

ORIGINAL ARTICLE

Illness perceptions and quality of life in families with child with atopic dermatitis



V. Siafaka^{a,*}, A. Zioga^b, T. Evrenoglou^c, D. Mavridis^d, S. Tsabouri^e

^a Department of Speech and Language Therapy, School of Health Sciences, University of Ioannina, Ioannina, Greece

^b Department of Pediatrics, University Hospital of Ioannina, Ioannina, Greece

^c Faculty of Medicine, Paris Descartes University, Paris, France

^d Department of Primary Education, University of Ioannina, Ioannina, Greece

^e Faculty of Medicine, School of Health Sciences, University of Ioannina, Ioannina, Greece

Received 23 February 2020; accepted 20 March 2020 Available online 20 May 2020

KEYWORDS

Atopic dermatitis; Children; Illness perceptions; Family quality of life; Disease severity; Chronicity

Abstract

Objective: To assess the Ouality of Life (OoL) of children with Atopic Dermatitis (AD) and their families and the impact of the mothers' illness perceptions on the family OoL. Materials and methods: Seventy-five children with AD (54 infants and 21 children) and their mothers participated in the study. The following questionnaires were administrated: 1. Brief Illness Perception Questionnaire (Brief IPQ); 2. Infant's Dermatitis Quality of Life Index (IDQOL); 3. Children's Dermatology Life Quality Index (CDLQI); 4. Dermatitis Family Impact Questionnaire (DFIQ) and 5. The Severity Scoring of Atopic Dermatitis (SCORAD). *Results*: Atopic dermatitis had a moderate impact on the QoL of the infants (6.67 ± 5.30) , children (7.86 \pm 7.19) and their families (9.42 \pm 7.03). The DFIQ was associated with certain dimensions of the Brief IPQ, specifically, with Illness Identity (greater symptom burden) (r = 0.615, p = 0.000), beliefs about the *Consequences* of the illness (r = 0.542, p = 0.000), the Concerns (r = 0.421, p = 0.000) and the Emotional Representations (r = 0.510, p = 0.000). Correlation was demonstrated between IDQOL and DFIQ (r = 0.662, p = 0.000) and between CDLQI and DFIQ (r = 0.832, p = 0.000), and a weaker correlation between SCORAD and DFIQ (r = 0.255, p = 0.035). The chronicity of the AD showed negative association with DFIQ (p < 0.001). Conclusions: The QoL of families with a child with AD is associated with the mother's illness perceptions about AD, the children's QoL and with both the severity and the chronicity of the disease. Therefore, clinicians should pay attention not only to the clinical characteristics of the children, but also to the parents' beliefs and emotions, to improve the family QoL. © 2020 SEICAP. Published by Elsevier España, S.L.U. All rights reserved.

* Corresponding author. E-mail addresses: siafaka@uoi.gr, vsiafaka@gmail.com (V. Siafaka).

https://doi.org/10.1016/j.aller.2020.03.003

0301-0546/© 2020 SEICAP. Published by Elsevier España, S.L.U. All rights reserved.

Introduction

Atopic dermatitis (AD) is a chronic, inflammatory, relapsing skin disease. Its severity ranges widely and it may present frequent exacerbations.¹ Up to 20% of children are estimated to be affected by AD, but its epidemiology is difficult to be assessed because of lack of uniformity in the definitions used and absence of a universally accepted approach. Its prevalence is constantly increasing, especially in urban areas, and association has been identified with the western lifestyle.² Both genetic and environmental factors appear to contribute to the pathophysiology of AD.^{1,2} The clinical manifestations of AD include itching, skin pain, poor sleep guality, low self-confidence and social distress. These symptoms may constitute a considerable burden, often unrecognized and underestimated, not only for the affected child, but for the whole family unit, with profound effects on the quality of life (QoL) of both the child and other family members.^{3,4}

Apart from the characteristics of the illness, a variety of psychosocial factors can affect the QoL of families with a child suffering from AD, including parenting and relationship characteristics (e.g., parental stress, parental locus of control, cohesion) and the family life-style.^{5,6} The parental perceptions about the chronic illness of a child may have a significant impact on the QoL of the whole family. Studies on families with a child who has a chronic illness have demonstrated that the Common Sense Model (CSM)^{7,8} provides a dynamic theoretical framework for understanding the process by which a parent/caregiver develops cognitive and emotional representations, which then lead to the adoption of specific coping strategies.^{9,10}

According to the CSM, the beliefs of the patients and their parents/caregivers about a disease and its treatment determine the ways in which they manage and adapt to the new situation created by the diagnosis. Patients and their caregivers modify their beliefs, feelings and behaviors in ways that may affect the illness outcome, their compliance with treatment and their QoL.^{11,12} Individuals build cognitive and emotional representations of a disease through the information they receive, previous personal medical experiences and cultural influences. Concerning AD in infants and children, there is a lack of studies investigating the parents' illness perceptions and their effects on the QoL of the family. Previous studies have focused mainly on the parenting behavior and parent-child relationship.^{12–14}

Therefore, the present study aimed at estimating the QoL of children with AD and their families and the impact of the mothers' illness perceptions about AD on the family QoL. The choice of mothers as the respondents in the study was based on the fact that they were the main caregivers of the study children with AD. The gender of the parent who estimates the QoL of the child and the family has been shown not to affect the results substantially, because family members tend to influence each other's illness perceptions and to present similar responses, reflecting shared experiences, information and social-emotional environment.^{12,13}

Material and methods

Participants

The sample consisted of 75 children with AD and their mothers, who provided a written informed consent to participate in the study. The diagnosis of AD had been made according to the criteria of Hanifin and Rajka.¹⁵ One of the major criteria of AD is chronicity, a term used in the present study, which is defined as duration of at least four weeks of symptoms in the course of six months of monitoring.¹⁶ The infants and children in the study were recruited during follow-up in an outpatient hospital clinic. Inclusion criteria were: a confirmed diagnosis of AD in the child, absence of other systemic illness, ability of the mother to understand and complete the questionnaires, and provision of the mother's written informed consent. No participant withdrew from the study.

Procedure and study instruments

The study was conducted in accordance with Ethical Standards as formulated in the World Medical Association Helsinki Declaration (2002) and an IRB statement that IRB approval was unnecessary was received. The study was cross-sectional and questionnaire based. The following questionnaires were used:

- 1. The Brief Illness Perception Questionnaire (Brief IPQ). This guestionnaire provides a rapid guantitative assessment of the nature and strength of the individual's perceptions concerning nine dimensions. Specifically, five items cover cognitive representations: illness identity (perception of symptoms related to the illness), timeline (perception regarding the duration of the illness), consequences, personal control (refers to the concept of control of the disease by the individual), treatment control (refers to the perception of the effectiveness of treatment); two items cover emotional representations: concerns and emotions (the extent to which the illness results in symptoms of anxiety and depression) and one item is on illness comprehensibility (coherence) and refers to the degree of understanding of the illness by the individual. Responses are given on a scale of 0-10, and higher values are indicative of a stronger perception. The last item, on the perceived cause of illness, is an open-ended question requiring the participants to rank the three most important causal factors. The questionnaire completed by the mother, and minor changes were made in the wording of the items in order to assess the mothers' perceptions about AD specifically.¹⁷
- 2. Infant's Dermatitis Quality of Life Index (IDQOL). It is designed to be completed by parents to assess the impact of AD on the QoL of infants aged 0-4 years. It consists of 10 items covering the symptoms of AD, time taken to get to sleep, total time disturbed, playing or swimming, enjoying family's activities, mealtime, problems with treatment, uncomfortable dressing and problems at

bath time. The answers are given on a Likert scale of 0-3 and the total score ranges from 0 to 30, with higher scores indicating more marked effects on QoL. The Greek language version of the questionnaire was used.¹⁸

- 3. Children's Dermatology Life Quality Index (CDLQI). It is designed for children aged from 4 to 16 years and consists of 10 questions regarding the experience of the child in different aspects of life affected by AD. There is also a Cartoon version in which each question is illustrated by a cartoon based on the theme of the question. The CDLQI can be analyzed under six headings: symptoms and feelings (questions 1 and 2); leisure (questions 4, 5 and 6); school or holidays (guestion 7); personal relationships (questions 3 and 8); sleep (question 9); and treatment (question 10). Each question is scored on a four-point Likert scale, and the total score ranges from 0 to 30 with the following categorization: 0-1: no effect, 2-6: small effect, 7-12: moderate effect, 13-18: very large effect and 19-30: extremely large effect. The questionnaire was completed by the children, assisted by the interviewers, who gave the instructions and read the questions aloud when necessary. The Greek language version of the questionnaire was used. 19,20
- 4. Dermatitis Family Impact Questionnaire (DFIQ). This is a disease-specific questionnaire designed to assess the impact of a child's AD on the QoL of the family.²¹ The questionnaire consists of 10 items concerning the effects of the child's disease on different domains of family life, including extra housework, emotional distress, physical fatigue, other peoples' reactions, social life, leisure activities, relationships, daily expenditure, time spent looking after the child, work or education. Each question is answered in a four-point Likert scale (0–3) and the total score ranges from 0 (=no impact) to 30 (=maximum effect).
- 5. Severity Scoring of Atopic Dermatitis (SCORAD). It is a clinical tool for assessing the severity of AD by physicians (pediatricians, allergists). In the present study for each child two pediatricians completed the SCO-RAD. It is composed of three parts: 1. The extent of involvement uses the rule of nines; 2. Six intensity items (erythema, oozing/crusting, edema/papulation, excoriation, lichenification and dryness); and c. subjective symptoms (daily pruritus and sleep loss) in the last three days/nights. A SCORAD of below 20 indicates mild AD (a few inflammatory lesions); between 20 and 40 is classified as moderate AD (intense inflammation and pruritus); and above 40 indicates severe AD (extensive, inflammatory). The maximum SCORAD score is 103.²²

Statistical analysis

Descriptive analysis was performed of the sociodemographic characteristics of the family and the demographic and clinical characteristics of the children. Mean values and standard deviation were reported for continuous variables and frequencies/proportions for categorical variables. Total mean scores for each participant were computed and were treated as continuous variables. For the Brief IPQ questionnaire, each dimension was treated as a continuous variable. The distribution of total scores was examined using the Shapiro–Wilk (S-W) and Kolmogorov-Smirnov (K-S) tests. When variables appeared to be normally distributed, associations were examined using Pearson's bivariate correlation coefficient and when the assumption of normality was questioned, the Spearman correlation coefficient was used. Correlations smaller than 0.3 denote a weak, clinically unimportant correlation; between 0.3 and 0.7 moderate correlation; and larger than 0.7 denote a strong correlation. Pearson's bivariate correlation coefficient was used to explore the relationship between IDQOL, CDLQI, DFIQ and SCORAD. To compare means or distributions across two groups, the t-test was used when normality was questioned. All statistical analyses were performed using the SPSS v.23.

Results

Characteristics of the participants

The sample consisted of 75 children with AD, specifically 54 infants, in the age range 3–42 months, and 21 older children, in the age range 4.4–13.0 years, and their mothers. The demographic characteristics of the study population are shown in Table 1. The majority of mothers were married

Table 1	Sociodemographic characteristics of the mothers
of childre	n with atopic dermatitis (N = 75).

Mother's age (years) Mean \pm SD (range)	34.19±4.66 (25-39)
Family status (N, %)	
Married	70 (93.3)
Divorced	5 (6.7)
Mother's Educational level (N,%)	
Primary school	1 (1.3)
High School	27 (36)
University degree	47 (62.6)
Mother's profession (N,%)	
Unemployed	16 (21.3)
Domestic work	14 (18.6)
Farmer	3 (4)
Private Employee	21 (28)
Civil Servant	13 (17.4)
Freelancer	5 (6.7)
Other	3 (4)
Residence (N,%)	
Apartment	32 (42.7)
House	41 (54.7)
Unspecified	2 (2.6)
Type of surroundings (N,%)	
Village	32 (42.7)
City	43 (57.3)
Smoking in the house (N,%)	
Yes	7 (9.3)
No	68 (90.7)

SD: Standard Deviation.

	Infants (<i>N</i> = 54)	Children (N=21)	Total (<i>N</i> = 75)
Age (months) (Mean \pm SD)	11.16 ± 9.35	89.38 ± 0.94	33.06±39.64
(median, range)	7 (3-42)	83 (53-157)	(3-157)
Gender (N, %)			
Воу	36 (66.7)	12 (57.1)	48 (64)
Girl	18 (33.3)	9 (42.8)	27(36)
Positive skin prick test (N, %)			
Yes	25 (46.3)	11 (52.3)	40 (53.3)
No	29 (53.7)	10 47.6)	35 (46.7)
Family history of allergies (N, 9	(6)		
Yes	37 (68.5)	14 (66.6)	51 (68)
No	17 (31.5)	7 (33.3)	24 (32)
Comorbidity (N, %)	· · ·	· · ·	· · /
Allergic Rhinitis	7 (12.9)	11 (52.3)	18 (24)
Food allergy	26 (48.1)	2 (9.52)	28 (37.3)
Asthma	3 (5.5)	3 (14.2)	6 (8)
	5 (5.5)	3 (1 112)	0 (0)
Chronicity (N, %) Yes	32	11	43 (57.3)
No	22	10	32 (42.7)
	<u>LL</u>	10	52 (72.7)
SCORAD (N, %)		2 (0 5)	((0)
Mild (1-15)	4 (7.4)	2 (9.5)	6 (8)
Moderate (16-40)	24 (44.4)	6 (28.6)	30 (40)
Severe (41–103)	26 (48.2)	13 (61.9)	39 (52)
Mean \pm SD	$\textbf{42.96} \pm \textbf{22.04}$	$\textbf{46.86} \pm \textbf{23.66}$	44.05 ± 22.41
Symptoms (N, %)			
Itching	46 (85.1)	20 (95.2)	66 (88)
Redness	51 (94.4)	21 (100)	72 (96)
Pain	15 (27.8)	6 (28.5)	21 (28)
Scratching	49 (90.7)	20 (95.2)	69 (92)
Blisters	16 (29.6)	7 (33.3)	23 (30.7)
Abrasions	34 (62.9)	16 (76.1)	50 (66.7)
Oozing	23 (42.6)	8 (38)	31 (41.3)
Hemorrhage	21 (38.8)	8 (38)	29 (38.7)
Dry skin	51 (94.4)	21 (100)	72 (96)
Rash	46 (85.1)	19 (90.4)	65 (86.7)
Skin thickening	14 (25.9)	8 (38.0)	22 (29.3)
Exfoliation	27 (50)	12 (57.1)	39 (52)

 Table 2
 Demographic and clinical characteristics of the children with atopic dermatitis.

SD: Standard Deviation, SCORAD: Severity Scoring of Atopic Dermatitis.

(93.3%), university graduates (62.6%), employees (78.7%) and city residents (57.3%). The clinical characteristics of the study children are shown in Table 2. The majority of the children were boys (64%), and most had a family history of allergies (68%). A positive skin prick test, according to the European Academy of Allergy and Clinical Immunology (EAACI) (i.e., wheal diameter \geq 3 mm), was recorded in 53.3% of the children.²³ The most common symptoms were redness, scratching and dry skin. Regarding disease severity, the total mean score of SCORAD was 42.96 ± 22.04 for the infants and 46.86 ± 23.66 for the children. Additionally, no significant difference in the distribution of SCORAD scores was found between boys and girls or between the two age groups.

Illness perceptions

Table 3 presents the mean scores on the dimensions of the Brief IPQ. Perceptions about the identity of the disease $(5.23\pm2.70, \text{ median 5})$ and about the possibility of serious consequences were low $(4.96\pm2.56, \text{ median 5})$, perceptions of worry and emotional effects were slightly elevated $(6.41\pm2.71, \text{ median 7} \text{ and } 6.08\pm3.06, \text{ median 7}$, respectively), while the strongest perception was that of controllability of the disease through treatment $(7.12\pm2.21, \text{ median 8})$. Regarding the mothers' beliefs about the causes of AD, inheritance (70.7%) and other external factors (64%) were included as the perceived main causes, while 28% of the mothers ranked internal factors,

Table 3	Scores of the mothers o	f children with AD on the Brief Illness	Perception Questionnaire (Brief IPQ).
---------	-------------------------	---	---------------------------------------

Brief IPQ – items	Mean \pm SD	Median	Interquartile Range (25,75)
Identity (symptoms)	5.23±2.7	5.0	4.5 (3.0, 7.5)
Consequences	$\textbf{4.96} \pm \textbf{2.56}$	5.0	4.0 (3.0, 7.0)
Timeline	5.71 ± 2.38	5.0	4.5 (3.5, 8.0)
Personal controllability	6.42 ± 2.54	7.0	4.0 (4.0, 8.0)
Treatment effectiveness	7.12±2.21	8.0	3.0 (6.0, 9.0)
Comprehensibility	6.84±2.3	7.0	4.0 (5.0, 9.0)
Illness concerns	6.41±2.71	7.0	3.0 (5.0, 8.0)
Emotional representations	$\textbf{6.08} \pm \textbf{3.06}$	7.0	6.00 (3.0, 9.0)
Cause (frequencies, %)*			
Heredity	55 (70.7%)		
External factors	48 (64%)		
Diet	22 (29.3%)		
Internal factors	21 (28%)		

* Refers to perceived cause as reported by mothers.

SD: Standard Deviation.

such as stress and personality traits, among the most important causal factors.

Quality of life measurements

For the infants, the total mean score of IDQOL was 6.67 ± 5.30 and the highest scores were observed in ''total time disturbed'' (0.93 ± 1.11) and in ''mood'' (0.80 ± 0.91) . For the older children, the total mean score on CDLQI was 7.86 ± 7.19 , and the three subscales of CDLQI on which the highest scores were reported were ''symptoms and feelings'' (1.30 ± 0.92) , ''problem with sleep'' (0.90 ± 0.99) and ''problems caused by the treatment'' (0.86 ± 0.79) .

Regarding the effects of the child's AD on the QoL of the family, the total mean score on DFIQ was 9.42 ± 7.03 , corresponding to a moderate effect. The AD had the highest impact on "family's expenditure" (1.19 ± 0.99), including costs related to treatment or clothes, on "helping with treatment on main caregiver's life" (1.08 ± 0.98) and on "housework" (1.03 ± 1.05) (e.g., washing and cleaning).

Quality of life associations

No statistically significant correlation was demonstrated between the demographic or clinical characteristics of the sample and the IDQOL score. Regarding CDLQI, the only correlation observed was between the total CDLQI score and SCORAD (r = 0.448, p < 0.05).

Concerning the QoL of the family, associations were demonstrated between the scores on DFIQ and certain dimensions of the Brief IPQ. Specifically, the total mean score on DFIQ was correlated with *illness identity* (high symptom burden) (r = 0.615, p = 0.000), belief about the *consequences* of the illness on various domains of the child's life (r = 0.542, p = 0.000), *concerns* about the illness (r = 0.421, p = 0.000), and *emotional representations*, which include negative reactions such as fear, anger and distress (r = 0.512, p = 0.000) (Table 4).

Table 4Correlations between DFIQ and IDQOL, CDLQI,SCORAD and Brief-IPQ.

	DFIQ
IDQOL	.662***
CDLQI	.832 ***
Brief-IPQ_	
Identity (symptoms)	.615 ***
Consequences	.542***
Timeline	NS
Personal Controllability	NS
Treatment effectiveness	NS
Illness Concerns	.421***
Comprehensibility	NS
Emotional representations	.512***
Cause	NS
SCORAD	.255*

IDQL: Infant's Dermatitis Quality of Life Index, CDLQI: Children Dermatology Life Quality Index, DFIQ: Dermatitis Family Impact Questionnaire, Brief – IPQ: Brief – Illness Perception Questionnaire.

Values are the Spearman's correlation coefficients.

^{***} *p* < .001.

* p < .05.

In addition, statistically significant correlations were observed between IDQOL and DFIQ (r=0.662, p=0.000) and between CDLQI and DFIQ (r=0.832, p=0.000). Correlation between SCORAD and DFIQ, although statistically significant, was weak (r=0.255, p=0.035) (Table 4). The association of the total score on DFIQ (DFIQ_{total}) with *chronicity* was investigated, using the non-parametric Mann–Whitney U statistic because the normality assumption was not met (S-W: $p_{no} < 0.001$, $p_{yes} = 0.226$, K-M: $p_{no} < 0.001$, $p_{yes} = 0.22$) (Fig. 1). Regarding chronicity, the results indicated that the QoL of families with a child suffering from AD for a longer period is more negatively affected (p < 0.001).

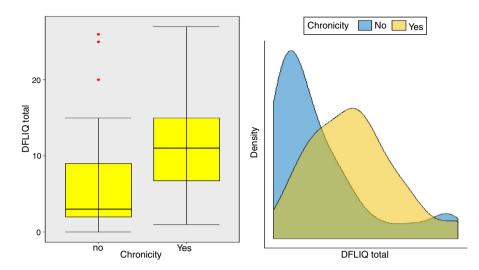


Figure 1 Distribution of scores on the Dermatitis Family Impact Questionnaire (DFLIQ) according to the chronicity of the atopic dermatitis in the child (N = 75). Boxplots and density plots for median comparisons and normality assumption; the dots in the boxplot indicate three outliers.

Discussion

The present study assessed the QoL of the children with AD and their families and the impact of the mothers' illness perceptions about AD on the family QoL, a subject that has not been adequately studied. The results showed that AD has a moderate impact on the QoL of infants and children, and on the family unit. Specifically, from the IDQOL scores it was observed that mothers report that AD affects their infants' mood (irritability, crying, etc.) and the time that they are disturbed. Mothers are involved in both practical and emotional terms in the management of AD and are able to identify and, possibly overestimate, even minor changes in the mood of their children.²⁴ Similarly, from the CDLOI dimensions with the highest scores, it was shown that AD affects mainly the emotional state of the children and their sleep. Studies in large samples indicate that mood changes and sleep disturbances are important issues for children with AD affecting their physical, emotional and social wellbeing.²⁵⁻²⁷ Our findings indicated that AD has a moderate impact on the QoL of infants and children with mean total scores corresponding to those of similar studies.^{28,29} Additionally, an international multicenter study highlighted that despite some national peculiarities, parents in different countries assessed the QoL of their children and the family QoL in similar ways.³⁰

Regarding the illness perceptions of the mothers and their impact on the family QoL, certain dimensions of the Brief IPQ were correlated with family QoL. Specifically, lower family QoL was significantly associated with stronger beliefs about symptom burden, fear of serious consequences on the child's life, higher levels of worry and strong emotional representations, which correspond to the experience of psychological distress symptoms. It appears that the high demands of caring for children suffering from AD increase parents' anxiety, depression, frustration and fatigue, while, at the same time, they become highly overprotective.^{5,6} It is reported that parents are concerned about the factors that trigger the aggravation of symptoms of AD, but also about the safety of the long-term use of topical corticosteroids. Because of this fear, they often seek alternative therapies, with dubious effectiveness and at an extra cost.³¹ Moreover, taking into consideration that emotional factors are involved in the evolution of the AD, parents' high levels of anxiety and their consequent overprotection behaviors are likely to impact on the child's physiological stress response system and the exacerbation of AD symptoms.

With regard to the main causes of AD according to the mothers' belief, the mothers in this study considered inheritance (70.7%) and external factors (64%) to be the major factors. Viewing inheritance to be the main cause of AD could lead to parental guilt, negative self-concept and increased depression or anxiety. Conversely, attributing the cause to external factors (e.g., the urban environment) places the responsibility for their child's condition beyond their own influence. According to the literature, parents' beliefs vary, attributing AD mainly to internal-naturalistic causes (e.g., body-malfunctioning),¹² or placing environmental factors in the first causative place and genetics last.³² Causal attributions interact through a complex process that results in the adoption by the parents of specific health behavior and care activities, with varying impact on coping and adjustment. All the subjective aforementioned perceptions are formed during the period of illness and guide the decision-making process, the symptoms management, and the QoL.33

Concerning the impact of AD on the family QoL (DFIQ), AD was reported to affect the family's expenditure, but also to increase the mothers' time spent on childcare and additional housework, findings that are in line with previous studies.^{24,34} With respect to the associations between children's QoL and family's QoL, correlations were demonstrated between the total mean scores on DFIQ and IDQOL and CDLQI. It is well documented that the more affected the QoL of children was, the more impaired the QoL of the family was, in particular, in the social domain, leisure and daily expenditure.^{24,35} Examining the impact of the chronicity of AD on the family's QoL – an association that has not been investigated adequately up to the present – it was found that the QoL of families with a child who suffers from AD for a long period of time is negatively affected. Regarding the association between the severity of the AD and the family QoL, a positive but weak correlation was observed in this study, possibly because of the way the symptoms and the treatment were perceived and managed by the parents. Several studies indicate a strong association between the severity of the AD and its impact on the family QoL. Additionally, it is reported that high levels of parental anxiety were accompanied by inadequate symptom management, overprotection, frustration and aggressiveness toward children's behaviors such as scratching.^{6,24,36}

Certain clinical implications emerge from the findings of this study. It is evident that recognition and understanding of the factors that affect the QoL of families with a child suffering from AD is important for clinicians, to help to reduce the impact of AD on both the children and their families. In addition to assessing the severity and chronicity of AD, physicians, therefore, should also focus on the parents' thoughts and emotional manifestations. By introducing parental illness perceptions as a key topic of discussion, the parent-doctor relationship can be significantly improved. In cases where the parental illness perceptions generate anxiety and ineffective coping strategies, the doctor can cooperate with the parents to help them to deal with the disease, and refer them to mental health professionals for psychological interventions when necessary.³⁷

Parents need information and education about symptom management skills, and should be included in the decision making and therapeutic planning process. This policy can reduce dysfunctional parenting practices and promote the wellbeing of both the children with AD and their families.³⁸ Better understanding of the disease may lead to positive effects on the QoL of the family and enhancement of compliance with recommended management practices.³⁹

AD in a child generates emotional, behavioral and interpersonal challenges within the family. Consultation and cognitive-behavioral interventions can be applied in a variety of clinical settings to help modify the parents' dysfunctional beliefs and reduce their anxiety, which will also improve clinical outcomes and the QoL of the family.⁴⁰

Limitations and suggestions

Cautious interpretation of the results is needed, as the present study has some limitations. First, it was based on a rather small convenience sample and the results cannot be generalized. Given the population receiving services from the specific outpatient clinic and the incidence of AD in infants and children, it was possible to recruit only 75 participants during the study period. Second, the study took place at an outpatient pediatric allergy clinic of a single tertiary center, which also limits the generalization of the findings. On the other hand, a strength of the study was the use of the Brief IPQ, which, as far as we know, has not been used in a similar population. Finally, as the present study was cross-sectional, it would be of further interest – in a longitudinal study – to examine the parents' illness perceptions

over a long-term disease course and to explore their association with the family QoL and the possible changes in parental illness perceptions following an intervention program.

Conclusions

In conclusion, AD appeared to have a moderate impact on the QoL of both the affected children and their families. The family QoL is associated with illness perceptions about AD of the mothers, and both the severity and the chronicity of the disease. Specifically, strong beliefs about the illness identity, the consequences of the AD, and mothers' intense concerns and emotional representations all have a negative impact on the QoL of the family. Pediatricians and allergists should address this aspect of childhood AD. The management of AD in infants and children should include multidisciplinary intervention, with the provision of psychoeducational programs for parents, to provide them with systematic and accurate information on the characteristics of AD, along with emotional support, to reduce the negative impact on family QoL.

Authors' contribution

Vassiliki Siafaka: Conceived and designed the research, collected data, contributed data tools and wrote the manuscript.

Aikaterini Zioga: Reviewed the literature, collected the data and wrote the manuscript.

Theodoros Evrenoglou: Contributed analysis tolls, performed the analysis.

Dimitrios Mavridis: Contributed analysis tolls, performed the analysis.

Sophia Tsabouri: Conceived and designed the research, collected data, contributed data tools, wrote the manuscript and was in charge of overall supervision.

Declarations

All authors discussed the results, provided critical feedback and contributed to the final manuscript

There is not prior presentation of study data as an abstract or poster.

Ethical approval

All procedures performed were in accordance with the ethical standards of the institutional research committee and with the Helsinki Declaration (1964) and its later amendments or comparable ethical standards. The study was approved by the Bioethics Committee of the University Hospital of Ioannina (Greece).

Consent to participate

A written informed consent was obtained from the adult participants.

Conflict of interest

No funding was received for this work from any organization. There is no conflict of interest.

References

- 1. Weidinger S, Beck LA, Bieber T, Kabashima K, Irvine AD. Atopic dermatitis. Nat Rev Dis Primers. 2018;4, http://dx. doi.org/10.1038/s41572-018-0001-z.
- Nutten S. Atopic dermatitis: global epidemiology and risk factors. Ann Nutr Metab. 2015;66 Suppl. 1:8–16, http://dx. doi.org/10.1159/000370220.
- Kaaz K, Szepietowski JC, Matusiak L. Influence of itch and pain on sleep quality in atopic dermatitis and psoriasis. Acta Dermato-Venereol. 2019;99:175–80, http://dx.doi. org/10.2340/00015555-3065.
- Bridgman AC, Block JK, Drucker AM. The multidimensional burden of atopic dermatitis: An update. Ann Allergy Asthma Immunol. 2018;120:603–6, http://dx.doi. org/10.1016/j.anai.2018.03.009.
- Im YJ, Park ES, Oh WO, Suk MH. Parenting and relationship characteristics in mothers with their children having atopic disease. J Child Health Care. 2014;18:215–29, http://dx.doi.org/10.1177/1367493513485824.
- Warschburger P, Buchholz HT, Petermann F. Psychological adjustment in parents of young children with atopic dermatitis: which factors predict parental quality of life? Br J Dermatol. 2004;150:304–11, http://dx.doi. org/10.1111/j.1365-2133.2004.05743.x.
- Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. Psychol Health. 2003;18:141–84, http://dx.doi.org/ 10.1080/088704403100081321.
- Leventhal H, Phillips LA, Burns E. The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. J Behav Med. 2016;39:935–46, http://dx.doi.org/10.1007/s10865-016-9782-2.
- Slusar MB, Nelson S. Caregiver illness perception of their child's early childhood caries. Pediatr Dent. 2016;38:425–31.
- Goldbeck L, Bundschuh S. Illness perception in pediatric somatization and asthma: complaints and health locus of control beliefs. Child Adolesc Psychiatry Mental Health. 2007;1, http://dx.doi.org/10.1186/1753-2000-1-5.
- Breland JY, McAndrew LM, Burns E, Leventhal EA, Leventhal H. Using the Common Sense Model of Self-regulation to review the effects of self-monitoring of blood glucose on glycemic control for non-insulin-treated adults with type 2 diabetes. Diabetes Educ. 2013;39:541–59, http://dx.doi.org/10.1177/0145721713490079.
- Salewski C. Illness representations in families with a chronically ill adolescent: differences between family members and impact on patients' outcome variables. J Health Psychol. 2003;8:587–98, http://dx.doi. org/10.1177/13591053030085009.
- Walker C, Papadopoulos L, Hussein M. Paediatric eczema and psychosocial morbidity: how does eczema interact with parents' illness beliefs? J Eur Acad Dermatol Venereol. 2007;21:63–7, http://dx.doi.org/10.1111/j.1468-3083.2006.01866.x.
- 14. Paller AS, McAlister RO, Doyle JJ, Jackson A. Perceptions of physicians and pediatric patients about atopic dermatitis, its impact, and its treatment. Clin Pediatr. 2002;41:323–32, http://dx.doi.org/10.1177/000992280204100505.
- Hanifin J, Rajka G. Diagnostic features of atopic dermatitis. Acta Dermato Venereol (Stockh). 1980;92 Suppl.:44–7, http://dx.doi.org/10.2340/00015555924447.

- Laitinen K, Kalliomaki M, Poussa T, Lagstrom H, Isolauri E. Evaluation of diet and growth in children with and without atopic eczema: follow-up study from birth to 4 years. Br J Nutr. 2005;94:565-74, http://dx.doi.org/10.1079/bjn20051503.
- Broadbent E, Petrie KJ, Main J, Weinman J. The brief illness perception questionnaire. J Psychosom Res. 2006;60:631–7, http://dx.doi.org/10.1016/j.jpsychores.2005.10.020.
- Lewis-Jones MS, Finlay AY, Dykes PJ. The infants' dermatitis quality of life index. Br J Dermatol. 2001;144:104-10, http://dx.doi.org/10.1046/j.1365-2133.2001.03960.x.
- Lewis-Jones MS, Finlay AY. The Children's Dermatology Life Quality Index (CDLQI): initial validation and practical use. Br J Dermatol. 1995;132:942-9, http://dx. doi.org/10.1111/j.1365-2133.1995.tb16953.x.
- 20. Holme SA, Man I, Sharpe JL, Dykes PJ, Lewis-Jones MS, Finlay AY. The children's dermatology life quality index: validation of the cartoon version. Br J Dermatol. 2003;148:285–90, http://dx.doi.org/10.1046/j.1365-2133.2003.05157.x.
- 21. Lawson V, Lewis-Jones MS, Finlay AY, Reid P, Owens RG. The family impact of childhood atopic dermatitis: the Dermatitis Family Impact Questionnaire. Br J Dermatol. 1998;138:107–13, http://dx.doi.org/10.1046/j.1365-2133.1998.02034.x.
- 22. Oranje AP, Glazenburg EJ, Wolkerstorfer A, de Waard-van der Spek FB. Practical issues on interpretation of scoring atopic dermatitis: the SCORAD index, objective SCORAD and the three-item severity score. Br J Dermatol. 2007;157:645–8, http://dx.doi.org/10.1111/j.1365-2133.2007.08112.x.
- 23. Position paper: Allergen standardization and skin tests. The European Academy of Allergology and Clinical Immunology. Allergy. 1993;48 Suppl. 14:48–82.
- Marciniak J, Reich A, Szepietowski JC. Quality of life of parents of children with atopic dermatitis. Acta Dermato-Venereol. 2017;97:711-4, http://dx.doi.org/10.2340/00015555-2633.
- Ramirez FD, Chen S, Langan SM, Prather AA, McCulloch CE, Kidd SA, et al. Association of atopic dermatitis with sleep quality in children. JAMA Pediatr. 2019;173:e190025, http:// dx.doi.org/10.1001/jamapediatrics.2019.0025.
- 26. Chernyshov PV. Gender differences in health-related and family quality of life in young children with atopic dermatitis. Int J Dermatol. 2012;51:290-4, http://dx.doi. org/10.1111/j.1365-4632.2011.04997.x.
- 27. Manzoni AP, Pereira RL, Townsend RZ, Weber MB, Nagatomi AR, Cestari TF. Assessment of the quality of life of pediatric patients with the major chronic childhood skin diseases. An Bras Dermatol. 2012;87:361–8, http://dx. doi.org/10.1590/s0365-05962012000300002.
- Jang HJ, Hwang S, Ahn Y, Lim DH, Sohn M, Kim JH. Family quality of life among families of children with atopic dermatitis. Asia Pac Allergy. 2016;6:213–9, http://dx. doi.org/10.5415/apallergy.2016.6.4.213.
- 29. Kim DH, Li K, Seo SJ, Jo SJ, Yim HW, Kim CM, et al. Quality of life and disease severity are correlated in patients with atopic dermatitis. J Korean Med Sci. 2012;27:1327–32, http://dx.doi.org/10.3346/jkms.2012.27.11.1327.
- Chernyshov PV, Jirakova A, Ho RC, Moed H, Caldeira AP, Alvarenga TM, et al. An international multicenter study on quality of life and family quality of life in children with atopic dermatitis. Indian J Dermatol Venereol Leprol. 2013;79:52–8, http://dx.doi.org/10.4103/0378-6323.104669.
- Chamlin SL. The psychosocial burden of childhood atopic dermatitis. Dermatol Therapy. 2006;19:104–7, http://dx.doi.org/10.1111/j.1529-8019.2006.00060.x.
- 32. Rodriguez-Orozco AR, Kanan-Cedeno EG, Guillen Martinez E, Campos Garibay MJ. Family functioning and illness perception of parents of children with atopic dermatitis, living without skin symptoms, but with psychosomatic

symptoms. Iran J Allergy Asthma Immunol. 2011;10:61-5, http://dx.doi.org/10.1001/ijaai.6165.

- Shiloh S, Rashuk-Rosenthal D, Benyamini Y. Illness causal attributions: an exploratory study of their structure and associations with other illness cognitions and perceptions of control. J Behav Med. 2002;25:373–94, http://dx. doi.org/10.1023/a:1015818532390.
- Yang EJ, Beck KM, Sekhon S, Bhutani T, Koo J. The impact of pediatric atopic dermatitis on families: a review. Pediatr Dermatol. 2019;36:66–71, http://dx.doi.org/10.1111/pde.13727.
- 35. Monti F, Agostini F, Gobbi F, Neri E, Schianchi S, Arcangeli F. Quality of life measures in Italian children with atopic dermatitis and their families. Ital J Pediatr. 2011;37, http://dx.doi.org/10.1186/1824-7288-37-59.
- Hebert AA, Stingl G, Ho LK, Lynde C, Cappelleri JC, Tallman AM, et al. Patient impact and economic burden of mild-to-moderate atopic dermatitis. Curr Med Res Opin. 2018;34:2177–85, http://dx.doi.org/10.1080/03007995.2018.1498329.

- 37. Staab D, von Rueden U, Kehrt R, Erhart M, Wenninger K, Kamtsiuris P, et al. Evaluation of a parental training program for the management of childhood atopic dermatitis. Pediatr Allergy Immunol. 2002;13:84–90, http://dx.doi.org/10.1034/j.1399-3038.2002.01005.x.
- Morawska A, Calam R, Fraser J. Parenting interventions for childhood chronic illness: a review and recommendations for intervention design and delivery. J Child Health Care. 2015;19:5–17, http://dx.doi.org/10.1177/1367493513496664.
- 39. Shin JY, Kim DW, Park CW, Seo SJ, Park YL, Lee JR, et al. An educational program that contributes to improved patient and parental understanding of atopic dermatitis. Ann Dermatol. 2014;26:66–72, http://dx.doi.org/10.5021/ad.2014.26.1.66.
- Morawska A, Mitchell AE, Burgess S, Fraser J. Fathers' perceptions of change following parenting intervention: randomized controlled trial of triple p for parents of children with asthma or eczema. J Pediatr Psychol. 2017;42:792–803, http://dx.doi.org/10.1093/jpepsy/jsw106.