

Topical corticosteroid phobia among caretakers of children with atopic dermatitis: A cross-sectional study using TOPICOP in Japan

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Abstract

Background/Objectives: The TOPICOP scale is an easy-to-use scale for assessing topical corticosteroid (TCS) phobia in atopic dermatitis (AD) patients and their caretakers. TCS phobia is a common problem among AD patients and their caretakers. The aim of this study was to examine the relationship between TCS phobia in caretakers of children with AD and the characteristics of patients using the TOPICOP scale.

Methods: Caretakers of AD patients who visited the allergy clinic at the National Center for Child Health and Development in Tokyo between February 2014 and May 2014 were recruited. Caretakers of patients in follow-up had already attended an education session on treatment at the institution. All participants completed an anonymous questionnaire on the characteristics of the respondents and patients using the Patient-Oriented Eczema Measure (POEM) and the Japanese version of TOPICOP.

Results: In total, 243 participants (88.9% female) completed the survey. The average TOPICOP score was 40.3 and the median POEM score was 4. The TOPICOP score was significantly higher for patients younger than 12 months old with moderate to very severe AD (POEM ≥ 8) whose caretaker had not attended an educational session ($P < 0.01$, respectively). There was no significant difference in the family history of AD, age, or gender of the respondents. In multivariable analysis, preattendance at an education session was the only significant factor accounting for a higher TOPICOP score ($P < 0.001$).

Conclusions: Regardless of their background, caretakers of AD patients can be affected from TCS phobia. Attending an educational session might ease their anxiety.

KEYWORDS

atopic dermatitis, questionnaire, steroid phobia, topical corticosteroid, TOPICOP

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This study was carried out with the approval of the hospital ethics committee of the National Center for Child Health and Development (Reception number: 761).

1 | INTRODUCTION

Topical corticosteroids (TCS) are the gold standard of treatment for atopic dermatitis (AD).¹ However, the concerns and misunderstandings patients and their families often have about TCS can affect adherence to treatment and patients' prognosis.^{2,3} Thus, it is important for health care workers to evaluate concerns about topical corticosteroid use or TCS phobia in AD patients. Kojima et al and Ohya et al reported that prevalence of TCS phobia among Japanese caregivers was 38.3% and 77.0%, respectively.^{4,5} Fukaya et al showed 83.7% adult patients had feelings of resistance about using TCSs in Japan.² However, there was no information about the level of phobia in these studies. Moret et al developed the TOPical Corticosteroid Phobia scale (TOPICOP) in 2009⁶ to serve as a global index of the extent of steroid anxiety in patients with AD. The TOPICOP is able to assess various degrees of steroid anxiety in routine clinical practice. We translated the scale into Japanese and reported the feasibility in 2015,⁷ and Stalder et al reported feasibility in 2017 based on an international feasibility study of TOPICOP conducted in 15 countries including Japan.⁸ The current study was additional analysis by using a part of Japanese data of the feasibility study. The aim of this study was to examine the relationship between the characteristics of caretakers of children with AD and TCS phobia using the Japanese version of TOPICOP.

2 | METHODS

2.1 | Participants

We enrolled the caretakers of new and follow-up patients with AD who visited the pediatric allergy clinic at the National Center for Child Health and Development in Tokyo between February 2014 and May 2014. Non-native Japanese speakers were excluded. All patients with AD and their caregivers attended a patient education session titled "Atopic Dermatitis Education Class (AD class)" on their first visit to the clinic. In the hour-long session, a pediatric allergist and a nurse explained the pathology and treatment of AD including the desired and adverse effects of TCS. After the session, most of the caretakers consented to having their child treated with TCS.

This study was carried out with the approval of the hospital ethics committee of the National Center for Child Health and Development (Reception number: 761) and was conducted in accordance with principles outlined in the Declaration of Helsinki.

2.2 | Questionnaire

Participants were asked to complete an anonymous questionnaire on their visit. Caretakers of new patients answered the questionnaire before the educational session and the doctor's examination and placed it in a box outside the consultation room.

The questionnaire consisted of the Japanese TOPICOP and Patient-Oriented Eczema Measure (POEM) with some additional questions about patient characteristics such as age, gender, and AD history as well as caretakers' characteristics such as age, gender,

family histories of AD, and AD class attendance (on the first visit to the clinic).

The TOPICOP score consists of 12 items assessing patients' worries and beliefs about TCS. As described previously,⁶ four response choices are offered for each item, from "never" to "always" or from "totally disagree" to "totally agree." Each response is assigned a score of 0, 1, 2, or 3, with the higher values indicating more severe TCS phobia.

We evaluated the TOPICOP scores for worry and belief categories as well as the total score. Each category has a maximum score of 100, and the score of each respondent who completed at least half the items was expressed as a percentage of the maximum score.

POEM is an eczema severity assessment scale for atopic dermatitis based on patient's or caretakers' judgment rather than a doctor's.⁹ Patients (ie, their guardians in this study) assessed eczema in their child in the past week using a 5-point Likert scale, and severity was judged based on the total score (0-28 points). The scores were classified as "almost normal" if 2 points or less, "mild" if 3-7 points, "moderate" if 8-16 points, "severe" if 17-24 points, or "most severe" if 25 points or higher.¹⁰

2.3 | Statistical analysis

The nonpaired *t* test was used to compare the TOPICOP scores with the respondents' age (39 years old or older) and gender, the patient's age (less than 12 months), AD severity (mild or moderate to very severe according to POEM), AD class attendance, and family history of AD (mother, father, or siblings). Multiple regression analysis was performed with all patient attributes as variables. We used JMP 11[®] for all the analyses and considered *P* < 0.05 as statistically significant in all comparisons.

TABLE 1 Characteristics of respondents and patients

	n ^a	
Respondents		
Age, years, median (range)	233	38 (range: 25-55)
Sex, female, n (%)	242	215 (88.8)
Patients		
Age, median (range)	238	4 (range: 0-17)
POEM, median (range)	243	4 (2-9)
Very severe (25-28), n (%)		2 (0.8)
Severe (17-24), n (%)		17 (7.0)
Moderate (8-16), n (%)		60 (24.7)
Mild (3-7), n (%)		72 (29.6)
Clear or almost clear (0-2), n (%)		92 (37.9)
AD class attendance: Pre-attendance, n (%)	237	95(40.1)
Family history of AD, n (%)	243	143 (58.8)
Mother history, n (%)	243	74 (30.5)
Father history, n (%)	243	77 (31.7)
Sibling history, n (%)	243	50 (20.6)

^aNumber of respondents and patients without missing value.

TABLE 2 Association of TOPICOP score and patient characteristics

a) Univariate analysis (t-test)													
Patient and respondent variables	TOPICOP worry score				P	TOPICOP belief score				P	Total TOPICOP score		
	Mean ± SD					Mean ± SD					Mean ± SD	P	
Total	32.9 ± 17.4					47.6 ± 20.7					40.3 ± 16.9		
Age of respondents													
< 39 years old	32.0 ± 17.8				0.3	48.4 ± 21.8				0.7	40.2 ± 17.7		
≥ 39 years old	34.4 ± 17.0					47.5 ± 18.2					41.1 ± 15.7		
Sex of respondents													
Male	32.5 ± 14.7				0.9	46.1 ± 22.4				0.7	39.3 ± 15.3		
Female	33.0 ± 17.8					47.8 ± 20.5					40.5 ± 17.1		
Age of patients													
< 12 months old	36.9 ± 16.1				0.1	56.5 ± 20.9				0.003	46.9 ± 16.7		
≥ 12 months old	32.4 ± 17.6					45.8 ± 20.3					39.2 ± 16.8		
AD severity													
Clear to mild	31.4 ± 17.0				0.05	45.0 ± 20.1				0.006	38.3 ± 16.6		
Moderate and more	36.1 ± 17.9					52.8 ± 21.1					44.5 ± 16.9		
AD class													
Not yet attended	35.4 ± 18.2				0.06	54.7 ± 20.0				< 0.001	45.1 ± 17.1		
Already attended	31.1 ± 16.6					42.6 ± 19.5					37.0 ± 15.9		
Family history of AD													
No	32.1 ± 16.5				0.6	48.2 ± 18.2				0.7	40.2 ± 15.3		
Yes	33.4 ± 18.0					47.1 ± 22.3					40.3 ± 18.0		
b) Multiple regression analysis ^{a,b}													
Patient and respondent variables	TOPICOP worry score				P	TOPICOP belief score				P	Total TOPICOP score		
	Unstandardized coefficients					Unstandardized coefficients					Unstandardized coefficients		
	95%CI					95%CI					95%CI		
	B	Lower	Upper	P		B	Lower	Upper	P		B	Lower	Upper
Age of respondents													
< 39 years old	0				0					0			
≥ 39 years old	4.40	-0.44	9.23	0.1	1.36	-4.03	6.74	0.6		3.08	-1.45	7.62	0.2
Sex of respondents													
Male	0				0					0			
Female	-0.03	-3.87	3.81	0.99	-1.88	-6.17	2.40	0.4		-1.02	-4.63	2.59	0.6
Age of patients													
< 12 months old	0				0					0			
≥ 12 months old	-2.86	-9.52	3.81	0.4	-4.09	-11.5	3.33	0.3		-3.67	-9.92	2.59	0.3
AD severity													
POEM < 8	0				0					0			
POEM ≥ 8	2.75	-2.25	7.76	0.3	2.60	-2.98	8.17	0.4		2.69	-2.01	7.39	0.3
AD class													
Not yet attended	0				0					0			
Already attended	-1.09	-2.24	0.06	0.1	-2.42	-3.70	-1.14	< 0.001		-1.74	-2.81	-0.66	< 0.001

(Continues)

TABLE 2 (Continued)

b) Multiple regression analysis ^{a,b}												
Patient and respondent variables	TOPICOP worry score				TOPICOP belief score				Total TOPICOP score			
	Unstandardized coefficients				Unstandardized coefficients				Unstandardized coefficients			
	95%CI				95%CI				95%CI			
	B	Lower	Upper	P	B	Lower	Upper	P	B	Lower	Upper	P
Family History of AD ^c												
No	0				0				0			
Yes	-0.15	-2.47	2.18	0.9	0.64	-1.94	3.23	0.6	0.22	-1.96	2.41	0.8

^aN = 222.^bMissing data were excluded from analysis.^cFamily history of AD was defined as a history of AD in the father, mother, or any sibling.

3 | RESULTS

The clinical characteristics of the participants are summarized in Table 1. In total, 243 participants comprising 215 (88.9%) females completed the questionnaire. The median patient age was 4 years (range: 0-17), and the median score on POEM was 4 (range: 2-9). Investigator-assessed AD severity was classified as clear (37.9%), almost clear (29.6%), mild (24.7%), moderately severe (7%), or very severe (0.8%).

The average TOPICOP score was 32.9 ± 17.4 for worry, 47.6 ± 20.7 for belief, and 40.3 ± 16.9 for the total score (see Table 2a). The total TOPICOP score showed a normal distribution (see Figure 1).

The AD class attendance rate was 59.9%. Of the participants who had already taken the AD class, 59.9% took the class more than 12 months before TOPICOP administration (data not shown). The attendance rates classified by patients' age and severity were the following: less than 12 months vs 12 months or more: 27.5% vs 66.5%; mild group vs moderate or more severe: 69.9% vs 39.7%, respectively.

The relationship between each patient characteristic and the TOPICOP score is shown in Table 2a. The TOPICOP score was significantly higher in younger patients and those with more severe AD (less than 12 months vs 12 months or more: 46.9 ± 16.7 vs 39.2 ± 16.8 , respectively ($P = 0.009$); clear to mild vs moderate to more severe: 38.3 ± 16.6 vs 44.5 ± 16.9 , respectively ($P = 0.007$)). AD class preattendance was also related to a higher TOPICOP score (preattendance vs attendance: 45.1 ± 17.1 vs 37.0 ± 15.9 ($P < 0.001$), respectively). The belief score also increased with these three factors (less than 12 months vs 12 months or more: 56.5 ± 20.9 vs 45.8 ± 20.3 ($P = 0.003$), respectively; clear to mild vs moderate to more severe: 45.0 ± 20.1 vs 52.8 ± 21.1 , respectively ($P = 0.006$); preattendance vs attendance: 54.7 ± 20.0 vs 42.6 ± 19.5 , respectively ($P < 0.001$)).

Family history of AD did not have any significant influence on the total TOPICOP, worry, or belief scores, which remained unchanged even when analyzed separately by the history of AD in the father, mother, or siblings. The age and gender of the respondents did not have a significant influence on the TOPICOP score.

In multiple regression analysis, respondents who had not attended an AD class yet showed only significantly higher beliefs and total TOPICOP scores than those who had attended (unstandardized coefficients (B) = -2.42 , 95% confidence interval (CI): -3.70 to -1.14 , $P < 0.001$ and $B = -1.74$, 95%CI: -2.81 to -0.66 , $P < 0.001$, respectively) (see Table 2b). None of the factors significantly affected the worry score.

4 | DISCUSSION

In this study, younger age, more severe eczema, and preattendance were associated with a higher total and belief score on the TOPICOP in univariate analysis. However, only AD class attendance was associated with a higher score in multiple regression analysis.

To our knowledge, this is the first report on the relationship between the TOPICOP score and disease background in caretakers of pediatric AD patients in Japan. In this study, fewer caretakers of young patients and patients with more severe AD attended AD class. On their first visit, caretakers would not have attended an educational session yet and might not have had any knowledge of how to treat AD. During follow-up after a long period of treatment, patients tended to have a milder disease condition than at the first visit. For these reasons, some patients in the infant and severe symptom groups did not attend the AD class.

Among caretakers who had attended class, the worry score did not decrease, although the belief score did. The TOPICOP is geared to an international audience, and the questions about worry might not address the concerns held by many Japanese caretakers.

Kojima et al reported in their cross-sectional study that a past history of AD in the father was a predictor of steroid phobia.⁴ In our study, AD history in any family member did not have a significant effect according to either univariate or multivariable analysis. This discrepancy was due to differences in the methods used to assess steroid phobia. We used TOPICOP, which consists of several questions, whereas past researchers used a simple yes/no question asking whether or not caretakers agreed to use TCS for their children. Such a simple question fails to capture the specific reasons for caretakers' concerns even after

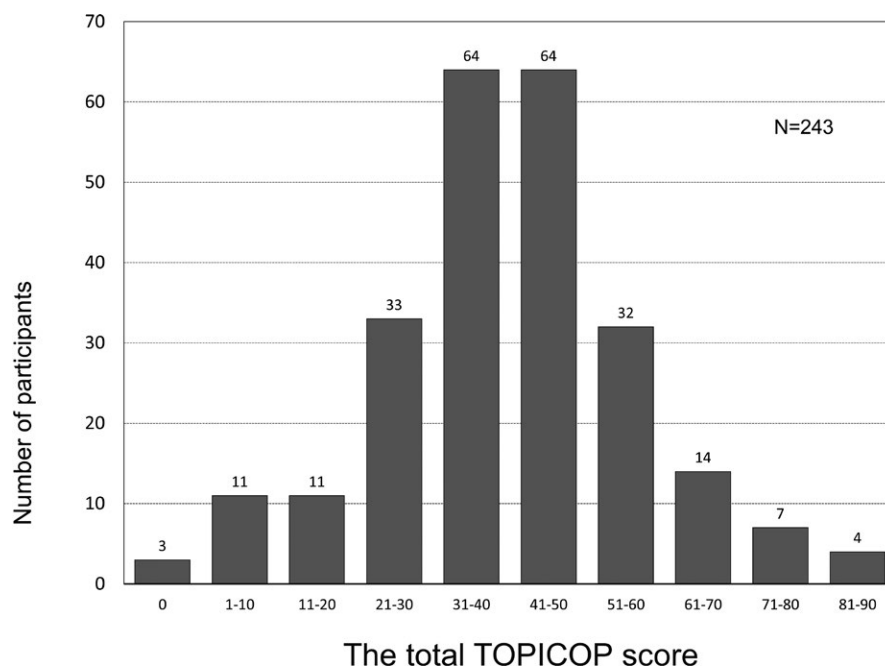


FIGURE 1 Distribution of TOPICOP scores

they have received instruction or treatment from health care workers. Although a past history of AD in a family member was apparently an important factor for detecting strong steroid phobia, it was insufficient for detecting steroid anxiety. However, regardless of the patient's background as described above, in clinical practice, attention should be given to steroid anxiety in the caretakers of AD patients.

Although previous studies reported the effect of patient education on AD in terms of eczema severity and quality of life,¹¹⁻¹³ they did not examine changes in steroid anxiety. Recently, in their prospective study using TOPICOP, Gonzales et al reported that therapeutic patient education (TPE) significantly decreased TCS phobia among AD patients and demonstrated that the scores for the belief and worry categories and the total score were significantly lower after TPE.¹⁴ Our findings generally agreed with their results except for the worry category score, which did not decrease significantly in our study possibly as a result of a difference in the timing of TOPICOP administration. In their study, TOPICOP was administered immediately after the TPE. However, in our study, more than half of the participants who had already taken the AD class had done so more than 12 months before TOPICOP was administered. This suggests that continuous intervention is needed to decrease worry in patients during AD treatment.

Our study has some limitations. First and most importantly, this cross-sectional study did not assess the TOPICOP score in the same individuals before or after their attendance at the AD class. Further, the attitude of caretakers who had already attended a class might have been influenced by success in treatment. Therefore, we were unable to evaluate the actual change in TOPICOP score according to class attendance. While TCC is still a major obstacle to AD treatment,^{15,16} we believe that the scores before attending class might reflect data from caretakers with no

attendance. Secondly, the questionnaire and the data from the medical records were not linked; therefore, the original disease severity of patients before starting treatment was unknown. In order to clarify these points, it is necessary to conduct a longitudinal study using TOPICOP to collect information about the course of the disease and its treatment.

In the present study, we demonstrated an association between the TOPICOP score and the characteristics of patients and their family.

Regardless of the patient's background, in clinical practice, attention should be given to steroid anxiety in the caretakers of AD patients, and attending an educational session might ease TCS phobia.

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