side effects may have more effect than having the same conversation with people having lower levels of education. In addition, this group is most likely having more access to internet and TV channels in comparison to other groups, which indicates a more personalized educational approach is required.

The most common concerns about the side effects of TCS were the cutaneous side effects and growth retardation for children. However, we found that the burden of concerns was variable. In a recent study about TCS use in eczema and skin thinning, there was no evidence of skin thinning after 20 weeks of daily treatment by applying potent topical TCS. This suggests the fear about skin atrophy expressed by carers and patients may be over exaggerated. Further, there was no clear evidence of growth retardation.⁸ A study conducted in 1992 by Hon et al reported growth retardation in an infant; however, this was due to the use of a potent topical steroid with a dose of 30 g/week for 3 years.⁸ The percentage of patients who experience systemic side effects is low and TCS are generally considered safe.¹⁹ For improved treatment adherence and disease control, physicians should constantly address this issue with patients and carers to alleviate their concerns. In fact, only 53% of participants in moderate-to-severe eczema group and 29% of those in the mild eczema group had discussed their concerns with doctors.¹⁹ Doctors, friends or relatives, television, and newspapers were main sources of advice about the side effects of TCS.⁸ In study, asked about sources of

information used by participants-dermatologists, other doctors, friends or family, or internet or media. We revealed that most common sources of information among participants were dermatologists (58.6%) followed by internet and media (36.1%). Moreover, 26.2% of participants stated they would never ask other doctors regarding TCS information.

Although TCS have been the main treatment for eczema for more than five decades,²⁰ we found in our investigation that 45.3% of participants preferred topical ointments that are steroid free. This finding is in the line with the study conducted by Li, where all the participants used ointments not containing steroids for eczema treatment due to fears over the significant negative impact of topical steroids on growth and development.²¹

Another interesting finding in the study was that 38.3% of participants did not start their TCS treatment until their condition deteriorated and flares started appearing. This result is in agreement with the study conducted by Li.²¹

Early treatment discontinuation and short-term application of TCS can lead to insufficient anti-inflammatory action, which can cause the disease to rebound.²² Our study had reached the same conclusion, where a high percentage of participants (46.8%) completely agreeing with stopping TCS as soon as possible. Moreover, approximately 71% of our participants who were on TCS expressed profound concerns related to their future health. This was mainly due to the fears of side effects resulting from long-term use of TCS and of impairments to growth and development.⁸ In a clinical setting, physicians should continuously advice patients and their carers to complete the pre-determined course of TCS treatment to achieve and maintain the targeted therapeutic effect. Moreover, this would avoid any deterioration of the condition or infection-related complications.¹²

There is a significant variation in the literature about the quantification and reporting of TCS phobia. However, with the recent development of the TOPICOP© scaling system, standardization and comparisons across different groups are now possible. The TOPICOP© scale was developed to assess steroid phobia in patients with atopic dermatitis.²³ However, we included patients with all types of eczema in our study to assess steroid phobia in a larger segment of the population, as presented by our samples.

Limitations

This study conducted in a single hospital in Saudi Arabia which may not reflect entire population in Saudi Arabia.

CONCLUSION

Patients with eczema (and their carers) have exaggerated fears about TCS. This results in non-adherence to treatment and the wasting of many prescribed TCS

preparations. Thus, it is very important to understand and emphasize the nature and extent of the prevalence of TCS fears. Further, it is important that targeted education is offered at the appropriate time, because fallacy and false information can threaten disease control (especially in pediatric age group). Dermatologists remain the most common and trusted sources of information on TCS. Therefore, they should exert more effort to improve the knowledge and practices of patients towards topical steroids. It is suggested that this is accomplished through individual patient counselling and increased engagement in social media with pre-planned content.

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REFERENCES

- Williams HC, Burney PG, Pembroke AC, Hay J. The U.K. Working Party's Diagnostic Criteria for Atopic Dermatitis. III. Independent hospital validation. *Br J Dermatol.* 1994;131:406-16.
- Williams H, Robertson C, Stewart A, Ait-Khaled N, Anabwani G, Anderson, R et al. Worldwide variations in the prevalence of symptoms of atopic eczema in the International Study of Asthma and Allergies in Childhood. *J Allergy Clin Immunol.* 1999;103:125-38.
- Foley P, Zuo Y, Plunkett A, Marks R. The frequency of common skin conditions in preschool-age children in Australia: atopic dermatitis. *Arch Dermatol.* 2001;137:293-300.
- Barbeau M, Bpharm HL. Burden of atopic dermatitis in Canada. *Int J Dermatol.* 2006;45:31-6.
- Lawson V, Lewis-Jones MS, Finlay AY, Reid P, Owens RG et al. The family impact of childhood atopic dermatitis: The Dermatitis Family Impact Questionnaire. *Br J Dermatol.* 1998;138:107-13.
- Hoare C, Li Wan Po A, Williams H. Systematic review of treatments for atopic eczema. *Health Technol Assess.* 2000;4:1-191.
- Furue M, Terao H, Rikihisa W, Urabe K, Kinukawa N, Nose Y et al. Clinical dose and adverse effects of topical steroids in daily management of atopic dermatitis. *Br J Dermatol.* 2003;148:128-33.
- Hon KL, Tsang YC, Pong NH, Luk DC, Lee VW, Woo WM et al. Correlations among steroid fear, acceptability, usage frequency, quality of life and disease severity in childhood eczema. *J Dermatol Treat.* 2015;26(5):418-25.
- Krejci-Manwaring J, Tusa MG, Carroll C, Camacho F, Kaur M, Carr D et al. Stealth monitoring of adherence to topical medication: adherence is very poor in children with atopic dermatitis. *J Am Acad Dermatol.* 2007;56:211-16.
- World Health Organization. Adherence to Long-term Therapies: Evidence for Action. Geneva: WHO. 2003.
- Charman CR, Morris AD, Williams HC. Topical corticosteroid phobia in patients with atopic eczema. *Bri j dermatol.* 2000;142(5):931-6.
- Li AW, Yin ES, Antaya RJ. Topical corticosteroid phobia in atopic dermatitis: a systematic review. *JAMA Dermatol.* 2017;153:1036-42.
- Moret L, Anthoine E, Aubert-Wastiaux H. TOPICOP©: a new scale evaluating topical corticosteroid phobia among atopic dermatitis outpatients and their parents. *PLoS One.* 2013;8:e76493.
- Stalder JF, Aubert H, Anthoine E, Futamura M, Marcoux D, Morren MA et al. Topical corticosteroid phobia in atopic dermatitis: international feasibility study of the TOPICOP score. *Allergy.* 2017;72:1713-9.
- Moawad S, Mahé E, Aubert-Wastiaux H, Phan A, Maruani A, Chiaverini C et al. Topical corticosteroid concerns among parents of children with psoriasis versus atopic dermatitis: a French multicenter cross-sectional study. *Am J Clin Dermatol.* 2018;19:261-5.
- Smith SD, Farrugia LL, Harris V. Evaluation of the influence of family and friends, and the Internet on patient perceptions of long-term topical corticosteroid use. *J Dermatol Treat.* 2017;28:642-6.
- Smith SD, Lee A, Blaszczyński A, Fischer G. Pharmacists' knowledge about use of topical corticosteroids in atopic dermatitis: pre- and post-continuing professional development education. *Australas J Dermatol.* 2016;57:199-204.
- Farrugia LL, Lee A, Fischer G, et al. Evaluation of the influence of pharmacists and GPs on patient perceptions of long-term topical corticosteroid use. *J Dermatol Treat.* 2017;28:112-8.
- Song SY, Jung SY, Kim EY. Steroid phobia among general users of topical steroids: a cross-sectional nationwide survey. *J Dermatol Treat.* 2018;30(3):245-50.
- Tofte SJ, Hanifin JM. Current management and therapy of atopic dermatitis. *J Am Acad Dermatol.* 2001;44(1):13-6.
- Li Y. Awareness of and phobias about topical corticosteroids in parents of infants with eczema in Hangzhou, China. *Wiley Online Library.* 2018;35(4):463-7.
- Beck LA, Boguniewicz M, Hata T, Schneider LC, Hanifin J, Gallo R et al. Phenotype of atopic dermatitis subjects with history of eczema herpeticum. *J Allergy Clin Immunol.* 2009;124:260-9.
- Choi E, Chandran NS, Tan C. Corticosteroid phobia: a questionnaire study using TOPICOP score. *Singapore Med J.* 2020;61(3):149-53.

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