



# Topical Steroid Phobia Among Mothers of Children with Atopic Dermatitis

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## ABSTRACT

**Objective:** Adherence to topical corticosteroids (TCS) is essential for the effective treatment of atopic dermatitis but some families have fears and concerns about TCS phobia. In this study, it was aimed to investigate the knowledge, opinions and fear about topical steroids among mothers of patients who used topical steroid therapy for their atopic dermatitis (AD) and its effect on drug compliance and disease severity.

**Materials and Methods:** Mothers were asked to fill in a questionnaire that consisted of 12 questions that evaluate the fears, beliefs, knowledge and behaviors about TCS usage.

**Results:** The questionnaire was answered by mothers of 141 children with AD. The mothers' most common (44.7%) beliefs about TCS were determined as "Cortisone creams damage your skin" and "Cortisone creams will effect my future health". The most common (71.6%) fear mothers had about TCS creams was determined as "Using cortisone creams too much". It was found that 83.3% of mothers who were found to be afraid of using TCS often were well educated ( $p=0.002$ ).

**Conclusion:** Most of our patients and mothers have fears about TCS and they don't have enough knowledge about their treatment. Therefore, they need assurance and information about TCSs that may include written and/or video-assisted information about TCS treatment given by healthcare professionals in order to decrease TCS phobia and increase compliance with the treatment.

**Keywords:** Atopic dermatitis, children, steroid phobia, topical steroid

## INTRODUCTION

Atopic dermatitis (AD) is the most common skin disease of childhood, characterized by intense itching and recurrent eczematous lesions. It is seen in 20% of children and its frequency is gradually increasing (1-3).

The mainstay of treatment consists of topical corticosteroids and moisturizers (4). However, some families approach corticosteroids with anxiety and fear (TCS phobia). This rate has been presented as 40-73% in previous studies (5,6). The rate differs between countries; it is reported as 67.5% in Korea and 38.2% in Denmark (7,8). In fact, even though topical steroids can cause local

and systemic side effects depending on their potency and duration of use, these side effects are minimal when used under the supervision of a physician.

The level of knowledge, beliefs and fears of the relatives of the patients on this issue can cause problems in the application of the required treatment and in compliance with the medication, leading to prolongation of treatment, lack of response to treatment, and a decrease in the child's quality of life (9,10). There have been attempts to develop various questionnaires to evaluate compliance with topical steroid therapy (11,12). With the help of these questionnaires, the knowledge level of parents on this subject and their perspectives can be assessed, so

that it becomes possible to provide the required support and information to eliminate the family's anxiety and prejudices.

In the literature, there are a limited number of studies evaluating topical steroid phobia in parents of pediatric patients with AD. However, to our knowledge, there are no studies conducted in our country (7,8,13,14).

In this study, it was aimed to investigate the knowledge, opinions and fears about topical steroids in mothers of the patients who used topical steroid therapy for AD and its effect on drug compliance and disease severity.

## MATERIALS and METHODS

### Patient Population

Mothers of AD children aged between 0 and 18 years were included in this study. The study was performed cross-sectional with patients who presented to the Health Sciences University of Okmeydanı Education and Research Hospital's Pediatric Allergy and Dermatology outpatient clinics for the first time between January 2019 and June 2019. AD was diagnosed according to the Hanifin-Rajka criteria (15).

### Topical Corticosteroid Phobia Assessment Questionnaire and Data Collection

Among the mothers of children using TCS with a diagnosis of AD, those who accepted to participate in the questionnaire were included in the study. Mothers were asked to complete the questionnaire that consisted of 12 questions evaluating their fears, beliefs, knowledge and behaviors about TCS usage, and that was an adaptation from the Topical Corticosteroid Phobia Assessment Questionnaire (TOPICOP) which Moret et al. developed in 2013 along with forms questioning socio-demographic data (12). We could not use the TOPICOP questionnaire since a validated Turkish version was not available, and thus the TOPICOP score could not be calculated.

Evaluation of the answers was made according to a 5-point *Likert scale*. Unlike the TOPICOP questionnaire, 'I have no idea' option was added to our questionnaire and the answers were expressed as "strongly disagree", "mostly disagree", "I have no idea", "mostly agree" and "strongly agree" for questions of knowledge and beliefs, while for fear questions the choices were given as "never", "rarely", "no idea", "sometimes", "always". The questionnaire was

tested for clarity and comprehensibility in the mothers of 10 children with AD using TCS before the start of the study. Clinical and demographic characteristics of the children and mothers who accepted to complete the questionnaires were recorded from their clinical files.

### Excluding Criteria

The mothers of children who did not speak Turkish and who used TCS for a different reason than AD were excluded from the study.

### Ethics

Local Ethics Committee approval was taken from the Health Sciences University of Okmeydanı Education and Research Hospital (2019-1082). Written informed consent was obtained from all the participants.

### Statistical Analysis

The research data were analyzed by the SPSS version 22.0 statistics program. While expressing the data, continuous variables were presented with arithmetic mean  $\pm$  standard deviation (minimum-maximum) and discrete variables with frequency and percentage distributions. The Kolmogorov-Smirnov ( $n > 50$ ) test was applied to examine whether the measurements in the study were non-normally distributed. Accordingly, descriptive statistics for continuous variables were expressed as the median, first quartiles and third quartiles. Categorical variables were described as number (n) and percentage (%). The 'chi-square test' was used to compare categorical variables. Statistical significance level was accepted as  $p < 0.05$ .

## RESULTS

The questionnaire was answered by mothers of 141 children with AD. The median age of the mothers and their children were 33 (Q1:29.5-Q3:33) years and 5 (Q1:3-Q3:7.5) years, respectively. Seventy-two of the children (51.1%) were girls. Among the participants, 49% were primary school graduates and the others were high school or university graduates. AD was accompanied by another allergic disease in 34% of the children.

It was determined that; the most common (44.7%) beliefs of the mothers about TCS were "Cortisone creams damage your skin" and "Cortisone creams will affect my child's future health". Among participating mothers, 62.4% had no idea about the survey questions. When the fear

of mothers towards TCS creams was evaluated, 71.6% of mother’s answer was “Using cortisone creams too much”. While the frequency of the response “I’m afraid of putting cream on certain zones like eyelids, where the skin is thinner” was 64.5%, the response percentage of “I don’t know of any side effects but I’m still afraid of TCs” was 57.4%. Moreover, when their attitudes towards TCS creams were evaluated, the frequency of the response “I stop the treatment as soon as I can” was determined as 55.3% (Table I).

Fifty-eight point three per cent of the mothers who graduated from university or high school answered the question “I am afraid even though I do not know about the side effects” and this was significantly higher than the mothers who graduated from primary education (p=0.02). The mothers’ fears and attitudes towards cortisone creams were not different according to the economic status of the family, the age of the mother, and the age of their children (p>0.05)

The distribution of the mothers’ fear and attitudes towards cortisone creams according to sociodemographic characteristics of their children is given in Table II.

Beliefs about the use of cortisone cream were significantly more common in mothers with higher education levels (p<0.05). The mothers’ beliefs towards cortisone creams were not different according to the economic status of the family, the age of the mother and the age of their children, the child’s additional allergic disease, and the SCORAD score (p>0.05) (Table III).

**DISCUSSION**

In our study, the mothers of children with AD did not know enough about the side effects of TCS, were afraid, and had false beliefs. Atopic dermatitis that could last for a lifetime is the most common dermatologic disease of childhood and it has no cure at the moment. One of the cornerstones of treatment is TCS and it is a very effective treatment in most of the patients during the active inflammation period (16). However, the phobia against TCS is increasing. In 2017, after the review of 16 studies, the rate of TCS phobia was reported to be 21-83.7% (17). In a study that evaluates the patients with AD and other dermatologic diseases, the TCS phobia rate was reported to be 35.8% and the TOPICOP score was 44% (13). In a multi-center study, total TOPICOP score was referred

**Table I. Topical corticosteroid phobia assessment questionnaire results**

<b>Beliefs</b>	<b>I strongly disagree n (%)</b>	<b>I mostly disagree n (%)</b>	<b>No idea n (%)</b>	<b>I mostly agree n (%)</b>	<b>I strongly agree n (%)</b>
Cortisone creams pass into the bloodstream	4 (2.8)	8(5.7)	88 (62.4)	21 (14.9)	20 (14.2)
Cortisone creams can lead to infections	15 (10.6)	17 (12.1)	85 (60.3)	14 (9.9)	10 (7.1)
Cortisone creams make you fat	15 (10.6)	18 (12.8)	67 (47.5)	21 (14.9)	20 (14.2)
Cortisone creams damage your skin	6(4.3)	13(9.2)	59 (41.8)	34 (24.1)	29 (20.6)
Cortisone creams will affect my child’s future health	4(2.8)	12 (8.5)	62 (44.0)	30 (21.3)	33 (23.4)
Cortisone creams can lead to asthma	5(3.5)	11(7.8)	104 (73.8)	11 (7.8)	10 (7.1)
<b>Fears and Attitudes</b>	<b>Never</b>	<b>Rarely</b>	<b>No idea</b>	<b>Sometimes</b>	<b>Always</b>
I’m afraid of putting cream on certain zones like eyelids where the skin is thinner	6 (4.3)	5 (3.5)	39 (27.7)	26 (18.4)	65 (46.1)
I don’t know of any side effects but I’m still afraid of topical corticosteroids	12 (8.5)	16 (11.3)	32 (22.7)	35 (24.8)	46 (32.6)
I’m afraid of applying too much cream	1 (0.7)	9 (6.4)	30 (21.3)	27 (19.1)	74 (52.5)
I wait as long as I can before I start to treatment myself (attitude)	15 (10.6)	16 (11.3)	33 (23.4)	41 (29.1)	36 (25.5)
I stop the treatment as soon as I can (attitude)*	10 (7.1)	16 (11.3)	37 (26.2)	26 (18.4)	52 (36.9)
I need reassurance about topical corticosteroids	2 (1.4)	4 (2.8)	60 (42.6)	12 (8.5)	63 (44.7)

\*This question was scored in reverse.

**Table II. Distribution of mothers' fear and attitudes towards topical corticosteroid according to sociodemographic and clinical characteristics**

		Fear 1 n (%)*	Fear 2 n (%)*	Fear 3 n (%)*	Attitude 4 (%)*	Attitude 5 n (%)*	Fear 6 n (%)*
Age group (years)	≤ 34	52 (57.1)	45 (55.6)	57 (56.4)	41 (53.2)	44 (56.4)	43 (57.3)
	≥ 35	39 (42.9)	36 (44.4)	44 (43.6)	36 (46.8)	34 (43.6)	32 (42.7)
p		0.89	0.74	0.90	0.35	0.93	0.87
Education	Primary/Middle School	38 (41.7)	35 (43.2)	41 (40.6)	29 (37.7)	28 (35.9)	35 (46.7)
	High School/ University	53 (58.3)	46 (56.8)	60 (59.4)	48 (62.3)	50 (64.1)	40 (53.3)
p		<b>0.02</b>	0.11	<b>0.002</b>	<b>0.003</b>	<b>0.001</b>	0.56
Employment Status	Employed	13 (14.2)	10 (12.3)	15 (14.8)	11 (14.3)	11 (14.1)	11 (14.7)
	Unemployed	78 (85.8)	71 (81.7)	86 (85.2)	66 (85.7)	67 (85.9)	64 (85.3)
p		0.96	0.46	0.71	0.97	0.97	0.86
Number of Children	1	17 (63.0)	16 (19.7)	22 (21.8)	15 (19.5)	20 (25.6)	15 (20.0)
	> 1	74 (64.9)	65 (80.3)	79 (78.2)	62 (80.5)	58 (74.4)	60 (80.0)
p		0.84	0.83	0.20	0.91	<b>0.02</b>	0.78
Economic Status of Family	Low	16 (17.5)	14 (17.3)	17 (16.8)	16 (20.8)	13 (16.7)	13 (17.3)
	Middle	50 (55.0)	44 (54.3)	55 (54.5)	39 (50.6)	40 (51.2)	41 (57.7)
	Good	25 (27.5)	23 (28.4)	29 (28.7)	22 (28.6)	25 (32.1)	21 (28.0)
p		0.64	0.61	0.28	0.68	0.18	0.69
Age of child (month)	< 24	18 (19.8)	14 (17.3)	19 (18.8)	16 (20.8)	17 (21.8)	13 (17.3)
	24-72	48 (52.4)	37 (45.6)	49 (48.5)	37 (48.0)	38 (48.7)	37 (49.4)
	> 72	25 (27.8)	30 (37.1)	33 (32.7)	24 (31.2)	23 (29.5)	25 (33.3)
p		0.06	0.054	0.43	0.27	0.11	0.93
Gender of child	Girl	46 (50.5)	39 (48.1)	47 (46.5)	38 (49.4)	37 (47.4)	40 (53.3)
	Boy	45 (49.5)	42 (51.9)	54 (53.5)	39 (50.6)	41 (52.6)	35 (46.7)
p		0.60	0.82	0.36	0.91	0.69	0.26
Child's atopic dermatitis duration (months)	< 24	44 (48.4)	35 (43.2)	49 (48.5)	37 (48.0)	35 (44.9)	35 (46.7)
	≥ 24	47 (51.6)	46 (56.8)	52 (51.5)	40 (52.0)	43 (55.1)	40 (53.3)
p		0.34	0.54	0.23	0.48	0.89	0.74
Child's additional allergic disease	Existent	33 (36.2)	30 (37.0)	33 (32.7)	28 (36.4)	28 (35.9)	24 (32.0)
	Absent	58 (63.8)	51 (63.0)	68 (67.3)	49 (63.6)	50 (64.1)	51 (68.0)
p		0.45	0.38	0.58	0.52	0.60	0.58
SCORAD score	Mild	47 (51.6)	41 (50.6)	52 (51.5)	39 (50.7)	38 (48.7)	35 (46.7)
	Moderate	30 (33.0)	28 (34.6)	36 (35.6)	24 (31.1)	29 (37.2)	30 (40.0)
	Severe	14 (15.4)	12 (14.8)	13 (12.9)	14 (18.2)	11 (14.1)	10 (13.3)
p		0.24	0.50	0.87	<b>0.04</b>	0.54	0.33
Atopy history in family	Existent	35 (38.5)	32 (39.5)	42 (41.6)	26 (33.8)	27 (34.6)	27 (36.0)
	Absent	56 (61.5)	49 (60.5)	59 (58.4)	51 (66.2)	51 (65.4)	48 (64.0)
p		0.95	0.73	0.20	0.22	0.31	0.55

\*column percentage

**Fear 1-** I don't know of any side effects but I'm still afraid of TCS. **Fear 2-** I'm afraid of putting cream on certain zones like the eyelids where the skin is thinner. **Fear 3-** I'm afraid of applying too much cream. **Attitude 4-** I wait as long as I can before treating myself. **Attitude 5-** I stop the treatment as soon as I can. **Fear 6-** I need reassurance about topical corticosteroids.

**Table III: Distribution of mothers’ beliefs about topical corticosteroids according to socio-demographic and clinical characteristics\***

Variables		Cortisone creams pass into the blood stream	Cortisone creams can lead to infections	Cortisone creams make you fat	Cortisone creams damage your skin	Cortisone creams will affect my child’s future health	Cortisone creams can lead to asthma
Age group (years)	≤ 34	27 (65.9)	13 (54.2)	22 (53.7)	35 (55.6)	32 (50.8)	12 (57,7)
	≥ 35	14 (34.1)	11 (45.8)	19 (46.3)	28 (44.4)	31 (49.2)	9 (42.9)
p		0.98	0.78	0.63	0.79	0.20	0.96
Education	Primary/Middle School	16 (39.0)	9 (37.5)	13 (31.7)	27 (42.9)	24 (38.1)	12 (57.1)
	High School/ University	25 (61.0)	15 (62.5)	28 (68.3)	36 (57.1)	39 (61.9)	9 (42,9)
p		0.13	0.21	<b>0.01</b>	0.19	<b>0.02</b>	0.41
Employment status	Employed	9 (22.0)	3 (12.5)	5 (12.2)	9 (14.3)	7 (11.1)	2 (9.5)
	Unemployed	32 (78.0)	21 (87.5)	36 (87.8)	54 (85.7)	56 (88.9)	19 (90.5)
p		0.09	0.79	0.66	0.97	0.34	0.50
Number of children	1	9 (22.0)	5 (20.8)	10 (24.4)	14 (22.2)	15 (23.8)	1 (4.8)
	> 1	32 (78.0)	19 (79.2)	31 (75.6)	49 (77.8)	48 (76.2)	20 (95.2)
p		0.58	0.81	0.31	0.40	0.20	0.06
Economic status of family	Low	9 (22.0)	8 (33.3)	5 (12.1)	11 (17.5)	9 (14.3)	5 (23.8)
	Middle	19 (46.3)	11 (45.9)	27 (65.9)	37 (58.7)	36 (57.1)	11 (52.4)
	Good	13 (31.7)	5(50.8)	9 (22.0)	15 (23.8)	18 (28.6)	5 (23.8)
p		0.49	0.19	0.16	0.58	0.32	0.87
Age of child (month)	< 24	7 (17.1)	6 (25.0)	6 (14.6)	13 (20.6)	12 (19.0)	3 (14.3)
	24-72	24 (58.5)	7 (29.2)	15 (36.6)	30 (47.6)	33 (52.4)	8 (38.1)
	> 72	10 (24.4)	11 (45.8)	20 (48.8)	20 (31.7)	18 (28.6)	10 (47.6)
p		0.28	0.08	0.06	0.45	0.42	0.35
Gender of child	Girl	20 (48.8)	10 (41.7)	22 (53.7)	33 (52.4)	32 (50.8)	9 (42.9)
	Boy	21 (51.2)	14 (58.3)	19 (46.3)	30 (47.6)	31 (49.2)	12 (57.1)
p		0.98	0.43	0.47	0.46	0.69	0.54
Child’s atopic dermatitis duration (months)	< 24	21 (51.2)	11 (45.8)	16 (39.0)	25 (39.7)	25 (39.7)	6 (28.6)
	≥ 24	20 (48.8)	13 (54.2)	25 (61.0)	38 (60.3)	38 (60.3)	15 (71.4)
p		0.37	0.96	0.33	0.22	0.22	0.09
Child’s additional allergic disease	Existent	13 (31.7)	8 (33.3)	16 (39.0)	24 (38.1)	24 (38.1)	8 (38.1)
	Absent	28 (68.3)	16 (66.7)	25 (61.0)	39 (61.9)	39 (61.9)	13 (61.9)
p		0.70	0.93	0.42	0.36	0.36	0.67
SCORAD score	Mild	23 (56.1)	11(45.8)	18 (45.0)	31 (49.2)	33 (52.4)	8 (38.1)
	Moderate	13 (31.7)	10 (41.7)	16 (40.0)	21 (33.3)	20 (31.7)	9 (42.9)
	Severe	5 (12.2)	3 (12.5)	6 (15.0)	11 (17.5)	10 (15.9)	4 (19.0)
p		0.80	0.77	0.54	0.21	0.40	0.32
Atopy history in family	Existent	21 (51.2)	17 (70.8)	23 (56.1)	40 (63.5)	37 (58.7)	14 (66.7)
	Absent	20 (48.8)	7 (29.2)	18 (43.9)	23 (36.5)	26 (41.3)	7 (33.3)
p		0.10	0.31	0.38	0.69	0.51	0.61

\* Distributions of the total number of mothers whose answers are “sometimes” and “always” are presented.

\*\*Column percentage.



to as 44.7%. In that study, the TOPICOP score was the highest in Taiwan, Ukraine and Poland, and was detected to be the lowest in Denmark, Brazil and Japan (18). The differences between countries could likely be caused by healthcare system and cultural factors. We could not use the TOPICOP questionnaire calculated score (a Turkish version was not available) and we did not have the opportunity to compare our results because of the lack of similar studies performed in our country.

When used improperly, TCSs can cause local side effects such as skin atrophy, purpura, striae, telangiectasia, depigmentation and acneiform changes on the face (19). Rarely, they may cause systemic side effects like hypothalamic-pituitary-adrenal suppression and growth failure (20). Although our questionnaire revealed that most of the participants lacked knowledge about side effects, the remainder had beliefs that TCSs could damage the skin (44.7%) and could negatively affect their child's health in the future (44.7%). In the study of Choi et al., similar to the results of our study, patients that used TCS stated that they were afraid of TCS causing skin damage (50%) and it could negatively affect their health in the future (46%) (13). In a questionnaire study that took place in England, 34.5% of the participants said that they feared their skin would get thinner (21). In a questionnaire study with high participation in Denmark, the fear score was reported as  $45.7 \pm 28.4\%$  (8).

After evaluating the questionnaire answers of the mothers, it was detected that highly educated mothers had more TCS phobia and misbeliefs related to TCSs compared to all mothers. Unlike our study, Genner et al. reported an inverse relationship between education level and TCS phobia (8). In a study that took place in Singapore, no connection was detected between the education level and TCS phobia (13). In addition to that, the global score was found as  $41.9 \pm 14.9\%$  in the TOPICOP questionnaire administered to healthcare professionals in Belgium, and TCS phobia was found mostly in pharmacists and general practitioners (21). Bos et al. stated that when they administered the TOPICOP questionnaire to both healthcare professionals and parents, they found the same TCS phobia level in parents and nurses (22). There are contradictory results between the education level and TCS phobia, and it shows differences between countries.

In our study, no relation was found between the children's age, gender, duration of the disease, comorbid

disease, and atopy history in the family. In a Denmark study, while it was stated that people who have atopy in family showed less fear, there were no differences with respect to these parameters in other studies (14, 23). In a Singapore study, it was stated that female participants and participants with daughters showed more fear but in our study only mothers were included and we did not detect any difference related to the children's gender (13). Similarly, in a Denmark study there was not any difference found between gender and age (8).

The compliance to treatment is of utmost importance in AD. Treatment non-compliance can lead to treatment failure and a decrease in the quality of life, thereby increasing the economic burden. One of the most important reasons of treatment failure is TCS phobia (11, 24-28). As a result, poor compliance leads to the use of stronger preparations or to systemic treatment, and this leads to more serious side effects (11). In our study, 54.6% of participants stated that they postponed the TCS treatment as long as possible, and 55.3% that they terminated the treatment as soon as possible. Also according to the SCORAD scores, mothers of children with severe AD were found to postpone the TCS treatment as long as possible. Similarly, in a study that was performed in Japan, it was found that parents of infants with severe AD who were younger than 12 months had higher TCS phobia. Gonzales et al could not detect a relation between the SCORAD level and TCS phobia (14, 23). We hypothesized that treatment compliance has decreased due to TCS phobia, which probably resulted in uncontrolled disease and high SCORAD scores.

In studies where the compliance with treatment was evaluated, it was reported that the patient-doctor relation should be strengthened, the treatment regimen should be simple, and the follow-up frequency should be increased (28, 29). Fifty-three point two per cent of the participants in our questionnaire stated that they needed to be informed about the use of TCS. Accordingly, in a double-blind study, it was reported that there was a significant decrease in the TOPICOP score after giving some patients an educational video and information about TCS, and there was an improvement in the knowledge and beliefs but not the fear score (30).

In conclusion; the frequency of TCS phobia might be affected by many factors such as the socioeconomic status and education level of the parents, cultural tendencies, a busy healthcare system, and time allocated to the patients.

However, we think that written and video assisted explanations of TCS treatment, practical training by specialist nurses, and ensuring doctor-patient confidence could decrease TCS phobia among parents and patients..

#### Conflict of Interest

None.

#### Authorship Contributions

Concept: Deniz Özçeker, Esra Yücel, Emek Özgür Kocatürk, Design: Deniz Özçeker, Esra Yücel, Nagihan Sahillioğlu, Emek Özgür Kocatürk, Data collection or processing: Deniz Özçeker, Esra Yücel, Nagihan Sahillioğlu, Analysis or Interpretation: Özlem Terzi, Literature search: Deniz Özçeker, Esra Yücel, Emek Özgür Kocatürk, Writing: Deniz Özçeker, Esra Yücel, Nagihan Sahillioğlu, Emek Özgür Kocatürk, Approval: Deniz Özçeker, Emek Özgür Kocatürk.

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