

# Topical corticosteroid phobia in atopic dermatitis: a study of its nature, origins and frequency

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## Summary

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**Background** Topical corticosteroids remain the mainstay of atopic dermatitis therapy. Many atopic dermatitis therapeutic failures appear to be attributable to poor adherence to treatment due to topical corticosteroid phobia.

**Objectives** To assess the facets, origins and frequency of fear of topical corticosteroid use among patients with atopic dermatitis.

**Methods** A questionnaire comprising 69 items, generated from information gathered during interviews with 21 patients and 15 health professionals, was given to consecutive patients consulting at the outpatient dermatology departments of five regional university hospitals or with 53 dermatologists in private practice.

**Results** A total of 208 questionnaires were analysed (including 144 from parents and 87 from adult patients, 27 of whom were also parents); 80.7% of the respondents reported having fears about topical corticosteroids and 36% admitted nonadherence to treatment. A correlation was found between topical corticosteroid phobia and the need for reassurance, the belief that topical corticosteroids 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 time possible or poor treatment adherence. Topical corticosteroid phobia was not correlated with atopic dermatitis severity.

**Conclusion** Topical corticosteroid phobia is a genuine and complex phenomenon, common among French patients with atopic dermatitis, that has an important impact on treatment compliance.

As defined by the U.K. Working Party's diagnostic criteria,<sup>1</sup> atopic dermatitis (AD) is a relapsing, chronic, inflammatory, cutaneous disorder that occurs mainly in childhood and sometimes persists into adulthood. AD currently affects 10–20% of children worldwide.<sup>2,3</sup> It is a public health concern because of its prevalence, cost and impact on quality of life.<sup>4,5</sup> Thus, the broad impact of AD warrants optimization of relevant support services.

Topical corticosteroids (TCS), the mainstay of AD treatment, are often required for months or years to control the disease. Although they have long been known to have side-effects, their efficacy and safety, when used appropriately, are well established.<sup>6–10</sup> Why some patients with AD do not respond

to TCS remains unexplained, but poor adherence to the prescribed regimen may underlie treatment failure. Indeed, adherence by patients with AD is known to be poor, at ~30%,<sup>11</sup> as it is for other chronic diseases.<sup>12</sup>

What is usually called corticosteroid phobia is frequent. Corticosteroid phobia is certainly a misnomer because the term 'phobia' defines an irrational fear.<sup>13</sup> In fact, corticosteroid phobia is the dedicated term to describe all types of fear about steroid use. In routine clinical practice, it is not unusual for patients to express fear or anxiety about using TCS and TCS phobia appears to be common (60–73% of patients),<sup>14,15</sup> potentially leading to poor adherence and lack of response to

treatment.<sup>15</sup> Nevertheless, TCS phobia appears to be a complex phenomenon not yet fully elucidated, with little in the literature about its origins or risk factors.

This study was designed to investigate the components, origins and frequency of TCS phobia, and factors associated with it among dermatology outpatients with AD.

## Methods

This prospective, multicentre study was conducted at five regional hospitals in France, in collaboration with 53 dermatologists in private practice. The first task of the study was to create a questionnaire. To generate items and generally explore the field of TCS phobia, we decided to start with a qualitative inquiry to examine the origins, expressions and consequences of TCS phobia in patients with AD. The questionnaire was developed after a qualitative and explorative analysis, according to focus group methodology<sup>16</sup> involving adult patients, parents of children with AD and health professionals (general practitioners and pharmacists). During these focus group sessions, we used several information-gathering techniques: patients' keywords ('For me TCS is...'), memory ('Do you remember the first time you were prescribed TCS?'), 'postcards' relating personal experiences ('Write a postcard to somebody from your family who asks your advice about TCS'), to collect data about patients' behaviours, emotions, cognitions, feelings and perceptions concerning TCS. Five such meetings were held. To reach data saturation, we used other sources (telephone interviews). These techniques require mastery of written and spoken language, French in our case.

Thirty-six people participated in this first part of the study: 12 adult patients, nine parents, eight general practitioners and seven pharmacists. The focus group sessions and interviews were then transcribed. Three researchers conducted a qualitative analysis to identify the emerging issues and items were selected by experts (three dermatologists and one psychologist). We obtained 51 items concerning the intensity, components and origins of fears, and patients' behaviours vis-à-vis their prescribed therapy. The first three items evaluated the intensity of the fears: (i) 'On this scale, where would you place the intensity of your worries about TCS?' (0, no fear at all; 10, very fearful); (ii) 'Do you have fears about treatment with TCS?'; and (iii) 'Concerning your treatment, how do you feel?' The first response was based on a 10-point visual analogue scale (VAS), and the following two had multiple-choice options. Other items covered the kinds of fear and beliefs, their origins, and behaviours vis-à-vis therapy. To explore the complexity of TCS phobia and its subtleties, we used items with multiple-choice responses rather than yes-or-no answers. Eighteen additional questions covering the characteristics of the patients and their disease were added: age; status (parent of child with AD or adult patient); profession; severity (self-evaluated: mild, severe, very severe); duration; disease burden ('On a scale from 0 to 10, how much bother has the eczema caused you over the last 3 days?'); previous treatment; and prior adverse events.

Thus, the final questionnaire used in the second part of the study consisted of 69 items. It was given to 208 consecutive patients with AD consulting at the hospital outpatient dermatology departments or dermatologists in private practice, between February and May 2009. Patients were asked to complete the questionnaire before the consultation. For all participants, the AD diagnosis was confirmed by the patient's dermatologists. All patients with AD were included, and parents were asked to complete questionnaires for their affected children under 15 years old. The first page of the document was a written explanation of the study that had to be signed by the respondent for participation. This study was approved by the local ethics committee.

## Statistical methods

Results are expressed as percentages or means  $\pm$  SD, and statistical analyses (univariate and multivariate) were conducted using SPSS 16 and R2.8.0 software (SPSS Inc., Chicago, IL, U.S.A.). Variables, expressed as Likert scales, were considered quantitative. For the univariate analysis, relationships between TCS phobia, as assessed with the VAS, and the covariates were evaluated using Spearman's correlation coefficient. When necessary, Student's *t*-test was used. Items with > 10% missing data were excluded. Previous studies on patients with AD evaluated TCS phobia using only one question with a yes-or-no response.<sup>14,15</sup> Because TCS phobia appears to be more complex and subtle, we chose to evaluate it with the first three items of the questionnaire: one VAS, and two with multiple-choice responses from the qualitative study. The results reported herein concern the univariate analysis using only the first item (VAS) as the dependent variable. Those obtained for the two other items were similar (data not shown).

Then a multivariate analysis was performed. The outcome (dependent) variable was the intensity of the VAS-assessed TCS phobia. Explanatory variables were selected among those significantly associated with the dependent variable in the univariate analysis ( $P < 0.05$ ) and a backward selection process was then applied to obtain the final model. Statistical significance for all analyses was set at  $P < 0.05$ .

## Results

A total of 208 patients were enrolled in five centres in France; nine hospital dermatologists and 53 dermatologists in private practice contributed 114 and 94 patients, respectively. The response rate to the questionnaire was 100%, and the non-response rate to items was < 10%, with the exception of two of the 51 items ('It's more difficult to use TCS on my child than on me', and 'I avoid putting TCS on my child's hands').

### Characteristics of the sample

Parents of children with AD accounted for 144 respondents (32 male, 112 female), 87 adults (27 men and 60 women) had AD, 27 of whom were patients and parents of an AD child, and

four additional adults were given TCS but we do not know whether they were prescribed for themselves or for their child. The mean  $\pm$  SD ages of the parents, their children and the 87 adult patients with AD were  $32.75 \pm 7.3$ ,  $4.9 \pm 4$  and  $30.5 \pm 10$  years, respectively. The patient data are summarized in Table 1. Concerning AD severity, 41.1% of the patients reported mild, 46.2% severe and 12.7% very severe disease. To measure the impact of the disease, the question, 'On a scale from 0 to 10, how much bother has the eczema caused you over the last 3 days?',<sup>17</sup> generated a mean response of  $5.2 \pm 2.9$ . The majority of patients (81.7%) were currently using or had used TCS. Concomitant treatments prescribed were moisturizing cream (93%), phototherapy (8%), topical tacrolimus (28%), ciclosporin (4%) and/or homeopathy (41%).

### Descriptive analysis

Notably, 80.7% of our patients admitted having fears about TCS. In response to the question, 'Do you have fears about treatment with TCS?', only 19.3% reported no fear at all. The intensity of those fears reached a mean of  $4.3 \pm 2.8$  on the

**Table 1** Patient characteristics

Characteristic	Parents			
	Adults with AD (n = 87)	of a child with AD (n = 144)	Children with AD (n = 144)	Indeterminate adults (n = 4)
Sex, n				
Male	27	32	83	2
Female	60	112	58	2
Age (years), mean $\pm$ SD	$30.5 \pm 10$	$32.7 \pm 7.3$	$4.9 \pm 4$	ND
Occupation, n				ND
Student	16	1		
Salaried	2	5		
manual worker				
Farmer	0	3		
Self-employed	4	10		
Office employee	43	78		
Not working	15	25		

AD, atopic dermatitis; ND, no data available.

10-point VAS scale. TCS phobia-intensity was comparable for adult patients with AD and parents of children with AD ( $4.5 \pm 3.5$  vs.  $3.0 \pm 2.6$ , respectively). When asked how they felt about their treatment, only 9.2% reported being confident in using TCS (Table 2); 36% of the patients admitted non-adherence to the prescribed regimen. Patients' beliefs and behaviours concerning TCS are summarized in Tables 3 and 4.

Many patients reported being worried about how to apply TCS, the right quantity to use and treatment duration. Patients also reported discrepancies in the information given by doctors and pharmacists (Table 5). Overall, 41.3% of the patients reported using alternative medicine therapies to treat their AD.

### Univariate analysis

The univariate analysis found correlations between TCS phobia and many items relating to types of fear, origins of fear or behaviours (Tables 3–5). The principal significant findings are the correlations between TCS-phobia intensity and the belief that TCS pass through the skin into the bloodstream, a lack of clarity about how to use the treatment, a lack of trust in the practitioner or discrepancies in the information provided by their physicians (about the area to treat, the amount of cream to apply and how to stop). Furthermore, TCS phobia was significantly correlated with poor adherence to treatment, belief in self-treating as late as possible and for the shortest time possible (Table 4), or a prior adverse event ( $t = -2.87$ ,  $P = 0.005$ ).

Pertinently, TCS phobia was not associated with patient age, sex or AD characteristics (its duration or severity). Consulting in a hospital or private practice had no significant influence on whether patients worried about using TCS.

### Multivariate analysis

The multivariate linear regression model identified the following six variables as being independent predictors of TCS-phobia intensity, as assessed with the VAS (Table 6): the need for reassurance, the belief that TCS pass through the skin into the bloodstream, a previous side-effect, inconsistent information about the quantity of cream to apply, self-treatment for the shortest time possible and poor treatment adherence.

**Table 2** Results of the response to the first three questionnaire items about topical corticosteroid (TCS)-phobia intensity

Item	Response					
	0	4.3				10
VAS <sup>a</sup>						
Do you have fears about TCS treatment?	No fear at all 19.3%	A little 26.1%	Moderately 37.2%	A lot 15%	Very fearful 2.4%	
How do you feel about TCS treatment?	Confident 9.2%	Comfortable 14%	Neutral 5.3%	Cautious 44.4%	Wary 20.8%	Anxious 6.3%

<sup>a</sup>Visual analogue scale scores range from 0 (no fear at all) to 10 (very fearful).

Table 3 Beliefs and representations

Item	I agree to a				r	P-value
	I completely disagree (%)	I don't really agree (%)	certain extent (%)	I completely agree (%)		
TCS are effective over a short time period	2.9	8.2	33.5	55.3	-0.08	NS
TCS are effective over a long time period	16.7	42.2	25	16.2	0.36	< 0.001
TCS pass into the bloodstream	12.8	20.4	34.2	32.7	0.35	< 0.001
TCS stunt growth	46.6	32.9	13.1	7.3	0.14	NS
TCS can lead to infections	47.3	35.2	10.9	6.9	0.38	< 0.001
TCS make you fat	39.4	19.7	27.1	13.8	0.25	< 0.001
TCS damage your skin	26.3	28.8	30.2	14.6	0.36	< 0.001
TCS will affect my future health	14.1	32.2	36.1	17.6	0.46	< 0.001
There is a dependency risk	24.8	24.9	29.8	20.5	0.42	< 0.001
I can become resistant to TCS	16.2	20.1	36.7	26.9	0.35	< 0.001
TCS become inefficient over time	14.8	27.6	37.9	19.7	0.38	< 0.001
TCS calm symptoms but don't treat the cause	12.8	13.2	17.16	56.9	0.38	< 0.001
TCS make eczema worse	57.6	30.8	8.3	3.4	0.42	< 0.001
TCS stop the eczema from coming up to the surface of the skin	7.1	32.5	1.7	18.7	0.11	NS
TCS can lead to asthma	47.2	39.1	9.1	4.6	0.24	< 0.001
I don't know of any side-effects but I'm still afraid of TCS	26.6	25.6	33	14.8	0.46	< 0.001
TCS are more dangerous than CS in tablet form	4.7	37.2	6.5	1.5	0.14	NS
TCS treatment takes time and effort	21.1	30.9	29.4	18.6	0.15	0.04
TCS treatment is complicated	42.2	44.1	9.3	4.4	0.17	0.02
TCS treatment helps me improve my quality of life	5.5	12.9	39.3	42.3	0.20	0.005
TCS increase my well-being	4.9	9.9	39.3	42.3	0.24	< 0.001
The advantages of TCS use outweigh the disadvantages	7.8	21.3	45.8	25	0.31	< 0.001

r, Spearman's rank correlation coefficient (correlation with the visual analogue scale score in univariate analysis); TCS, topical corticosteroids; NS, nonsignificant.

Table 4 Patient behaviours concerning treatment

Item	Never (%)	Sometimes (%)	Often (%)	Always (%)	r	P-value
I'm afraid of applying too much cream	27.2	32.5	25.2	15	0.47	< 0.001
I'm afraid of using the cream for too long	19.8	31.8	29	19.3	0.63	< 0.001
I'm afraid of putting cream on certain zones like the eyelids, where the skin is thinner	27.9	19.1	20.6	32.3	0.48	< 0.001
It's more difficult to use TCS on my child than on me	32.9	18.2	16.5	32.4	0.36	NA
If my doctor prescribed TCS then I would apply the prescription	1	15.5	21.3	62.3	0.25	< 0.001
I wait as long as I can before treating myself	39.1	28.5	20.8	11.6	0.24	< 0.001
I stop the treatment as soon as I can	24.3	23.8	32.5	19.4	0.41	< 0.001
I am careful to rub the cream in well when I apply it	1.4	7.2	26.6	64.7	0.07	NS
I avoid putting TCS on my child's hands	23.6	9	12.9	54.5	0.18	NA
When my doctor asks me how many tubes I've used I am scared	56.6	22.7	3.1	7.6	0.33	< 0.001
I need reassurance about TCS	17.4	26.4	24.4	31.8	0.54	< 0.001

r, Spearman's rank correlation coefficient (correlation with visual analogue scale score in univariate analysis); TCS, topical corticosteroids; NS, nonsignificant; NA, not applicable (nonresponse rate > 10%).

## Discussion

The results of this study confirm the high TCS-phobia rate among French patients with AD and its impact on therapeutic compliance. The concept of 'steroid phobia' first appeared in the context of asthma.<sup>18,19</sup> Later, the frequency of TCS phobia and its impact on patient adherence to therapy were studied in AD. However, the various components of TCS phobia and

the complexity of the phenomenon revealed in everyday clinical practice warranted further investigation.

An original feature of our study is the methodology used to develop the questionnaire. Qualitative analysis using focus groups to generate items enabled us to construct a series of items and questions that explored the real-life attitudes, beliefs and behaviours of patients, and different facets of TCS phobia.

Table 5 Given information and coherence of messages

Item	Never (%)	Sometimes (%)	Often (%)	Always (%)	r	P-value
Have you spoken about the following points related to TCS with your doctor?						
Health consequences	42.2	27.4	18.1	12.2	0.07	NS
The way to apply the cream	14.6	23.9	28.3	31.2	0.08	NS
The amount of cream to apply	16	19.4	27.2	37.4	0.16	0.03
The length of time of a treatment	4.4	13.1	26.2	56.3	0.10	NS
If you have consulted several doctors has the information been the same concerning the following points?						
To which zones you should apply the cream	8.6	16.7	30.9	43.6	0.19	0.008
The amount of cream to apply	14.3	24.6	31.8	43.6	0.24	0.001
How to stop treatment	28.1	21.4	18.9	31.6	0.21	0.003
Possible side-effects	49.7	23.3	14.2	12.7	0.12	NS
Have you received clear information from your doctor about TCS?	31.5	29.4	22.3	16.7	0.25	< 0.001
Do you trust your doctor?	1.5	11.1	35.7	51.8	0.27	< 0.001
I received the same information from doctors and pharmacists	20	29	32	19	0.25	< 0.001
One of these groups has already warned me about using TCS						
Doctors	45.5	31.2	17.3	5.9	0.11	NS
Pharmacists	46.8	31.5	14.8	6.9	0.10	NS
Friends or family	15.8	25.1	39.9	19.2	0.23	0.001
The media	42.3	32.8	19.9	5	0.06	NS

r, Spearman's rank correlation coefficient (correlation with the visual analogue scale score in univariate analysis); TCS, topical corticosteroids; NS, nonsignificant.

Dimension	Variable	$\beta$ -Coefficient (95% CI)	P-value
Fear	Need reassurance	0.67 (0.36–0.99)	< 0.00001
Belief/representation	TCS pass into the bloodstream	0.63 (0.28–0.98)	< 0.001
Origin/communication	Previous adverse event	0.67 (0.03–1.31)	< 0.05
	Discrepancies about quantity	0.34 (0.01–0.66)	< 0.05
Strategy of action	Treat oneself the shortest time possible	0.61 (0.30–0.93)	< 0.001
	Poor adherence	0.53 (0.12–0.94)	< 0.05

CI, confidence interval; TCS, topical corticosteroids.

Table 6 Multivariate analysis

Patients were enrolled from hospital outpatient dermatology departments and dermatologists in private practice to avoid any recruitment bias in an exclusively hospital-based sample. Indeed, patients consulting at hospital departments may have more severe AD or more TCS fear leading to therapeutic failure. Patients recruited in both settings comprised a homogeneous group. However, because on average fewer than two patients were included per private practice clinician, we cannot exclude a recruitment bias. Indeed, although we recommended giving the questionnaire to consecutive patients with AD, it might have been distributed to those with more severe AD or with TCS phobia. In this study, TCS phobia was not associated with either the characteristics of AD (duration, impact and severity) or the patient (age, sex or type of consultation). Thus, TCS phobia can affect all patients with AD. Moreover, the majority of study patients were women. Another study limitation is that AD severity was self-evaluated.

No severity score, such as the Scoring AD (SCORAD) index, was applied.

An important finding of our study is the confirmation of the high frequency of TCS phobia in patients with AD. Indeed, eight out of 10 patients reported being afraid of using TCS.

High rates were also found previously. Fischer<sup>20</sup> found that 40% of patients thought TCS were dangerous. In a questionnaire study involving 200 patients with AD, Charman *et al.*<sup>14</sup> found that 73% of the patients or parents of children with AD reported being worried about using TCS. In 2006, using the same questionnaire, Hon *et al.*<sup>15</sup> found that 60% of 233 patients had fears about TCS. The higher rate found in our study might be explained by the use of questions with multiple-choice responses or cultural differences. Notably, TCS-phobia rates differed in China,<sup>15</sup> the U.K.<sup>14</sup> and France, highlighting cultural diversity in how the general population perceives corticosteroids.

We also showed that the intensity and focus of the fears varied among patients. Indeed, because of the multiple-choice options, we were able to bring to light nuances in the intensity of the TCS fear and concern from 'not at all' to 'very fearful' and from 'confident' to 'anxious'. Although the majority of patients had moderate fear, some had extreme anxieties.

The findings of this study revealed that some patients had specific fears about TCS use, most of which concerned adverse events, predominantly cutaneous side-effects. Some patients worried about systemic side-effects, principally growth retardation and weight gain. Although similar fears have been described before,<sup>14,15,20,21</sup> patients' worries about how to apply TCS (how much, how long and where) and their fear of doing the wrong thing have not been reported previously. Patients also feared TCS dependency or addiction and loss of efficacy; eight out of 10 patients considered TCS to be effective over a short time period, and only 41.2% saw them as effective over the long term. The same worries were reported by Charman *et al.*,<sup>14</sup> Hon *et al.*<sup>15</sup> and Fukaya.<sup>22</sup>

Our observations also identified indeterminate worries or nonspecific concerns. The former were raised by 47.8% of the patients, who said they did not know the side-effects of TCS but were still afraid of using them. According to Charman *et al.*,<sup>14</sup> 24% of their patients worried about long-term nonspecific adverse events. These nonspecific fears might be associated with a lack of information, information discrepancies or with the term 'steroid'. Notably, some patients who did not admit to being worried about using TCS expressed TCS phobia through their behaviours (need for reassurance or reducing doses). Thus, TCS phobia is a complex phenomenon that manifests as specific or indeterminate fears, or only as specific behaviours. Consequently, it cannot be explored with questions having only yes-or-no responses.

The results of this study suggest several origins of fear or worry about TCS use. First, verbal information given by caregivers seems to play an important role. Indeed, a lack of clear advice was significantly correlated with TCS phobia. Inconsistent information about the quantity to use, the area to treat and treatment duration induced worries. Patients reported discrepancies concerning all these treatment aspects among dermatologists, dermatologists and general practitioners, and between practitioners and pharmacists. These variations might be attributable to advances in our understanding of TCS and their safety over the years, and perhaps even reflect TCS phobia among caregivers themselves,<sup>23</sup> especially those trained long ago.

We also found that the family circle and other people in the patient's entourage play a prominent role in the origin of fears by perpetuating unhelpful attitudes, negative beliefs and misconceptions about TCS, as previously reported.<sup>14,15,21</sup>

Our observations confirm the impact of TCS phobia on treatment adherence: the greater the fear, the poorer the compliance. Several groups<sup>11,20,24</sup> attributed many therapeutic failures to poor adherence and suggested that TCS phobia played a contributory role. Only Ohya *et al.*<sup>25</sup> failed to detect an impact on adherence. TCS phobia and treatment compliance

are associated concepts, but remain separate: patients can be treatment-compliant and still have worries about it. As mentioned above, TCS is associated with patient-initiated dose-reduction strategies and such behaviours may be the only way fear is expressed. Many patients reported waiting until their AD got worse or applying TCS only as a last resort to avoid potential side-effects.

Our findings suggest several areas in which action can be taken to reduce patients' TCS phobia. First, as in previous studies,<sup>14,15,20</sup> we underscore the role of information provided by doctors. Information of poor quality, lacking in clarity or containing discrepancies breeds fear. Health professionals in the focus groups admitted that their own fears might be responsible for inadequate information and inappropriate warnings given to patients. Lack of knowledge about TCS may also contribute, and requires continuing education of practitioners to keep them abreast of new findings and thereby reassure their patients.

Lastly, our observations emphasize the importance of educational support for the patient. Verbal information given by caregivers to patients or parents could be supplemented with written information on AD, treatments used and their side-effects, and treatment regimens (with clear details of how much to apply, where to apply, how long to apply for). Exploring a patient's perceptions and beliefs about TCS phobia allows information to be targeted individually. Patients also require emotional support. The quality of the patient-doctor relationship is critical to ensuring treatment adherence and patient self-efficacy. A good patient-doctor relationship, trust in the physician and reassurance about treatment are essential to reduce TCS phobia.

Our results indicate that TCS phobia is complex and that its evaluation requires a scale or score. Estimating TCS phobia with yes-or-no responses is too simplistic and cannot detect different types of fear or their intensities. Its frequency, impact and the observation that all types of patients are affected warrant its systematic exploration in the context of AD.

### What's already known about this topic?

- Topical corticosteroid phobia or anxieties about topical corticosteroid use are common among patients or parents of children with atopic dermatitis and potentially lead to poor adherence and lack of response to treatment.

### What does this study add?

- Topical corticosteroid phobia, a genuine and complex phenomenon, common among French patients with atopic dermatitis, is associated with a prior adverse event and inconsistent information about the treatment.
- Furthermore, it has an important impact on therapeutic adherence.

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