

Factors Associated with Steroid Phobia in Caregivers of Children with Atopic Dermatitis

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Abstract: Topical corticosteroids (TCS) are first-line therapeutic agents for atopic dermatitis (AD). Some patients express irrational fear and anxiety about using TCS, which leads to poor outcomes for AD. Although it is important to understand the factors underlying steroid phobia so that its effects can be minimized, few studies have addressed this subject. Here, we used a questionnaire to investigate predictive factors for steroid phobia in the caregivers (usually mothers) of children with AD. We studied 436 children with AD (mean age 47.6 mos, range 2–236 mos) who newly visited our AD outpatient unit. The caregivers were asked to complete a medical history questionnaire regarding AD. Steroid phobia was analyzed for correlations with other patient and caregiver variables. Overall, 38.3% of the caregivers were reluctant to use TCS on their children's skin. Patient characteristics female sex (odds ratio [OR] = 1.85 vs male; $p = 0.005$), child's paternal history of AD (OR = 1.94; $p = 0.03$), and frequent changing of clinics (OR = 1.25; $p = 0.03$) were predictive factors for steroid phobia. AD severity did not correlate with steroid phobia. Our findings suggest that greater attention to the patient's sex and clinical background of patients with AD is important to the success of AD therapy, regardless of AD severity.

Topical corticosteroids (TCS) are first-line therapeutic agents for atopic dermatitis (AD) (1). In daily clinical practice, it is common for patients to express irrational fear and anxiety about using TCS (steroid phobia) (2–6). Steroid phobia may lead to poor patient adherence to

TCS therapy, resulting in poor control of AD (3,5), and poor control of AD may lead to physical, psychological, and social isolation, including sleep disturbance, teasing, and school refusal, which are thought to be more serious problems than the adverse effects of TCS (3,7).

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Furthermore, those problems result in lower quality of life, not only for children with AD, but also for their families (8), sometimes even leading to family disruption (3). Some patients and caregivers with steroid phobia choose alternative and unproven therapies, which may cause exacerbation of AD (9). Others choose strict dietary therapy that results in malnutrition or failure to thrive (10).

In Japan, steroid phobia is widespread because of confusion and misinformation regarding AD therapies, including strict dietary restriction therapy, in the 1980s and negative media publicity that has exaggerated the adverse effects of TCS since the 1990s (11). Moreover, alternative and unproven therapies have gained popularity as an “atopy industry” (12). Incorrect information has often been disseminated over the Internet (13). In addition to these problems, Japan has experienced scams and lawsuits regarding alternative therapies, deaths due to malnutrition caused by extreme dietary restriction therapy, teasing-linked suicides, and at worst, family suicides (13).

Although steroid phobia is a serious problem, few studies have investigated the factors associated with it (14). The present study was designed to shed light on this, with the ultimate objective of improving the treatment of AD.

MATERIALS AND METHODS

Patients

The present study was conducted on new outpatients (and their caregivers) with AD aged 1 month to 20 years of age who visited the Outpatient Unit of the Division of Allergy, National Center for Child Health and Development, Tokyo, from April 2003 to June 2006. Patients were excluded if they had other forms of inflammatory dermatitis. The hospital ethics committee of the National Center for Child Health and Development approved this study, and it was conducted in accordance with the principles outlined in the Declaration of Helsinki.

Clinical Background and Data

Allergists diagnosed AD. The severity of AD in each patient was assessed using the scoring of atopic dermatitis (SCORAD) index (15) and then classified into one of four categories according to that index (remission 0, mild 1–25, moderate 25–49, and severe ≥ 50) (16). Age, sex, age at onset of AD, duration of eczema, parental history of AD, current usage of TCS, and results of blood tests (eosinophil and total immunoglobulin E [IgE] levels) were confirmed from the medical records for each patient.

Questionnaire

The caregiver attending a child patient—in most cases (approximately 95%) the mother—was asked to complete a questionnaire before the doctor examined the child. The questionnaire consisted of items concerning perceptions regarding TCS and the history of AD therapy. The items regarding perceptions of TCS included caregiver’s steroid phobia, adverse effects, and perceived image of TCS therapy. Steroid phobia was assessed by asking “Would you agree to use TCS on your child’s skin?” Those who answered “never” or “no, I’d rather not use TCS if I can avoid it” were defined as having steroid phobia. Preconceptions regarding adverse effects and the image of TCS therapy were ascertained by asking open-ended questions. The history of AD therapy was also ascertained using open-ended questions, and frequency of changing clinics, use of alternative therapies, and negative experiences with doctors were determined. Caregivers were also asked about the history of nonadherence to TCS therapy, how they applied TCS to the child, and the use of soap to bathe the child (Table 2).

Statistical Analyses

To check the validity of the single-item question about steroid phobia, the chi-square test was used to analyze for associations between the question “Would you agree to use TCS on your child’s skin?” and the caregiver’s image of TCS, history of nonadherence to TCS therapy, the caregiver’s preconceptions regarding adverse effects, application of TCS, and use of alternative care. Then we performed bivariate logistic analysis of steroid phobia against patient sex, age, onset age, duration of eczema, severity of AD, parental history of AD, eosinophil count, total IgE level, frequency of changing clinics, and negative experience with doctors. Finally, we performed multiple logistic analysis to identify factors associated with steroid phobia, using as explanatory variables the factors that showed a marginal association with steroid phobia with $p < 0.4$ in the bivariate analysis. Data were analyzed using STATA software (Windows version 8.0; StataCorp, College Station, TX). $p < 0.05$ was considered to indicate statistical significance in all comparisons. The postestimated goodness-of-fit (Hosmer-Lemeshow) was confirmed for logistic regression analysis.

RESULTS

Patients

Four hundred forty-eight caregivers completed the questionnaire. We excluded 12 patients who had other

forms of inflammatory dermatitis, leaving 436 patients for the analyses: 286 male (65.6%) and 150 female (34.4%). Their mean age was 47.6 ± 48.9 months (range 2–236 mos). The characteristics of the patients are summarized in Table 1.

Confirmation of the Single-Item Question on Steroid Phobia

The incidence of steroid phobia measured using a single-item question was 38.3% of all caregivers (Table 1) and 58.7% of those with a history of nonadherence to TCS therapy (Table 2). We used the chi-square test to confirm the validity of the single-item question about steroid phobia, “Would you agree to use TCS on your child’s skin?” There were strong correlations between negative perceptions regarding TCS (negative image of TCS, history of nonadherence to TCS therapy, strong apprehension regarding adverse effects of TCS, not a current user of TCS, and preference for alternative care) and the question (Table 2). Because these negative perceptions of TCS are a crucial component of steroid phobia, we considered this single-item question about steroid phobia to be useful.

Bivariate Analyses

In the bivariate analyses, female sex (odds ratio [OR] = 1.59, 95% confidence interval [CI] = 1.06–2.39), duration of eczema (OR = 0.93, 95% CI = 0.88–0.99), and paternal history of AD (OR = 1.91, 95% CI = 1.06–3.44) were significantly associated with steroid phobia; severity of AD and blood sample data were not (Table 3).

Multivariate Analyses

To evaluate the effects of confounding factors, a logistic regression model was adjusted for patient sex, age, duration of eczema, parental history of AD, frequency of changing clinics, and negative experience with doctors. In the multivariate analyses, female sex (adjusted OR [aOR] = 1.85, 95% CI = 1.20–2.85), child’s paternal history of AD (aOR = 1.94, 95% CI = 1.03–3.58), and frequent changing of clinics (aOR = 1.25, 95% CI = 1.03–1.53) were significantly associated with steroid phobia (Table 4).

DISCUSSION

We found that the predictive factors for steroid phobia in caregivers of children with AD are patient female sex,

TABLE 1. *Characteristics of Patients*

	Mean (range) or	SD or %
Demographic		
Patient’s sex M/F	286/150	65.6/34.4
Patient’s age (months)	47.6 (2–236)	48.9
< 12	120	27.5
12–72	217	49.8
> 72	99	22.7
Clinical characteristic		
Onset age	10.4 (1–191)	21.3
< 12	338	77.5
12 < < 36	74	17.0
36 <	16	3.7
Duration of eczema	36.8 (0–224)	43.3
Severity of (SCORAD) index		
Remission (0)	12	2.8
Mild (1–25)	159	36.5
Moderate (> 25)	175	40.1
Severe (> 50)	90	20.6
Parental history of	102	23.4
Mother	60	13.8
Father	51	11.7
Both	9	2.1
Eosinophil count (/μL)	662.3 (0–5,592.4)	689.5
< 294	93	
294–467	93	
467–793	93	
> 793	93	
Eosinophil count (%)	6.74 (0–34.8)	4.86
< 3.55	93	
3.55 < < 5.7	95	
5.7 < < 8.7	92	
8.7 <	92	
Total IgE (IU/mL)	2259.2 (2–97,600)	8692
< 53.9	93	
53.9 < < 310	93	
310 < < 1,141	93	
1,141 <	94	
Steroid phobia		
Caregivers who were reluctant to use	167	38.3
Past consultation for AD		
Frequency of changing	2.1 (0–6)	1.2
Caregivers who had negative experiences with	80	18.4
Application of TCS		
Use of TCS		
Non-current	24	5.5
Past user	64	14.7
Current user	334	76.6
Caregivers who apply TCS sparingly at doctor’s	171	39.2
Caregivers who apply TCS sparingly at own	81	18.8
Caregivers who apply TCS liberally at doctor’s	58	13.3
Caregivers who apply TCS liberally at own	35	8
Alternative		
Caregivers who preferred alternative	71	16.3
Caregivers who don’t use soap to bathe the child	25	5.7

AD, atopic dermatitis; SCORAD, Scoring Atopic Dermatitis; TCS, topical corticosteroids.

TABLE 2. Confirmation of Single-item Question About Steroid Phobia

Category	Steroid phobia (+) (N = 167)	Steroid phobia (-) (N = 262)	p-Value†
Image of TCS held by caregiver			
Negative	96 (62.3)	88 (37.1)	< 0.001*
Positive	7 (4.5)	65 (27.4)	
Both negative and positive	50 (32.5)	75 (31.6)	
Other	1 (0.6)	9 (3.8)	
History of non-adherence with TCS (by caregiver)			
Yes	90 (57.7)	63 (25.0)	< 0.001*
No	66 (42.3)	189 (75.0)	
Preconceptions regarding adverse effects of TCS (by caregiver)			
Adverse effects on the skin (including skin thinning and darkening)			
Yes	112 (67.1)	128 (48.9)	< 0.001*
No	55 (32.9)	134 (51.1)	
Skin thinning			
Yes	54 (32.3)	59 (22.5)	0.024*
No	113 (67.7)	203 (77.5)	
Skin darkening			
Yes	35 (21.0)	28 (10.7)	0.003*
No	132 (79.0)	234 (89.3)	
Systemic adverse effects of TCS			
Yes	57 (34.1)	53 (20.2)	0.001*
No	110 (65.9)	209 (79.8)	
Application of TCS			
Use of TCS			
Non-current user	11 (6.7)	10 (4.0)	< 0.001*
Past user	41 (25.2)	23 (9.1)	
Current user	111 (68.1)	219 (86.9)	
Caregivers who apply TCS sparingly at doctor's instruction	66 (50.0)	105 (49.3)	0.16
Caregivers who apply TCS sparingly at own judgment	38 (28.8)	43 (20.2)	
Caregivers who apply TCS liberally at doctor's instruction	17 (12.9)	41 (19.2)	
Caregivers who apply TCS liberally at own judgment	11 (8.3)	24 (11.3)	
Alternative care			
Caregivers who preferred alternative care			
Yes	37 (22.2)	34 (13.0)	0.013*
No	130 (77.8)	228 (87.0)	
Caregivers who don't use soap to bathe the child			
Yes	8 (4.9)	17 (6.6)	0.46
No	156 (95.1)	240 (93.4)	

*p < 0.05.

†Chi-square test.

Data given in parentheses are expressed as percentage.

child's paternal history of AD, and frequent changing of clinics for the patient but not severity of AD. These results suggest that greater attention to the clinical background of patients with AD is important in addressing steroid phobia, regardless of the severity of AD.

The incidence of steroid phobia among caregivers was 38.3% (Table 1), which is consistent with previous studies. A report from Hong Kong showed that 40% of patients with moderate and 60% of patients with severe AD expressed concern about using TCS, but there was no association between steroid phobia and severity of AD (6). In the United Kingdom, 72.5% of patients with AD worried about using TCS, and 36.5% of those had been nonadherent to TCS therapy (4). Of caregivers of children with AD in Australia, 40% answered that TCS was dangerous, and 20% said it was too dangerous to use on their child's skin (17). In France, 80.7% of

the parents of children with AD and people with AD reported having fears about TCS, and 36% admitted nonadherence to treatment (18). Although methodologic differences make it difficult to compare these percentages directly, approximately one-third of parents are reluctant to use TCS on their children. Medical care providers need to be sensitive to this anxiety about using TCS in their daily clinical practice.

We also confirmed the validity of the single question about steroid phobia, "Would you agree to use TCS on your child's skin?" by finding strong correlations with negative perceptions regarding TCS (negative image of TCS, history of nonadherence to TCS therapy, strong apprehension regarding adverse effects of TCS, not a current user of TCS and preference for alternative care) (Table 2). This result was similar to a recent study that reported a correlation between steroid phobia and the need for reassurance, the belief that topical corticosteroids

TABLE 3. Correlation with Steroid Phobia (Bivariate)

	Bivariate OR	95% CI	p-Value
Patient's sex			
Male	Reference		0.025*
Female	1.59	1.06–2.39	
Patient's age (mos)			
< 12	Reference		0.027*
12–72	1.06	0.67–1.67	
> 72	0.54	0.30–0.96	
Onset age (mos)			
< 12	Reference		0.87
12–36	1.14	0.69–1.90	
> 36	1.05	0.38–2.88	
Duration of eczema (yrs)	0.93	0.88–0.99	0.018
Severity of AD (SCORAD index)			
Remission (0)	Reference		0.8
Mild (1–25)	0.59	0.18–1.90	
Moderate (25–50)	0.63	0.20–2.04	
Severe (> 50)	0.7	0.21–2.33	
Parental history of AD			
Mother			
No	Reference		0.39
Yes	1.28	0.73–2.22	
Father			
No	Reference		0.031*
Yes	1.91	1.06–3.44	
Eosinophil count (/μL)			
< 294	Reference		0.82
294–467	0.89	0.49–1.63	
467–793	0.86	0.47–1.58	
793 <	1.12	0.62–2.03	
Eosinophil count (%)			
< 3.55	Reference		0.51
3.55–5.7	0.75	0.40–1.38	
5.7–8.7	1.06	0.58–1.92	
> 8.7	1.16	0.64–2.10	
Total IgE (IU/ml)			
< 53.9	Reference		0.81
53.9–310	0.75	0.41–1.37	
310–1,141	0.93	0.51–1.68	
> 1,141	0.91	0.50–1.65	
Past consultation for AD			
Frequency of changing clinics	1.14	0.96–1.34	0.13
Caregivers with negative experience with doctors			
No	Reference		0.14
Yes	1.45	0.89–2.37	

*p < 0.05.

pass through the skin into the bloodstream, a prior adverse event, inconsistent information about the quantity of cream to apply, a desire to self-treat for the shortest possible time, or poor treatment adherence (18). Our observation suggests that appropriate education of patients to remedy negative perceptions of TCS would be one good strategy for addressing steroid phobia, as others have noted (2,4,19).

In this study, most patients and caregivers (91.3%) had used TCS, at least in the past (Table 1), which suggests that only a few caregivers had totally rejected TCS therapy for their child at the onset of AD. This implies that, whether the caregivers of children with AD

TABLE 4. Correlation with Steroid Phobia (Multivariate)

	†Multivariate OR	95% CI	p-Value
Patient's sex			
Male	Reference		0.005*
Female	1.85	1.20–2.85	
Patient's age (mos)			
< 12	Reference		
12–72	1.03	0.62–0.73	0.9
> 72	0.55	0.20–1.53	0.25
Duration of eczema (years)	0.96	0.86–1.07	0.45
Parental history of AD			
Mother			
No	Reference		0.39
Yes	1.15	0.64–2.05	
Father			
No	Reference		0.034*
Yes	1.94	1.03–3.58	
Past consultation for AD			
Frequency of changing clinics	1.25	1.03–1.53	0.026*
Caregivers with negative experience with doctors			
No	Reference		0.78
Yes	1.08	0.63–1.85	

*p < 0.05.

†Adjusted for all values listed above.

become steroid phobic or not depends on the experience during AD therapy that they have received. An earlier study on factors related to steroid phobia suggested that a preconception of ineffectiveness or adverse effects of TCS was associated with steroid phobia (14).

Our results indicate that the patient's sex, a paternal history of AD, and frequent changing of clinics for the patient were associated with steroid phobia (Table 4).

There have been no studies focusing on patient sex as an association factor for steroid phobia. In our study, we found that misinterpretation of skin darkening as a TCS side effect was significantly associated with steroid phobia (Table 3). Light skin, bright eyes, and black hair have long been considered essential factors for beauty in Japanese girls (20). Thus, we assume that our finding may be due to a cultural factor in Japan that—together with the misinterpretation—leads the parents of girls to be reluctant to use TCS for their children.

We found that the child's paternal—but not maternal—history of AD was associated with steroid phobia (Tables 3 and 4). If parents had experienced treatment failure in the past, they tended to feel steroid phobia for their children. On the other hand, parental history of AD could be a remedy for steroid phobia because they may have been advised about or read correct knowledge regarding TCS during their previous experience with TCS therapy. We should have asked whether the parents had experienced treatment failure in the past, but in Japan, steroid phobia was widespread in 1980s (12). Therefore some parents with AD had not received

appropriate or successful TCS therapy and might have negative perceptions of TCS. Although our results showed that one of the predictive factors for steroid phobia was child's paternal history of AD, this might be because the caregivers of most Japanese children with AD are their mothers. Mothers would have more chances to acquire the correct knowledge regarding TCS from doctors, and any steroid phobia they might have might be relieved. On the other hand, fathers would have less opportunity to be in contact with their children's doctor, and their steroid phobia might remain. Family or relatives have also been reported to be major sources of steroid phobia (4,6,9). Thus, a father with a history of AD might cause steroid phobia in the mother-caregiver. We believe that these results indicate that correct information regarding TCS is needed not only for mother-caregivers, but also for father-partners.

Frequent changing of clinics suggests a history of treatment failure or distrust of medical care services, because in Japan patients can go to clinics without any referral. This finding of frequent changing of clinics might indicate that negative experiences with doctors, including ineffectiveness of TCS, are associated with steroid phobia.

On the other hand, AD severity was not associated with steroid phobia, which is consistent with previous studies (6,18). Furthermore, as others have noted (14,21), in our study, personal negative experiences and attitudes such as a preconception of ineffectiveness might have been more important as factors underlying steroid phobia than objective factors such as AD severity evaluated by a doctor. This finding suggests that AD severity should not be a factor in evaluating whether a patient has steroid phobia.

This study has a number of limitations. First, it was conducted at a national medical center where most patients would know that doctors would use TCS for AD therapy. Therefore, strongly phobic patients might have been underrepresented. Further studies of such patients should be undertaken to compare with our results. Second, the questionnaire about steroid phobia was not validated in other studies (4,6,17,18), although we confirmed that a single-item question, "Would you agree to use TCS on your child's skin?" was associated with negative perceptions of TCS (Table 2). Although we tried to identify negative experiences with doctors using open-ended questions regarding history of AD therapy, a future study should have multiple-choice questions and focus on a history of treatment failure and the patient-doctor relationship. Third, because of the cross-sectional study design, the presumed cause-and-effect relationship between predictive factors and steroid phobia may be the reverse; for example, steroid phobia may have been the

reason for frequent changing of clinics. Fourth, other unmeasured factors, such as parental level of education, social status, and personality, might have confounded the results. Further studies should be done regarding these factors in steroid phobia, although medical expense would not be burden for Japanese caregivers because there are medical care subsidies for children in Japan.

In conclusion, our study suggests that greater attention to patient sex, paternal history of AD, and frequency of changing clinics for the patient will aid physicians in addressing steroid phobia, whereas AD severity does not play any role. It is necessary to devote sufficient time to careful elucidation of the clinical background of patients with AD from their caregivers. This would help physicians understand any steroid phobia of caregivers and contribute to overcoming steroid phobia in patients with AD and their caregivers.

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