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The Impact of Atopic Dermatitis and Corticophobia on the Quality of Family Life

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ABSTRACT The aim of the study was to investigate the impact of atopic dermatitis (AD) in children and corticophobia on the quality of family life. Children with AD and their parents were included in a cross-sectional study. The severity of AD was self-assessed using the Patient Oriented-Scoring of Atopic Dermatitis (PO-SCORAD) index, and the severity of corticophobia using the Topical Corticosteroid Phobia (TOPICOP) score, and the general impact of AD on family quality of life using the Family Dermatology Life Quality Index (FDLQI). We included 330 parents, mostly mothers (99.4%) and children with a median age of 3 years (interquartile range, IQR 1.5-5.0 years). The median values of the PO SCORAD index and TOPICOP score were: 19.1 (IQR 13.6-24.1) and 58.3 (IQR 41.7-72.2), respectively. The median FDQLI score was 12 (IQR 7-16). The influence of independent variables such as parental age, child's age, child's gender, family history of allergies, place of residence, parental education, associated allergic disease in the child, PO SCORAD, and the TOPICOP score on the FDLQI was analysed. The significant models were the age of the parents (protective factor), the PO SCORAD index, and the TOPICOP score, which together accounted for 26.1% of the variability of FDLQI. Concusion of the study is that AD in children, its severity, and the parent's fear of chronic corticosteroid treatment impair the quality of family life.

KEY WORDS: atopic dermatitis, children, family quality of life, corticophobia

INTRODUCTION

Atopic dermatitis (AD) is the most common inflammatory chronic skin disease occurring in childhood, with an estimated prevalence of approximately 20% (1). AD is part of the "atopy spectrum disorders" in a complex interplay with food allergies, asthma, and allergic rhinitis (2). It has a significant influence on the quality of life (QoL) for children and families due to emotional, social, and somatic stresses, including daily activities, sleep patterns, and incurred family expenses.

The QoL in terms of the overall satisfaction of children and parents is an essential component in planning therapy and long-term follow up of AD. A child's QoL is mostly affected due to difficulty in falling asleep and intermittent sleep, especially when experiencing eczema eruptions. These children experience reduced sleep efficiency on account of frequent waking, shorter total sleep time, difficulty in waking up, as well as daytime drowsiness and irritability (3). AD in children also affects the QoL for families. High levels of anxiety and depression have been identified in parents. Parents often experience exhaustion, frustration, helplessness, guilt, and instability in their marital and other family relationships. They also experience more absenteeism from work, stress concerning childcare, and challenges in disciplining children and limited social activities (4).

The main therapies for AD are emollients for preventing skin dryness and topical anti-inflammatory agents for skin inflammation, topical corticosteroids (TCS), and topical calcineurin inhibitors (TCI). The process of prescribing TCS requires counselling concerning the limitations of its use due to possible adverse events. According to the Food and Drug Administration, the most common adverse events are irritation, dryness, folliculitis, and certain rare conditions such as hypertrichosis, acneiform eruptions, hypopigmentation, skin atrophy, and perioral dermatitis (5). There are no precise data on the true incidence of the mentioned adverse events due to the heterogeneous monitoring methodology in multiple studies. However, several meta-analyses and guidelines reported long-term safety (>12 weeks) of low-to-mid potency TSC in pediatric patients with AD (6,7). Systemic side-effects were also described, along with a precaution for infants due to the larger surface area-to-body-weight ratio and the possibility of percutaneous absorption and suppression of the hypothalamic-pituitary-adrenal axis (HPA axis) (8,9). Despite rare case reports, meta-analyses reported a low rate of reversible HPA axis suppression using mid to low-potency TCS (6,7).

Table 1. Demographics of parents and children

Demographics of parents	N (%)
Gender	
Male	2 (0.6)
Female	328 (99.4)
Married	290 (87.9)
Divorced	6 (1.8)
Unmarried community	34 (10.3)
Place of living	
Urban	239 (72.4)
Rural	91 (27.6)
Education	
Elementary school	4 (1.2)
High school	142 (43)
Bachelor’s degree	55 (16.7)
Master´s degree or doctorate	129 (39.1)
Employed	239 (72.4)
Allergy in family	214 (64.8)
Demographics of children	
Gender	
Male	177 (53.6)
Female	153 (46.4)
Breastfeeding	283 (85.8)
Allergic disease	166 (50.3)
Asthma	34 (10.3)
Allergic rhinitis	45 (13.6)
Food allergy	158 (47.9)

While current guidelines recommend the use of TCS for routine treatment of flares over a period of 3-5 days, including a proactive treatment concept defined as a long-term, low-dose, anti-inflammatory treatment applied to previously affected areas of skin in children in a safe manner, there is still significant concern and fear in using TCS among patients, among parents of affected children, and among health care workers. These phenomena of excessive worry, anxiety, suspicion, and skepticism regarding corticosteroids for treatment purposes are known as corticophobia. The estimated prevalence of corticophobia ranges from 21.0% to 83.7% (10). Patients experiencing corticophobia show a low adherence to the use of TCS, resulting in omitting or starting therapy late, including early discontinuation or changing the dose of the prescribed therapy, which may result in poor disease control, more visits to the physician, increased health care costs, and consequently poorer QoL (11-13).

The aim of the current study was to investigate the impact of AD in children and corticophobia on the quality of family life.

PATIENTS AND METHODS

The study included 330 parents of children diagnosed with AD by a physician in the previous 12 months. The AD diagnosis was established in a clinical examination using Hanifin and Rajka criteria (14). We used medical records to identify and contact the parents of children with AD, who were examined once or several times (follow-up) in the outpatient clinic at the Pediatric Department of General Hospital “Dr Josip Bencevic”, Slavonski Brod, Croatia. The study received approval from the local ethics committee. Informed consent was obtained from all parents and children (when possible). We approached parents during scheduled visits or via email to respond to four types of questionnaires:

1. Demographical characteristics of patients and family members, i.e. urban or rural residence as defined by national administrative units by national legislation.

2. Parents self-assessed AD severity in the last three days using the Patient-Oriented SCORing of Atopic Dermatitis (PO SCORAD) index while adhering to detailed illustrated and oral instructions. An evaluation of the severity of AD was based on objective and subjective symptoms, i.e. the skin surface area affected by eczema, dryness of skin without eczema, evaluation of the severity of eczema (redness of skin affected by eczema, swelling, oozing or crusting, scratching, and thickening), pruritus, and sleep loss (15,16). The PO SCORAD index was calculated based on individual items: extent (100%), intensity (0-3), and subjective symptoms (0-20) [SCORAD (0-103) = extent (0-100/5) + intensity (0-18×3.5) + subjective items (0-20)]. Participants were allocated into three groups according to the self-estimated severity of AD, classified as mild AD (a PO SCORAD index of 0-25), moderate AD (a PO SCORAD index of 26-50), and severe AD (a PO SCORAD index of 51-103) (17).

3. The Topical Corticosteroid Phobia (TOPICOP©) scale was used to assess the fear of using TCS among parents of children with AD. The questionnaire comprised 12 items, covering three important dimensions in terms of "knowledge and beliefs" (6 items), "fears/worries" (3 items) and "behavior" (3 items). Four response choices were offered, from "totally disagree" to "totally agree", with points attributed to each answer (0, 1, 2 or 3), and a possible maximum score of 36. Higher values corresponded to a more severe phobia. Individual scores for all patients who responded to at least half of the items, plus one in an additional dimension, were calculated by summing responses to items and then dividing the obtained value by the number of items completed, yielding a maximum score of 36 and expressed as a percentage. The mean score for a dimension was the sum of individual scores divided by the number of respondents. TOPICOP scores ranged from 0 to 100 (18,19).

4. The Family Dermatology Life Quality Index (FDLQI) was used to estimate the impact of AD in children on the QoL for parents. The questionnaire comprised 10 questions on the consequences of the child's skin disease on different aspects of the parent's QoL in the last month such as emotional distress, physical well-being, relationships, reactions of other people, social life, free time, time spent looking after the child, extra housework, work or education, and expenditure. Each question could be answered by choosing 1 of the 4 possible answers, with a score ranging from 0 to 3. The maximum score was 30

Table 2. Impact of children's atopic dermatitis on the Family Dermatology Life Quality Index (FDLQI)

Over the last month how much…	Number (%) participants				
	0	1	2	3	Total
emotional distress have you experienced due to your child's skin disease (e.g. worry, depression, embarrassment, frustration)?	57 (17.3)	102 (30.9)	94 (28.5)	77 (23.3)	330 (100)
has your child's skin disease affected your physical well-being (e.g. tiredness, exhaustion, contribution to poor health, sleep/rest disturbance)?	65 (19.7)	106 (32.1)	94 (28.5)	65 (19.7)	330 (100)
has your child's skin disease affected your personal relationships with him/her or with other people?	158 (47.9)	81 (24.5)	48 (14.5)	43 (13)	330 (100)
have you been having problems with other peoples' reactions due to your child's skin disease (e.g. bullying, staring, need to explain to others about his/her skin problem)?	184 (55.8)	91 (27.6)	31 (9.4)	24 (7.3)	330 (100)
child's skin disease affected your social life (e.g. going out, visiting or inviting people, attending social gatherings)?	222 (67.3)	54 (16.4)	26 (7.9)	28 (8.5)	330 (100)
has your child's skin disease affected your recreation/leisure activities (e.g. holidays, personal hobbies, gym, sports, swimming, watching TV)?	206 (62.4)	65 (19.7)	27 (8.2)	32 (9.7)	330 (100)
time have you spent on looking after your child (e.g. putting on creams, giving medicines or looking after their skin)?	7 (2.1)	55 (16.7)	136 (41.2)	132 (40)	330 (100)
extra housework have you had to do because of your child's skin disease (e.g. cleaning, vacuuming, washing, cooking)?	49 (14.8)	80 (24.2)	99 (30)	102 (30.9)	330 (100)
has your child's skin disease affected your job/study (e.g. need to take time off, not able to work, decrease in the number of hours worked, having problems with people at work)?	205 (62.1)	68 (20.6)	36 (10.9)	21 (6.4)	330 (100)
has your child's skin disease increased your routine household expenditure (e.g.travel costs, buying special products, creams, cosmetics)?	36 (11)	73 (22)	115 (35)	106 (32)	330 (100)

Table 3. Family Dermatology Life Quality Index (FDLQI) in relation to the characteristics of parents and children

	Median (IQR)	P
Place of living		
Urban	11 (7-16)	0.53
Rural	12 (8-16)	
Education		
Elementary/High School	12 (7-16)	0.75
Bachelor	10 (7-16)	
Graduate/Postgraduate	11 (7-16)	
Gender of the child		
Male	12 (7-17)	0.19
Female	10 (6-16)	
Allergic comorbidity		
Asthma		
No	11 (7-16)	0.39
Yes	12 (10-17)	
Allergic rhinitis		
No	12 (7-16)	0,73
Yes	12 (7-18)	
Food allergy		
No	11 (6-15)	**0.02**
Yes	13 (7-18)	
Total score FDLQI[1]	12 (7-16)	

[1]FDQLI-Family Dermatology Life Quality Index

points, whereas the minimum was 0 points. The higher the score, the lower the parent's QoL (20). We used the Croatian version of the FDLQI (21).

Statistical methods

Categorical data are presented as absolute and relative frequencies. The normality of the distribution of numerical variables was tested by the Shapiro-Wilk test. Numerical data were described by the median and limits of the interquartile range. Differences in numerical variables between the two independent groups were tested, due to deviations from normality, using the Mann-Whitney U test, and between three and more than three independent groups using the Kruskal-Wallis's test. The correlation of numerical variables was evaluated based on the deviation from the normal distribution using Spearman's correlation coefficient ρ. All P values were two-sided. The significance level was set to $\alpha = 0.05$. MedCalc Statistical Software version 19.1.7 (MedCalc Software Ltd, Ostend, Belgium; https://www.medcalc.org; 2020) and SPSS version 16.0 (SPSS Inc., Chicago, IL, USA) were used for statistical analysis.

Table 4. Correlation of FDLQI1 with age of parents, children, severity score and TOPICOP3

	Spearman's correlation coefficient (Rho) FDLQI[1]
Age of parents	-0.123 (0.03)
Age of children	-0.043 (0.44)
PO SCORAD[2] total score	0.449 (<0.001)
TOPICOP[3] total score	0.247 (<0.001)
Domains scores:	
Knowledge and beliefs	0,301 (<0.001)
Fear	0,170 (0.002)
Behavior	0,064 (0.25)

[1]FDQLI-Family Dermatology Life Quality Index; [2]PO SCORAD-Patient- Oriented SCORring of Atopic Dermatitis; [3]TOPICOP- The Topical Corticosteroid Phobia

RESULTS

Demographic data

Data on parents

The study included 330 parents, predominantly mothers (99.4%). The median age of the parents was 33 years (interquartile range, IQR 30-37 years), ranging from 18 to 49 years. In all, 290 parents (87.9%) were married and 239 (72.4%) lived in urban areas. In terms of the level of education, the majority of participants had a high school or university education. A total of 239 (72.4%) parents were currently employed (Table 1).

Data on children

The median age of children was 3 years (IQR 1.5-5.0 years), ranging from three weeks to 18 years. The first symptoms of AD occurred in infancy (median 3 months, IQR 2-6). According to gender, there was a slight male predominance (177 male children or 53.6% of the total). AD treatment included moisturizer for 294 children (89%), oil baths for 131 (39.7%), TCS for 166 (50.3%), and wet wrap for 74 (22.4%). The parents of 166 children (50.3%) reported the presence of another allergic disease. Food allergies were the most prevalent allergic comorbidity, present in 158 children (47.9%). The most prevalent cause of food allergies was eggs, in 83 children (52.5%). More than two-thirds of the children had a positive family history of allergic diseases. The most common

Table 5. Influence of independent variables on FDLQI[1] (multivariable regression (stepwise))

	ß	$r_{partial}$	$r_{semipartial}$	P	R^2	R^2_{adj}
FDLQI[1]						
Constant	6.01				0.261	0.254
Age of parents	-0.14	-0.136	0.118	0.01		
PO SCORAD[2]	0.37	0.459	0.444	<0.001		
TOPICOP[3]	0.07	0.246	0.218	<0.001		

[1] FDQLI-Family Dermatology Life Quality Index
[2] PO SCORAD-Patient- Oriented SCORring of Atopic Dermatitis
[3] TOPICOP- The Topical Corticosteroid Phobia
ß – regression coefficient

allergic diseases in the family were allergic rhinitis, i.e., in 106 children (32.1%), followed by atopic dermatitis in 99 (30%), asthma in 68 (20.6%), and food allergies in 61 children (18.5%) (Table 1).

PO SCORAD

According to estimates by parents, the median extent of affected skin was 12% (IQR 6-12%, min-max 0-100%). Only 6 children (1.8%) had 100% of their skin affected. Dryness of the skin was observed in 292 children (88.4%). The intensity of skin lesions varied, with the most common being erythema in 304 children (92.12%) and excoriation in 272 (82.42%), with edema and oozing observed in the half of the patients. The median for pruritus was 7 (IQR 5-8, min-max 0-10), while the median for sleep loss was 5 (IQR 2-8, min-max 0-10). The median PO SCORAD index was 19.1 (IQR 13.6-24.1, min-max 0-49). In all, 263 children (79.7%) had a mild PO SCORAD index and 67 (20.3%) had a moderate index.

TOPICOP

Worries and attitudes about TCS were assessed using 12 claims grouped into three domains of TOPICOP. The internal consistency of Cronbach's alpha was 0.855. Medians and interquartile ranges of each domain score were as follows: knowledge and beliefs 42.8% (IQR 28.6-61.9), worry 75.0% (IQR 58.3-91.6), and behavior 77.8% (IQR 44.4-100.00). The total median TOPICOP score was 58.3 (IQR 41.7-72.2).

FDLQI

The internal consistency of Cronbach's alpha was 0.855. FDLQI score was most affected by the time spent on caring for the child's skin, with a positive answer among 323 participants (97.9%), a positive answer for increased general household expenditures among 294 (89%), and a positive answer for extra housework among 281 participants (85.2%) (Table 2). The median across the entire scale was 12 (IQR 7-16).

There was no significant difference in the FDLQI score in terms of place of residence, level of education, gender of the child, and whether the child had asthma or allergic rhinitis as a comorbidity. The FDLQI score was significantly worse in situations where children were allergic to food, with a median of 13 (IQR 7-18) (Mann-Whitney U test, P = 0.02) (Table 3).

Spearman's correlation coefficient was used to assess the relationship between the FDLQI and the ages of parents and children, as well as PO SCORAD and beliefs or fears about TCS use. We found a negative and significant correlation of parental age with FDLQI (Rho = -0.123), though somewhat statistically weaker. Older parents rated the FDLQI higher younger respondents, though the relationship was weak. The age of a child with AD did not affect the quality of life for families (Table 4). The strongest association with the FDLQI score was the PO SCORAD. FDLQI score was lower among children with more severe AD (Rho = 0.449). Greater concerns and fears about TCS use indicate a lower FDLQI sores (Table 4).

The influence of independent variables such as parental age, child's age, child's gender, family history of allergy, place of residence, parental education, child's gender, associated allergic disease in a child, PO SCORAD, and TOPICOP on the FDLQI were analysed using multivariate linear regression. The significant models incorporated the parents' age (as a protective factor), PO SCORAD and TOPICOP, which together explained 26.1% of the variability in FDLQI scores. The link between PO SCORAD and FDLQI was stronger when the influence of other variables in the model was adjusted ($r_{partial}$ = 0.459) than the link between other variables from the model (Table 5).

DISCUSSION

The chronic course and severe symptoms of AD in childhood demand the entire family's involvement in caring for the child. This study assessed the impact of AD in children in terms of parental concerns in using TCS on FDLQI score.

In the current study, emollients and TCS were the most applied therapy for skin dryness caused by eczema flares. For more than 50 years, TCS have been used in treating AD and have shown to provide a potent anti-inflammatory effect. Despite the most frequently reported local and sporadically systemic adverse effects, there great caution is associated with using TCS and some patients express great fear. This is known as corticophobia. Participants in the current study expressed increased fear of TCS with a total TOPICOP score of 58.3 (IQR 41.7-72.2). The higher score was linked to the fear domain, i.e. 75.0% (IQR 58.3-91.6), whereas the lowest score was attributed to beliefs or attitudes, i.e. 42.8% (IQR 28.6-61.9). Published studies reported a lower total and domains score (22,23). In comparison with the results of a prospective, multicentre study conducted in 15 countries, our total TOPICOP score was higher than the total score of the study, i.e. 44.7% (20). Total and domain scores were different among countries (20). The divergence among domain scores was not always in parallel, suggesting different origins of TCS phobia for each country. Our results of the total TOPICOP score were among the highest total scores, for instance, as in countries like Poland (58.4%), Ukraine (55.1%), and Taiwan (52.2%) (20). Further analyses of the individual domain scores revealed a higher score for the fear (75.0%) and behaviour domain (77.8%) in our population than in Ukraine (70.0% and 70.2%, respectively) and Poland (69.3% and 71.9%, respectively), which were at the top of the investigated countries (20). Scores for the knowledge domain were lower (42.8%) than in other domains, although ranking among the higher comparable countries such as Poland (45.1%), Belgium (43.8%), and Taiwan (41.0%) (20). Systematic reviews of the literature cite several possible factors associated with a higher fear of application of TCS, such as non-adherence to a systemic education program for patients, the tendency towards traditional and herbal medicine, TCS phobia among health care workers (pediatricians, general practitioners, nurses, pharmacists), and a gap in interprofessional practice within the health care system (24). The origins of corticophobia among parents are complex and have a negative effect on TCS adherence (12, 25). Sources used by patients to obtain information about TCS include health care professionals, friends and relatives, broadcast media, print media, and the Internet, but the main source of such information is health care professionals (10,26,27). The Internet, relatives and friends are, as expected, a source of information about herbal, natural, and traditional preparations, leading to a distancing from TCS. However, some studies reported TCS phobia among health care workers, which may also have a negative effect on TCS adherence (10). Health care nurses expressed a similar level of TCS phobia as parents, while medical doctors, depending on their specialization, reported a lower level of TCS phobia (11).

Some researchers investigated the risk factor and possible interventions for reducing TCS phobia. Nonetheless, patient education about the specific therapy significantly decreased TCS phobia among patients with AD (23,28). Some studies reported an improved total TOPICOP score after educating the parents, but only the knowledge domain showed a lower score, with no improvement in the fear domain score (21,28). Kojima *et al.* reported that girls with AD, a children's paternal history of AD, and frequently changing clinics were predictive factors, whereas AD severity did not correlate with steroid phobia (29).

In applying FDLQI, we observed that AD impacted the QoL for families. The most significant impact on the QoL for caregivers was time spent on skin care for the child. The second impact was increased routine household expenditure, such as extra housework. In the current study, a high proportion of children had food and respiratory allergic diseases. Food allergy significantly decreased QoL, while respiratory allergy did not have the same impact. The daily use of emollient therapy (non-prescription medical products), preparing hypoallergenic meals and controlling the home environment, increased levels of housework, and a higher household budget were noticeable. Moreover, self-reported emotional distress and poor physical well-being among parents was present, namely, AD decreased the QoL in the emotional and somatic domain. Relationships with family members and other people had become disturbed. Reactions of other people to the skin disease left a bad impression on the parents, especially regarding the need to provide burdensome explanations. Published studies also reported a similar impact of AD on total FDLQI and FDLQI subdomains such as time spent looking after the child, extra housework, and expenditure (21,30,31).

Previous studies identified a difference in the FDLQI score between mothers and fathers (31). In the current study, 99.4% of participants were mothers, so we were not able to perform a similar analysis. We investigated whether factors such as parental age, the child's gender, associated child allergy disease, PO SCORAD, family history of atopy, place of living and TOPICOP were somehow linked to the FDLQI score. A significant identified association to the model was the age of parents (protective), PO SCORAD, and the total TOPICOP score. Previous studies also identified a correlation between PO SCORAD and QoL (21,32). The severity of the disease, measured in terms of SCORAD, PO-SCORAD, sleep disturbance, and itching, was the most investigated and a strongly associated factor with impairment of QoL for families (21,32). The QoL for children was also strongly influenced in terms of markers of AD severity, like itching, sleep disturbance, and age (33-36). The observed association between the FDLQI score and TCS phobia in our study highlights that the fear of chronic therapy associated with possible adverse effects negatively impacts the emotional domain related to the QoL. To the best of our knowledge, this association has been reported for the first time. Some authors have reported the negative influence of parents, such as perceived stress and QoL for families (21).

CONCLUSION

AD and TCS phobia negatively affect the FDLQI score. Thus, for physicians, this complex situation requires a long, patient, stepwise, and individual approach in education with building trust with parents regarding therapy.

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