

Quality of Life in Families with Children with Atopic Dermatitis

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Abstract

Background: Atopic dermatitis (AD) is a common childhood disease of increasing prevalence that not only changes the life of the affected children, but also affects the social and emotional functioning of their families.

Objectives: The aim of our study was to assess the quality of life (QOL) of parents with children with AD and its predictors.

Methods: One hundred seventy-one parents of children with AD attending the outpatient Pediatric Dermatology Unit, Children's Hospital Zagreb, participated in the study. The severity of AD was estimated using the Scoring Atopic Dermatitis (SCORAD) index. Parents were asked to complete the Croatian version of the Family Dermatology Life Quality Index (FDLQI), the Patient-Oriented (PO) SCORAD, the Perceived Stress Scale (PSS), and a general questionnaire during a regular follow-up visit.

Results: Family QOL is significantly correlated with the SCORAD score (correlation coefficient $[r] = 0.578$), PO SCORAD ($r = 0.447$), itching ($r = 0.528$), sleeplessness ($r = 0.583$), and PSS ($r = 0.464$). When these factors were entered into a regression analysis, they predicted as much as 67% of the variance of QOL (FDLQI), with significant predictors being PO SCORAD, PO sleeplessness, and PSS, and they remained significant even after controlling for a number of general and medical factors.

Conclusions: The severity of illness as perceived by dermatologists and parents is similar, and itching, sleeplessness, and perceived stress are strong QOL predictors of parents caring for children with AD.

Because atopic dermatitis (AD) starts in early infancy and follows a chronic relapsing course, it places an extra burden on these children and their caregivers. Early infancy is a challenging period for every parent, during which they face a new challenge

almost every day. A chronic illness such as AD presents an additional problem that can have a major influence on parents during this already sensitive period of their life. Restriction of normal family life, difficulties with complicated treatment regimens, and

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caring for a child with eczema leads to parental exhaustion and feeling of hopelessness, guilt, anger, and depression (1,2).

The aim of our study was to assess the quality of life (QOL) of parents of children with AD and to determine its predictors.

MATERIALS AND METHODS

Population

One hundred seventy-one families with children suffering from AD were included in the study. Participants were recruited among parents of children with AD who attended the outpatient Pediatric Dermatology Unit, Children's Hospital Zagreb, during a 5-month period (from November 2013 to March 2014). The inclusion criteria were defined as child's age from 3 months to 7 years, diagnosis of AD according to Hanifin and Rajka (3), and dermatitis duration of at least 3 months. The study did not include parents of children with AD who had another chronic disease other than one belonging to the AD group.

The local medical ethics committee approved the protocol. The study was performed according to the principles of the Helsinki Declaration and all participants provided written informed consent.

Data Collection and Questionnaires

The parents of children with AD were asked to join the study during a regular follow-up visit. The severity of AD in each patient was assessed using the Scoring of Atopic Dermatitis (SCORAD) index (4,5). The general SCORAD questionnaire consists of questions about the parent (sex, age, marital status, educational level, employment status, parental history of atopy, perceptions regarding topical corticosteroids) and patient (sex, age, number of children in the family, age at onset of AD, animal contact, exposure to cigarette smoke, breastfeeding, AD therapy) characteristics.

Parents were asked to complete the Patient-Oriented (PO) SCORAD index (6,7), the Perceived Stress Scale (PSS) (8), and the Croatian version of the Family Dermatology Life Quality Index (FDLQI) (9,10). The PO SCORAD index is a self-assessment score allowing parents to evaluate the course of AD comprehensively, using subjective and objective criteria derived from the SCORAD (6,7). The PSS is a psychological instrument that measures the perception of stress during the past month (8). It

measures the degree to which situations in one's life are appraised as stressful and includes questions regarding feelings and thoughts about such situations (8). The FDLQI is a dermatology-specific instrument that measures the adverse effect on the health-related QOL of family members of patients with skin disease (9,10). It consists of 10 questions regarding the effect of a patient's skin disease on different aspects of the family caregivers' QOL, such as emotional and physical well-being, relationships, social life, leisure activities, burden of care, effect on job or study, housework, and expenditures. Participants answer on a 4-point scale: 0, not at all or not applicable; 1, a little; 2, a lot; 3, very much (9,10). The scores of individual items (0–3) are added to give a total score that ranges from 0 to 30; higher scores indicate poorer QOL (9,10). To obtain a valid Croatian version of the FDLQI, we followed the guidelines for the cross-cultural adaptation of health-related QOL measures (11).

Statistical Analyses

Statistical analyses were performed using SPSS version 17.0 (SPSS, Chicago, IL). Descriptive statistics, the Student *t* test, Pearson correlation coefficients (*r*), and multiple regression analyses were calculated.

RESULTS

Data on 171 family members, mostly mothers (~91%), were collected. Parents were 20 to 50 years old (mean age 31.6 ± 5.1 years). Participant characteristics are summarized in Table 1. Although 88.9% of parents believed that they knew everything they needed to know about corticosteroids, 61.5% of them had a strong fear of corticosteroids. "Steroid phobia" was significantly correlated with the use of corticosteroids 2 months before inclusion in our study ($r = 0.253$, $p = 0.006$) and with the amount of corticosteroids used ($r = 0.253$, $p = 0.006$).

Data on patients show that 60.2% were boys ages 3 to 84 months (mean age 23.7 ± 24.6 mos). The average age of AD onset was 6.3 ± 12.1 months. Patient characteristics are summarized in Table 2.

Hanifin and Rajka diagnostic criteria that were found in all patients were pruritus, typical morphology and distribution, chronic or chronically relapsing dermatitis, early age of onset, intolerance to wool and lipid solvents, course influenced by environmental or emotional factors, and xerosis (29% mild, 58% moderate, 13% severe xerosis). Other criteria were family history of atopy (72.5%), itching when

TABLE 1. *Parent Characteristics*

Characteristic	n (%)
Sex	
Female	156 (91.2)
Male	15 (8.8)
Educational level	
High school graduate	94 (55.0)
College graduate	15 (8.8)
University degree	62 (36.2)
Marital status	
Married	166 (97.1)
Unmarried	5 (2.9)
Employment status	
Employed	60 (35.1)
Unemployed	25 (14.6)
Maternity leave	86 (50.3)
Personal history of atopy	
No	112 (61.9)
Yes	69 (38.1)
Knowledge about corticosteroids	
No	19 (11.1)
Yes	152 (88.9)
Corticophobia	
Strong fear	50 (29.2)
Medium strong fear	55 (32.2)
Slight fear	39 (22.8)
No fear	11 (6.4)
No data	16 (9.4)

sweating (45.9%), personal history of atopy (45.0%), immediate (type 1) skin test reactivity (36.3%), high serum immunoglobulin E (36.3%), Dennie–Morgan infraorbital fold (19.3%), pityriasis alba (15.6%), cheilitis (14.8%), secondary cutaneous infections (12.6%), and nonspecific hand or foot dermatitis (10.4%). Other Hanifin and Rajka's minor criteria were present in fewer than 10% of patients. None of the patients had keratoconus or anterior subcapsular cataracts.

SCORAD index, PO SCORAD index, pruritus, sleep loss, and PSS scores are shown in Table 3. Correlation between the SCORAD index and PO-SCORAD index was statistically significant and high ($r = 0.79$).

The overall mean FDLQI score was 13.6 ± 6.0 (Table 4). The most frequently reported problem was time spent looking after the child (mean score 2.3). Other frequently reported problems were household expenditures (mean score 1.9), emotional distress (mean score 1.7), and extra housework (mean score 1.7). The lowest-scoring FDLQI items were effect on job or study (mean score 0.7) and social life (mean score 0.7).

Family QOL was significantly correlated with the SCORAD index, PO SCORAD index, itching, sleep disturbance, and PSS (Table 5).

TABLE 2. *Children's Characteristics*

Characteristic	n (%)
Sex	
Female	68 (39.8)
Male	103 (60.2)
Number of children in the family	
1	78 (45.6)
2	66 (38.6)
≥ 3	27 (15.8)
Pets	
Dog	29 (17.0)
Cat	7 (4.1)
More pets	26 (15.2)
No pets	109 (63.7)
Parents smoking	
Yes	71 (41.5)
No	100 (58.5)
Atopy in the family	
Yes	124 (72.5)
No	47 (27.5)
Breastfeeding (≥ 6 mos)	
Yes	106 (62.0)
No	55 (32.2)
No data	10 (5.8)

TABLE 3. *Test Scores*

Test	Range	Mean $\pm$ standard deviation
SCORAD	2–79	38.7 ± 16.4
Patient-Oriented SCORAD	18–76	42.7 ± 13.7
Pruritus	0–10	6.2 ± 2.6
Sleep loss	0–10	4.6 ± 3.0
Perceived Stress Scale	6–34	20.0 ± 5.8

SCORAD, Scoring Atopic Dermatitis.

DISCUSSION

Caring for a child with AD involves skin treatment regimes, adjustments to family lifestyle, and financial costs (1,2). As a result of an increasing incidence of AD, there has been more interest in the identification of predictors of lower QOL in individuals with AD and their families. Major predictors related to family QOL in children with AD in the current study were SCORAD index, PO SCORAD index, itching, sleep disturbance, and perceived stress.

As in a previous study (12), we found that mothers are usually the primary caregivers and carry the major burden of caring for children with chronic conditions. In our study, 45% of participating parents had a personal history of atopy, and slightly less than three-quarters of children with AD had atopy in the family. The increase in the incidence of AD in recent decades supports the importance of environmental factors in the development of AD. Information on environmental factors (pets, smoking), parents' education, marital

TABLE 4. Family Dermatology Life Quality Index Results

Item	Range	Mean $\pm$ standard deviation
Total	0–30	13.6 $\pm$ 6.0
Emotional distress	0–3	1.7 $\pm$ 0.8
Physical well-being	0–3	1.6 $\pm$ 1.0
Personal relationships	0–3	1.0 $\pm$ 0.9
Problems with other peoples' reactions	0–3	1.1 $\pm$ 1.0
Social life	0–3	0.7 $\pm$ 0.9
Recreational and leisure activities	0–3	0.9 $\pm$ 1.0
Time spent looking after child	0–3	2.3 $\pm$ 0.7
Extra housework	0–3	1.7 $\pm$ 0.9
Job or study	0–3	0.7 $\pm$ 0.9
Routine household expenditure	0–3	1.9 $\pm$ 0.9

TABLE 5. Correlation Between Family Dermatology Life Quality Index (FDLQI) and Scoring Atopic Dermatitis (SCORAD), Patient-Oriented (PO) SCORAD, Itching, Sleep Disturbance, and Perceived Stress Scale (PSS)

Test	FDLQI
SCORAD	
<i>r</i>	0.578*
p-value	<0.001
<i>n</i>	171
PO SCORAD	
<i>r</i>	0.447*
p-value	<0.001
<i>n</i>	120
Itching	
<i>r</i>	0.528*
p-value	<0.001
<i>n</i>	171
Sleep disturbance	
<i>r</i>	0.583*
p-value	<0.001
<i>n</i>	171
PSS	
<i>r</i>	0.464*
p-value	<0.001
<i>n</i>	120

*Significant at 1% probability.
r, Pearson correlation coefficient.

status, employment status, number of children in the family, and breastfeeding was collected in our study. Family QOL did not significantly correlate with genetic predisposition (parental history of dermatitis, atopy in the family) or other above-mentioned factors. Pruritus was the only Hanifin and Rajka diagnostic criterion that significantly correlated with family QOL.

Previous studies (13,14) have shown many factors underlying corticophobia, such as patient female sex, child's paternal history of AD, and frequent changing of clinics for the patient, but cortico phobia did not correlate with AD severity. In our study, corticophobia did not significantly correlate with family QOL.

A characteristic of AD is its uneven course, with flares and remissions, including clinical variations between consultations. Periodic assessment by a doctor is insufficient to evaluate comprehensively the course of the disease or the efficacy of the treatment (7). Self-assessment can allow better monitoring of disease status and require greater patient involvement in the treatment process (7). Several self-assessment tools for AD have been proposed. The PO SCORAD is simple to understand, uses basically the same criteria as the SCORAD, and allows comparison between doctor and patient evaluations (6,7). The results of our study confirmed the results of other studies (6,7). Correlation between SCORAD and PO-SCORAD scores was statistically significant ($r = 0.79$), which indicates similar perception of illness severity between parents and dermatologists.

We showed that AD had a great effect on parents' QOL. Most published studies on the FDLQI measured family QOL of adults with skin diseases (9) or family QOL in patients with congenital erythropoietic porphyria (15), psoriasis (16,17), vitiligo (18), or recessive dystrophic epidermolysis bullosa (19). Chernyshov et al (20) measured FDLQI in children with AD younger than 4 years old, and the mean score was 11.8. The highest-scoring items on the FDLQI were questions on emotional distress, time spent looking after a relative or partner, and increased household expenditures (20). The three most frequently reported problems in our study were the same, but in a different order: time spent looking after the child, household expenditures, and emotional distress. The lowest-scoring FDLQI items were effect on job or study, because almost two-thirds of participants were on maternity leave or unemployed.

Our results showed that parents of children with AD have significantly more stress in their lives than the general population their age (21). The level of stress of parents in our study, according to the PSS, was 20.0, while the level of stress of the average person, age 30 to 40 years, according to the PSS is 13 (21). Stress has a negative influence on QOL. A number of factors are believed to moderate the effect of psychological stressors, ranging from environmental factors such as social support to more individual factors such as prior experience and coping (22). Therefore parents' psychological support (stress management) during AD educational programs may improve their QOL. Further studies are needed on the influence of AD education on parents' stress and anxiety.

This study had two limitations. First, it did not explore parental knowledge of AD and its influence

on QOL. Second, data were collected during the winter. AD tends to improve during the summer and get worse in the winter, so recruitment times may represent a positional confounding factor.

In conclusion, AD had a stronger influence on the QOL of parents whose children had a higher SCORAD index, a higher PO SCORAD index, and greater itching and sleep disturbance and who perceived more stress in their life.

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