



UDC 616.5-002.2

DOI: <https://doi.org/10.22141/2224-0551.18.1.2023.1554>

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Study of the impact of atopic dermatitis in children on the quality of life of families

For citation: *Child`s Health*. 2023;18(1):18-22 doi: 10.22141/2224-0551.18.1.2023.1554

Abstract. Background. Atopic dermatitis is a chronic, relapsing eczema. Although atopic dermatitis occurs mainly in children, it greatly affects the life of the whole family. The purpose was to assess the quality of life of the families of children with atopic dermatitis and to study the correlation between the severity of atopic dermatitis and the quality of life of family members according to the Family Dermatology Life Quality Index (FDLQI) questionnaire. **Materials and methods.** The study included 104 patients with atopic dermatitis aged 6 months to 17 years (median of 6 [3; 9] years) who were treated at the Allergy Department of the Kyiv City Children's Clinical Hospital 2. Clinical parameters included age, sex of the patients, disease duration and severity of atopic dermatitis. The latter was assessed by the SCORing for Atopic Dermatitis (SCORAD) tool. Spearman's rank correlation index was used for analysis of correlation between FDLQI and SCORAD indicators. $P < 0.05$ was considered statistically significant. **Results.** The quality of life of the family of 104 children with atopic dermatitis was assessed using the FDLQI questionnaire. Four parents (3.8 %) reported no impact of the disease on the family's quality of life, 65 (62.5 %) — a mild effect, 34 (32.7 %) — a moderate impact, parents of 1 patient (1.0 %) noted a very large effect. The average FDLQI was 6.4 ± 2.8 . There was a correlation between the FDLQI and the SCORAD severity index ($R_o = 0.714$, $p < 0.01$). In the subgroup of children under 4 years of age, a strong correlation between the FDLQI and the SCORAD was found ($R_o = 0.789$, $p < 0.01$). Child's age and disease duration were not associated with the quality of life score ($R_o = -0.011$, $p > 0.05$ and $R_o = 0.076$, $p > 0.05$, respectively). In the subgroup of children aged 4–17 years, a strong positive correlation of FDLQI and the SCORAD was also determined ($R_o = 0.714$, $p < 0.01$). The age of the children and the duration of the disease were not related to the quality of life score ($R_o = -0.011$, $p > 0.05$ and $R_o = -0.027$, $p > 0.05$, respectively), although in the subgroup of younger children (4–7 years) we noted a tendency towards a greater influence of the disease on the family's quality of life. **Conclusion.** In this study, most parents of children with atopic dermatitis reported a mild to moderate impact of the disease on their quality of life. The FDLQI of family members correlated with the severity of atopic dermatitis.

Keywords: atopic dermatitis; quality of life; questionnaire; children

Introduction

Atopic dermatitis (AD) is a chronic, relapsing eczema. Although AD occurs mainly in children, it greatly affects the life of the whole family [1, 2].

Today, we assess the burden of the disease on the child and the family as a whole through the assessment of quality of life [3–5]. AD directly impacts daily activities via discomforts due to skin symptoms, sleeping habits, and causes higher levels of depression, stress and fatigue [6–8]. Chronic skin disease is also associated with skin defects — stigma,

which in a certain way affect the relationships between children in the children's team.

The difficulties associated with the care and treatment of a child with AD also strongly affect the family's quality of life: parents often experience stress, frustration, fatigue, especially due to poor response to therapy and new relapses [9–11].

The Family Dermatology Life Quality Index (FDLQI) is a questionnaire designed for adult family members (aged 16 years and older) or caregivers of a child with any skin di-



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sease, particularly AD [12]. It is self-explanatory and can be filled out by parents without the need for detailed explanation. Filling out the questionnaire takes two to three minutes.

The purpose was to assess the quality of life of the family of children with AD and to study the correlation between the severity of AD and the quality of life of family members according to the FDLQI questionnaire.

Materials and methods

The study included 104 patients with AD aged 6 months to 17 years (median of 6 [3; 9] years) who were treated at the Allergy Department of the Kyiv City Children's Clinical Hospital 2, 54 boys (51.9 %) and 50 girls (48.1 %). This study was approved by the ethics commission of Bogomolets National Medical University (Protocol No. 2 dated October 21, 2020), all patients/parents of sick children gave informed consent to participate. AD was diagnosed according to the Hanifin and Rajka criteria.

Clinical parameters of the patients included age, sex, disease duration and severity of AD. The severity of AD was assessed by the SCORing for Atopic Dermatitis (SCORAD) tool. The median severity index was 30 [26; 55].

Inclusion criteria were age 6 months to 17 years, duration of AD more than 1 year. Exclusion criteria were treatment with systemic corticosteroids within the past 4 weeks, presence of any other dermatologic disease within the past 4 weeks, severe systemic disease or malignancy, psychiatric disorder, and psychomotor impairment.

To conduct the survey, permission to use the FDLQI questionnaire in children was obtained from the author, professor A.Y. Finlay (University of Wales College of Medicine, Cardiff, UK) [11].

The total score is calculated by summing the scores for each question, resulting in a maximum of 30 and a minimum of 0.

The questions are designed to be completed with a one-month recall period.

Evaluation of each question:

- Not at all/not relevant = 0.
- A little = 1.
- Quite a lot = 2.
- Very = 3.
- Not applicable = 0.
- Unanswered questions = 0.

The Family Dermatology Life Quality Index

1. Over the last month, how much emotional distress have you experienced due to your relative/partner's skin disease (e.g., worry, depression, embarrassment, frustration)?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

2. Over the last month, how much has your relative/partner's skin disease affected your physical well-being (e.g., tiredness, exhaustion, contribution to poor health, sleep/rest disturbance)?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

3. Over the last month, how much has your relative/partner's skin disease affected your personal relationships with him/her or with other people?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

4. Over the last month, how much have you been having problems with other peoples' reactions due to your relative/partner's skin disease (e.g., bullying, staring, need to explain to others about his/her skin problem)?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

5. Over the last month, how much has your relative/partner's skin disease affected your social life (e.g., going out, visiting or inviting people, attending social gatherings)?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

6. Over the last month, how much has your relative/partner's skin disease affected your recreation/leisure activities (e.g., holidays, personal hobbies, gym, sports, swimming, watching TV)?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

7. Over the last month, how much time have you spent on looking after your relative/partner (e.g., putting on creams, giving medicines or looking after their skin)?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

8. Over the last month, how much extra housework have you had to do because of your relative/partner's skin disease (e.g., cleaning, vacuuming, washing, cooking)?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

9. Over the last month, how much has your relative/partner'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)?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

10. Over the last month, how much has your relative/partner's skin disease increased your routine household expenditure (e.g., travel costs, buying special products, creams, cosmetics)?
Not at all/Not relevant *A little* *Quite a lot* *Very much*

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The higher the indicator, the more the quality of life deteriorates. The questionnaire can also be expressed as a percentage of the maximum possible score of 30.

If one question is left unanswered, it was scored as 0 and marks were summed and expressed as usual with a maximum of 30.

If two or more questions were unanswered, the questionnaire was not evaluated. If two or more answer options were marked, then the answer option that scored the highest number of points was recorded. If the answer is between two marks, the lower of the two scoring options was recorded.

Spearman's rank correlation index was used for correlation analysis of FDLQI and SCORAD indicators. A *p*-value < 0.05 was considered statistically significant.

Results

The quality of life of the family of patients with AD was assessed using the FDLQI questionnaire among parents of 104 children. Four parents (3.8 %) reported no impact of the disease on the family's quality of life, 65 (62.5 %) noted a small effect, moderate impact was reported for 34 children (32.7 %), very large effect — for 1 (0.1 %) patient (Table 1, Fig. 1). The average FDLQI was 6.4 ± 2.8 . Among the interviewed parents, 83 mothers (79.8 %) and 21 fathers (20.2 %) filled out the questionnaire.

In the subgroup of children under 4 years of age, a strong correlation between the FDLQI and the SCORAD was found ($R_o = 0.789$, $p < 0.01$). Children’s age and disease duration were not associated with the quality of life score ($R_o = -0.011$, $p > 0.05$ and $R_o = 0.076$, $p > 0.05$, respectively).

In the subgroup of children aged 4–17 years, a strong positive correlation of FDLQI and the SCORAD was also determined ($R_o = 0.714$, $p < 0.01$). The age of the children and the duration of the disease were not related to the quality of life score ($R_o = -0.011$, $p > 0.05$ and $R_o = -0.027$, $p > 0.05$, respectively), although in the subgroup of younger children (4–7 years) we noted a tendency towards a greater influence of the disease on the family’s quality of life.

In children with mild severity of AD according to the SCORAD, the average FDLQI was 4.3 ± 1.7 points ($n = 16$), which indicates a weak influence of AD on the quality of life

of family members. In children with a moderate AD severity, the FDLQI was 6.4 ± 1.7 points ($n = 34$) showing an average impact of the disease on the quality of life. The average FDLQI in the group of children with severe AD ($n = 21$) was 9.6 ± 2.6 also indicating a moderate effect of the disease on the quality of life of parents (Fig. 2).

Discussion

In this study, the quality of life of families in children with AD was studied. The results of the questionnaire were quite diverse and correlated to a large extent with the severity of the disease. According to the results of the survey, parents of 3.8 % of children reported no impact of the disease on the family’s quality of life, 62.5 % of parents reported a small impact on the quality of life, moderate impact was reported in 32.7 %, very large impact — in 1.0 %. It should be noted that some questionnaires were filled out by the mother, and some by the father, which in a certain way could affect the results — the heterogeneity of the answers. In our opinion, the father may define the burden of the disease as less severe, but this is difficult to verify.

There was a correlation between the FDLQI and the SCORAD ($R_o = 0.714$, $p < 0.01$). The answers to the questions of the FDLQI questionnaire were analyzed. The majority of respondents answered “Not at all” (0 points) and “A little” (1 point) to the question about the impact of the child’s illness on relationships with other people (No. 3), the reaction of other people to the child’s skin problems (No. 4), about the impact on social life (No. 5), entertainment/leisure (No. 6) and work and study (No. 9). This may be related to the cultural and socio-psychological character-

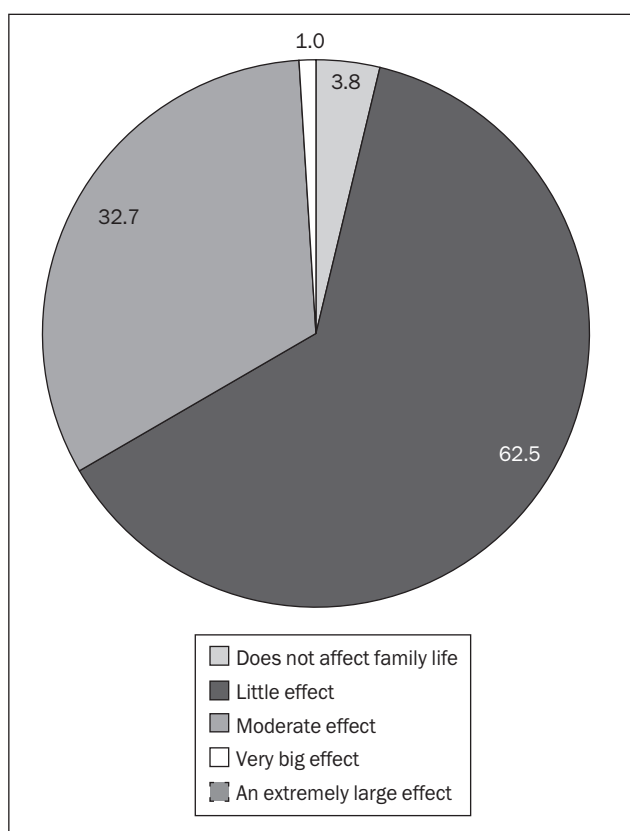


Figure 1. Distribution of children (%) depending on the result of the FDLQI questionnaire

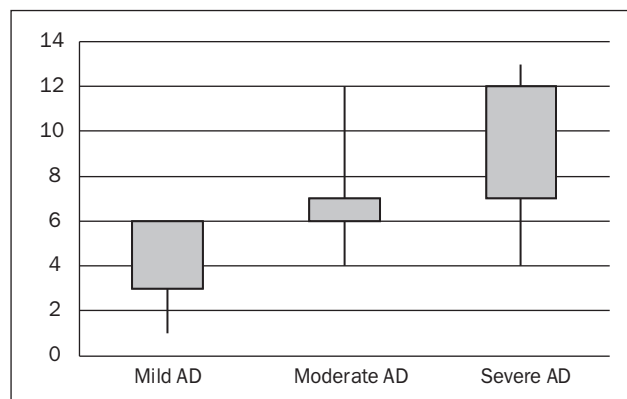


Figure 2. Average FDLQI score in subgroups depending on AD severity

Table 1. Distribution of FDLQI score

Score	Respondents	
	n	%
0–1 = does not affect family life	4	3.8
2–6 = little effect	65	62.5
7–12 = moderate effect	34	32.7
13–18 = very big effect	1	1.0
19–30 = an extremely large effect	0	0

ristics of the population, which was the reason for assessing the impact of AD on the family's quality of life as moderate.

In previous studies it was demonstrated that parents of affected children may experience sleep disturbances, feelings of guilt, blame, worry, and frustration as a consequence of their child's skin disorder [13–17]. It is described in the study of Gieler et al. [18] that single mothers of children with AD had higher levels of stress than single mothers of healthy children. Extra time required to care for a child with AD can be a burden for families [13]. In the study of Ražnatović Đurović M., where Dermatitis Family Impact questionnaire was used, poorer quality of life of parents was associated with female gender, younger age of children and more severe AD [19]. In a similar study of a younger age group (0–4 years) [20], parents had poorer quality of life if their infants had more severe, concomitant atopic disease or family history of atopy. One study demonstrated that children's AD had a more significant influence on quality of life of mothers than that of fathers (mean FDLQI 17.1 ± 5.3 vs. 14.7 ± 5.8 points; $p < 0.001$) [21]. When studying the impact of AD using the Dermatitis Family Impact questionnaire, it was shown that chronicity of the AD showed negative association with DFIQ ($p < 0.001$) [22].

Conclusions

In this study, most parents of children with atopic dermatitis reported a mild to moderate impact of the disease on their quality of life. The FDLQI of family members correlated with the severity of atopic dermatitis. Therefore, FDLQI questionnaire in the Ukrainian version is a reliable tool for assessing the quality of life of families of pediatric patients with atopic dermatitis.

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Received 02.01.2023

Revised 10.01.2023

Accepted 16.01.2023 ■

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Conflicts of interests. The author declares the absence of any conflicts of interests and own financial interest that might be construed to influence the results or interpretation of the manuscript.

Sources of funding. The study was financed at the expense of the state budget of the scientific-research work of the Department of Pediatrics 2 of the Bogomolets National Medical University. State registration code 0120U100804.

Acknowledgments. The author expresses her gratitude to the patients and their parents.

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Вивчення впливу atopічного дерматиту в дітей на якість життя сімей

Резюме. Актуальність. Атопічний дерматит — це хронічне рецидивуюче захворювання шкіри. Хоча атопічний дерматит зустрічається переважно в дітей, він сильно впливає на життя всієї родини. **Мета:** оцінити якість життя сім'ї дітей з атопічним дерматитом та вивчити кореляцію між тяжкістю атопічного дерматиту та якістю життя членів сім'ї за опитувальником Family Dermatology Life Quality Index (FDLQI). **Матеріали та методи.** У дослідження були включені 104 пацієнти з атопічним дерматитом віком від 6 місяців до 17 років (медіана 6 [3; 9] років) з алергологічного відділення Київської міської дитячої клінічної лікарні № 2. Клінічні показники включали вік, стать, тривалість захворювання та тяжкість атопічного дерматиту. Останню оцінювали за індексом SCORAD. Для кореляційного аналізу показників FDLQI та SCORAD використовували індекс рангової кореляції Спірмена. $P < 0,05$ вважалось статистично значущим. **Результати.** За допомогою опитувальника FDLQI оцінено якість життя сімей 104 пацієнтів з атопічним дерматитом. Четверо батьків (3,8 %) повідомили про відсутність впливу захворювання на якість життя сім'ї, 65 (62,5 %) — про незначний вплив, 34 (32,7 %) — помірний, батьки 1 пацієнта (1,0 %) вказали на дуже великий

ефект. Середня оцінка за опитувальником FDLQI становила $6,4 \pm 2,8$ бала. Спостерігалася кореляція між показником FDLQI та індексом тяжкості за SCORAD ($R_0 = 0,714$, $p < 0,01$). У підгрупі дітей віком до 4 років виявлено сильний кореляційний зв'язок між параметрами FDLQI та SCORAD ($R_0 = 0,789$, $p < 0,01$). Вік дітей та тривалість захворювання не були пов'язані з оцінкою якості життя ($R_0 = -0,011$, $p > 0,05$ та $R_0 = 0,076$, $p > 0,05$ відповідно). У підгрупі дітей віком 4–17 років також встановлено сильний позитивний кореляційний зв'язок показників FDLQI та SCORAD ($R_0 = 0,714$, $p < 0,01$). Вік дітей та тривалість захворювання не були пов'язані з оцінкою якості життя ($R_0 = -0,011$, $p > 0,05$ та $R_0 = -0,027$, $p > 0,05$ відповідно), хоча в підгрупі дітей молодшого віку (4–7 років) відзначено тенденцію до більшого впливу хвороби на якість життя сім'ї. **Висновок.** У цьому дослідженні більшість батьків дітей з атопічним дерматитом повідомили про легкий або помірний вплив захворювання на якість їхнього життя. Показник FDLQI членів родини корелював із ступенем тяжкості атопічного дерматиту.

Ключові слова: атопічний дерматит; якість життя; анкета; діти