

# Evaluation of corticophobia in patients with atopic dermatitis and psoriasis using the TOPICOP<sup>®</sup> score

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## Abstract

**Introduction:** Atopic dermatitis (AD) and psoriasis (PS) are skin diseases that have a significant impact on the quality of life. The correct application of corticosteroids in topical treatment is highly effective and safe for patients. Excessive and irrational fear of these drugs based on incorrect information is increasingly observed at dermatological clinics.

**Methods:** To assess the extent of corticophobia, we conducted a single-center cross-sectional survey using the TOPICOP<sup>®</sup> questionnaire.

**Results:** The study included 57 patients (56% female) with AD and 58 patients (60% female) with PS. The combined TOPICOP<sup>®</sup> score averaged around 44, showing no significant difference between the two skin conditions. However, consistently higher scores were observed among female participants compared to males.

**Conclusions:** The prevalence of corticophobia was comparable to that reported in other similar studies and was higher among female patients, which replicates previous findings. Patients with AD, who were younger on average than patients with PS, often relied on friends, acquaintances, family members, and the internet as their main information sources. Providing correct and reliable information to patients is crucial for ensuring treatment adherence.

**Keywords:** atopic dermatitis, psoriasis, corticosteroids, corticophobia, compliance

Received: 28 October 2023 | Returned for modification: 4 December 2023 | Accepted: 12 December 2023

## Introduction

Atopic dermatitis (AD) and psoriasis (PS) are complex, chronic inflammatory skin conditions that have a considerable impact on the quality of life for affected individuals. Common features of both conditions include recurring flareups, the presence of red scaly patches on the skin, and persistent itching (1).

AD, also known as atopic eczema, is characterized by dry and itchy skin. Clinically, the disease presents as an erythematous rash, dry and inflamed skin, severe itching, and skin changes that are often accompanied by bacterial, fungal, or other infections. Improvement and deterioration of the skin on various parts of the body are characteristic of AD, and during exacerbations inflammation can spread to the entire skin. AD usually begins in childhood and often disappears by puberty, although it frequently occurs or reoccurs in adolescents and/or adults (2–3).

In contrast, PS presents as raised and inflamed patches of skin covered with silvery scales called plaques (4, 5). It is a chronic autoimmune disease that primarily affects the skin but can also be associated with arthritis and other comorbidities (6). It presents as itchy and/or sore plaques on the skin, commonly found on the knees, elbows, scalp, palms, or soles. It is more common in individuals under the age of 40 years, with a peak incidence between 16 and 22 years. In addition, there is a later peak in incidence observed between 57 and 60 years (7).

The treatment of both AD and PS typically involves the use of topical corticosteroids (TCS), which are effective in reducing inflammation and managing symptoms in the initial stage of the disease. In addition to establishing basic skin care, regular and appropriate skin treatment with corticosteroid creams may contribute to the successful treatment of such skin disorders (8).

Treatment of AD, for example, includes adequate skin hydration, avoidance of allergens, supportive care, and anti-inflammatory treatment with TCS (9–13).

An increasing number of patients are hesitant to utilize corticosteroids for the topical treatment of AD and PS because of fear of unwanted side effects, such as thinning of the skin, systemic side effects, and hypertrichosis. Therefore, appropriate choice of preparations is of the utmost importance. Various creams and ointments are employed for topical treatment and are prescribed by doctors based on the patient's medical condition and skin changes (3, 14). TCS are safe and effective agents for reducing disease recurrence, and side effects are minimal if topical treatments are used properly, precisely as prescribed (13–15). Appropriate use of TCS often achieves permanent disease control. Improper and irresponsible use of TCS can cause unwanted local side effects and in some instances rare systemic side effects (16). Common local side effects include skin thinning, purpura, striae, telangiectasia, hyperpigmentation, and acne (10, 17).

Swift access to information, both accurate and misleading content on the internet, coupled with the proliferation of conspiracy theories about well documented side effects and a sense of distrust toward medical professionals, has contributed to the rise of anxiety and apprehension among many patients regarding the use of TCS. This heightened unease, suspicion, or skepticism surrounding the utilization of corticosteroids is commonly referred to as corticophobia (11, 15). Online forums and blogs frequently exacerbate corticophobia by spreading false information about medications. Corticophobia is believed to affect 20% to 80% of people, and is inversely proportional to patients' education levels according to some studies (10–11). Patients with AD often refuse TCS because of misinformation, lack of education, and uncertainty (11).

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Therefore, physicians and healthcare professionals must assume greater responsibility for providing appropriate treatment policies and ensuring patient compliance by addressing misinformation and providing reliable advice. Given that many individuals in outpatient clinics may be hesitant to disclose their fear, and numerous patients remain silent about it, we aimed to explore the increasingly prevalent corticophobia in greater detail.

Our objective was to assess the firsthand experiences of patients with AD and PS, examining the efficacy of TCS treatments and investigating the potential occurrence of both local and systemic side effects. In this non-interventional study, we utilized the TOPICOP® score, a questionnaire designed to ascertain whether the use of corticosteroid ointments for the treatment of AD and mild forms of PS is justified or if patients' fears are substantiated. The TOPICOP® score is a valuable tool for evaluating corticophobia in dermatology patients, measuring their levels of fear and anxiety regarding TCS use. Numerous studies employing this score have highlighted the notable prevalence of corticophobia, typically yielding total scores between 30 and 50. Furthermore, these studies have consistently indicated a higher prevalence of corticophobia among female patients and, in some instances, among patients with lower educational levels (18–20).

Participants in the study stand to benefit from receiving information that can alleviate fear and discomfort associated with the use of TCS. This knowledge ensures the correct application of TCS to the skin, ultimately optimizing treatment outcomes. Importantly, there were no identified risks, harms, or burdens to the participants, and no adverse events were reported during the course of the study.

## Methods

We enrolled individuals aged 18 years and older with a confirmed diagnosis of AD or PS that had previously utilized TCS and provided informed consent by signing a consent form. Exclusion criteria were age under 18 years and those that had never used TCS. The diagnoses were established by a proficient dermatology specialist based on clinical features. The severity of psoriasis was determined following the European guidelines (21), with additional precision provided by referencing the French (22) and Italian (23) guidelines. For atopic dermatitis, the European Task Force for Atopic Dermatitis / European Association of Dermatovenerologists (ETFAD/EADV) Eczema Task Force 2020 position paper was used for a more accurate definition of disease severity (1).

## Data collection

All patients completed three questionnaires:

- A basic internal questionnaire, which was used to gather the demographic information presented in Table 1.
- The TOPICOP® (Topical Corticosteroid Phobia) (24) questionnaire. This validated questionnaire contains 12 items, which aim to cover two important dimensions or domains relative to “worries” or “fears” (six items) and “beliefs” or “knowledge” (six items) about topical corticosteroids. A higher TOPICOP® score indicates a higher level of corticophobia. This questionnaire was designed to determine whether the treatment of AD and PS with corticosteroid ointments justified the fear that was felt.
- The Dermatology Life Quality Index (DLQI) (25) questionnaires to assess the impact of the patients' diseases and treatment on their quality of life.

Questionnaires were distributed to patients treated at the Dermatology Clinic of the Ljubljana University Medical Center, Slovenia. All participants received a detailed written and verbal explanation of the study purpose. We relied on the consistency of patients when completing the questionnaire.

**Table 1 | Demographic data of subjects in the study.**

	Atopic dermatitis (n = 57)	Psoriasis (n = 58)
Age (years), mean (SD)	29.7 (10.7)	47.1 (14.7)
Sex, n (%)		
Male	25 (43.9)	23 (39.7)
Female	32 (56.1)	35 (60.3)
Disease duration (years), mean (SD)	18.4 (10.5)	20.8 (15.2)
Highest educational level, n (%)		
Primary school	1 (1.8)	4 (6.9)
Secondary school	29 (50.9)	31 (53.4)
Vocational college	7 (12.3)	6 (10.3)
Bachelor's/master's	19 (33.3)	14 (24.1)
Doctorate	1 (1.8)	3 (5.2)
Employment status, n (%)		
Employed	26 (45.6)	44 (75.9)
Unemployed	6 (10.5)	2 (3.4)
In school	24 (42.1)	4 (6.9)
Retired	1 (1.8)	8 (13.8)

SD = standard deviation.

## Statistical analysis

The total TOPICOP® score and domain subscores for each participant were calculated as a percentage of the total questions answered, resulting in scores ranging from 0% to 100%. The Mann–Whitney *U* test was used for non-normally distributed data, and the unpaired parametric *t*-test was used for normally distributed data. When multiple groups were compared, one-way analysis of variance (ANOVA) was performed. Statistical analyses were performed using GraphPad Prism software (version 9.0 Windows; GraphPad Software, San Diego, CA, USA). Statistical significance was set at  $p < 0.05$ . Multivariate linear regression analysis was performed using IBM SPSS version 25.0.

## Results

The TOPICOP® questionnaires were administered to a total of 115 patients, aged over 18 years, all of whom were diagnosed with either AD or PS by a dermatologist and received treatment at the Dermatology Clinic of the Ljubljana University Medical Center, Slovenia. In the AD group, 56% of participants were female, while in the PS group, 60% were female. On average, patients with AD were approximately 17 years younger than those with PS, as indicated in Table 1.

The distribution of disease severity for both AD and PS was relatively balanced, with a slightly higher proportion of PS patients experiencing more severe disease. However, approximately half of the patients in each group were categorized as having either mild, moderate or severe disease, as detailed in Table 2. The distributions of the DLQI scores were similar for both diseases (Table 3).

There were no significant differences observed in the total and domain TOPICOP® questionnaire scores among subjects with AD, PS, and the combined group (AD + PS) (Table 4).

The difference in the percentage of the total TOPICOP® questionnaire scores (questions 1–12) between males and females for both diseases showed that the scores were consistently higher in female patients than in male patients (Fig. 1).

Figure 2 illustrates that patients undergoing biological therapy

had lower total TOPICOP® scores compared to those who were not on such therapy.

Within the subgroup of patients with AD, Figure 3 shows that information sources such as friends, acquaintances, family members, and the internet played a significant role and were consulted almost as frequently as certified dermatologists.

Figures 4 and 5 indicate that there were no statistically significant differences between the total TOPICOP® scores and scores in individual domains.

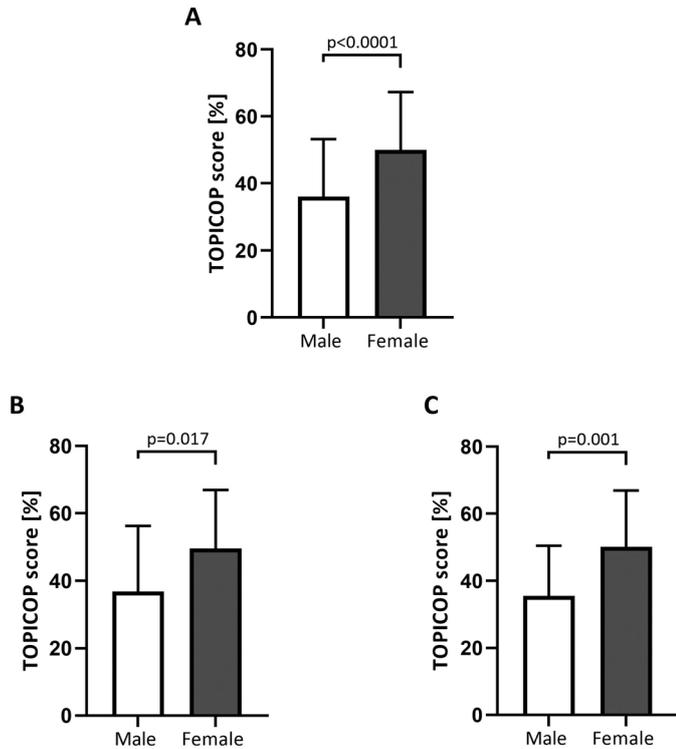


Figure 1 | Histograms depicting the percentage distribution of total TOPICOP® questionnaire scores (males and females) across (A) all patients, (B) patients with atopic dermatitis, and (C) patients with psoriasis.

Table 2 | Atopic dermatitis severity based on SCORing Atopic Dermatitis (SCORAD) (26), and Eczema Area and Severity Index (EASI) scores (27), psoriasis severity based on the Psoriasis Area and Severity Index (PASI) (28), and Dermatology Life Quality Index (DLQI) (25) scores.

	Atopic dermatitis (n = 57)	Psoriasis (n = 58)
Mild	30 (52.6%)	24 (41.4%)
Moderate	14 (24.6%)	34 (58.6%)
Severe	13 (22.8%)	

Table 3 | Distribution of Dermatology Life Quality Index (DLQI) scores.

	Atopic dermatitis (n = 57)	Psoriasis (n = 58)
Median	5.0	9.5
Min	0.0	0.0
Max	30.0	27.0
IQR	13.5	12.5

IQR = interquartile range.

Table 4 | Total TOPICOP® questionnaire scores of subjects in the atopic dermatitis, psoriasis, and combined groups. Presented as the median interquartile range (IQR) of the percentage of scores achieved.

	n	Q 1–6 (%)	Q 7–12 (%)	Q 1–12 (%)
Atopic dermatitis	51	44.0 (39.0–61.0)	44.0 (17.0–61.0)	44.0 (28.0–58.0)
Psoriasis	58	50.0 (37.5–56.0)	44.0 (20.8–61.0)	44.0 (31.0–56.5)
Combined	109	44.0 (39.0–56.0)	44.0 (17.0–61.0)	44.0 (31.0–57.0)

Q = quartile.

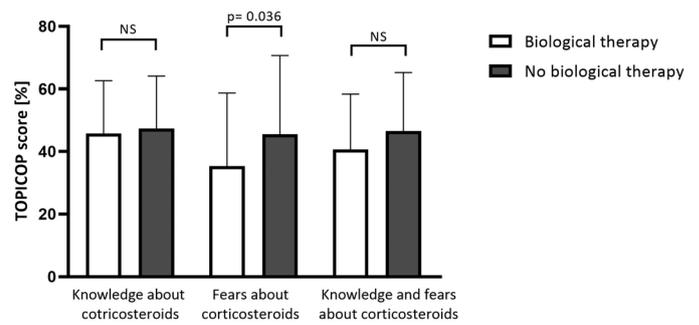


Figure 2 | Histogram illustrating the percentage distribution of total TOPICOP® questionnaire scores for individuals undergoing biological therapy and those without biological therapy. NS = not significant.

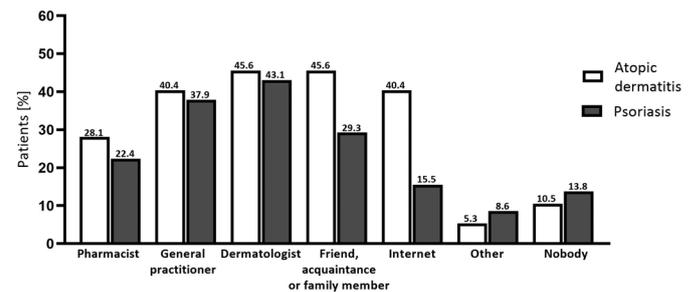


Figure 3 | Histogram displaying the sources of information from professionals that warned individuals with atopic dermatitis or psoriasis about the risks associated with local corticosteroids.

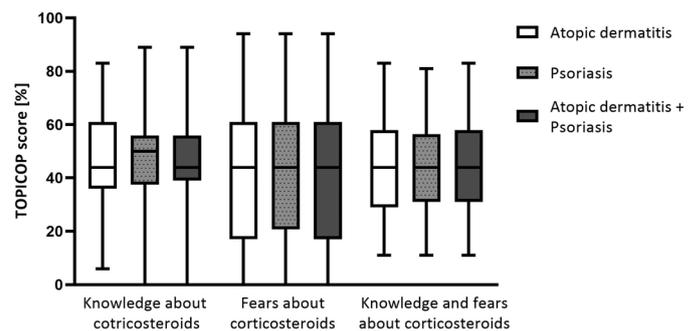


Figure 4 | Boxplots presenting the total TOPICOP® questionnaire scores in subjects with atopic dermatitis, psoriasis, and combined groups, along with the domain scores of knowledge and fears, respectively.

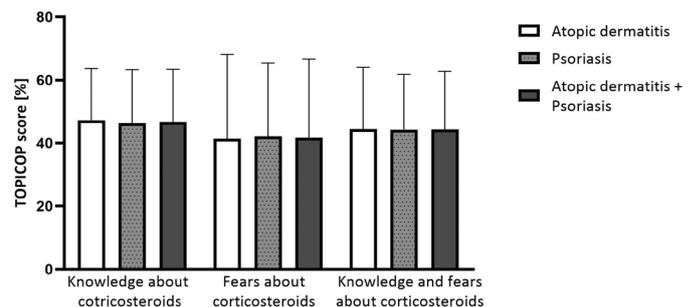


Figure 5 | Histogram representing the percentage of the total TOPICOP® questionnaire scores in subjects with atopic dermatitis, psoriasis, and combined groups, and the domain scores of knowledge and fears, respectively.

## Discussion

Our study emphasizes the pivotal role of providing accurate and reliable information in promoting patient treatment adherence. It underscores the importance of addressing corticophobia by gaining a deeper understanding of patient experiences and concerns. The outcomes of our study align with findings from other internationally published studies (18–20), reinforcing the widespread prevalence of corticophobia and the need for targeted interventions to address it.

The combined score of the TOPICOP® questionnaire was approximately 44, with no significant difference between the two skin diseases or between the total score and domain scores; however, it was consistently higher in female patients than in male patients. This suggests that female patients may be more prone to corticophobia, and they may require additional support and education to overcome their fear. Interestingly, individuals that received biological therapy had slightly lower scores than those that did not. This may be due to the fact that patients on biological therapy usually have more severe forms of the disease and are more likely to be under the care of a specialist, who can provide more accurate and trustworthy information about the use of topical corticosteroids. Another explanation may be that most patients on biologics manage their disease well and do not need TCS as often or at all compared to the years before biologics, and so they do not feel insecure about using TCS. Among patients with AD, friends, acquaintances, family members, and the internet were the main sources of information, used as frequently as certified dermatologists. This highlights the need for healthcare providers to provide accurate and trustworthy information to their patients and address any misconceptions or fears they may have about the use of TCS. Patients with AD were also younger on average than those with PS. This may be due to the fact that AD is more common in children and young adults, who may be more susceptible

to corticophobia due to their lack of experience with the condition and its treatment, and their greater exposure to the internet with all the misinformation. Other studies have identified a relationship between lower education levels and higher levels of corticophobia (18-20). However, most likely because of limited statistical power, our study did not identify such a relationship.

The main advantage of our study was the use of the standardized TOPICOP® questionnaire, which made it comparable to existing and future studies. The main limitation was the small sample size.

## Conclusions

Our study revealed that corticophobia disproportionately affects women compared to men, with patients on biological therapy exhibiting slightly lower levels of corticophobia than those without. In addition, patients with AD were more likely to rely on friends, acquaintances, family members, and the internet as their primary sources of information compared to patients with PS. Understanding patients' experiences with their skin condition after corticosteroid use, their preferred information sources, and their fears is crucial for a more tailored approach to prevent corticophobia, ultimately promoting treatment compliance. The rejection of corticosteroids often stems from irrational fears and misinformation. Our study not only aligns with existing findings but also contributes additional insights to this important topic.

## Acknowledgement

The authors thank all fellow dermatologists that participated in the research for establishing the correct diagnosis and treatment of the disease according to its severity. The authors also thank Maja Zorko for arranging and preparing the data for statistical data processing.

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