

# An International Multi-center Study on Self-assessed and Family Quality of Life in Children with Atopic Dermatitis

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**ABSTRACT** Atopic dermatitis (AD) is a common childhood chronic inflammatory skin condition that greatly affects the quality of life (QoL) of affected children and their families. The aim of our study was to assess QoL and family QoL of children with AD from 4 different countries and then compare the data, evaluating the effects of AD severity and age of children. Data on the Children's Dermatology Life Quality Index (CDLQI) and the Dermatitis Family Impact (DFI) questionnaires and the SCORAD index of 167 AD children 5-16 years old from Ukraine, Czech Republic, Singapore, and Italy was used for the study. SCORAD correlated with the CDLQI in all 4 countries and with DFI in all countries except Singapore. Only in Czech children did the CDLQI correlate with their age. No significant correlations between age and DFI results were found. AD symptoms and expenditures related to AD were highly scored in all countries. Impact of AD on friendship and relations between family members were among the lower scored items, and family problems did not increase proportionately with duration of AD in any of the four countries. Self-assessed health-related QoL of children with AD in our study correlated better in most cases with disease severity than family QoL results. Parents of school children with AD were generally less stressed, tired, and exhausted than parents of preschool children. These data together with results showing that duration of AD in children does not affect relations between parents and other family members is optimistic news for families with children with AD who did not recover until adolescence.

**KEY WORDS:** atopic dermatitis, quality of life, children

## INTRODUCTION

Atopic dermatitis (AD) is a common childhood chronic inflammatory skin condition of increasing prevalence that greatly affects the quality of life (QoL)

of affected children and their families and is a significant direct and indirect financial burden for national healthcare systems and the patients' families (1-8).

The interest for health-related (HR) QoL in children with dermatologic conditions is growing (9). The results of an international multicenter study on QoL and family QoL in children with AD under 4 years of age were recently published (8). Parents in different countries assessed QoL and family QoL of their small children with AD in similar way (8). However, the risk factors for atopic dermatitis are different in preschool and school children (10). There is also a possibility of adult-child concordance when using proxy-ratings instead of self-assessment (9). It is important to obtain information from both children and parents whenever possible and to use proxy-rating results as a single measure only in the youngest age group (<5 years of age) (11).

The Children's Dermatology Life Quality Index (CDLQI) (12) HRQoL questionnaire is designed for use in children with skin condition from age 5 to age 16. The CDLQI questionnaire is self-explanatory and can be simply handed to the patient who is asked to fill it in with the help of the child's parent or guardian. The Dermatitis Family Impact (DFI) questionnaire was described as covering "secondary" effects of skin disease (13).

The aim of our study was to compare the data on self-assessed QoL and family QoL of children with AD from different countries, considering also the effects of AD severity and the age of children.

## PATIENTS AND METHODS

### Study population

The authors who published a study on CDLQI and the DFI assessment in children with AD were found by means of literature search using PubMed, Scopus, and EBSCO host and contacted to obtain the data set. Inclusion criteria were: children with AD from 5 to 16 years of age, diagnosis of AD made using Hanifin and Rajka or Williams' criteria (14, 15), and presence of Scoring of Atopic Dermatitis (SCORAD) index results (16). Four international centers agreed to participate. Data on 167 children with AD from 4 countries (Ukraine, Czech Republic, Singapore, and Italy) from 5 to 16 years old that had no other manifesting diseases

were used for the study. Patients from Singapore and Italy were selected from participants of local studies (7,17). All patients visited dermatologists. In most cases the parent who filled in the DFI questionnaire was mother. Ethical permission for the study was granted by the local ethic research committees.

### QoL assessment

Original (English), Ukrainian, Czech, and Italian versions of the CDLQI (12) and the DFI (13) questionnaires were used. Permission to use the CDLQI and the DFI questionnaires was granted by its authors and copyright owners Professor Andrew Y. Finlay and Dr. M. S. Lewis-Jones.

The 10 questions of the CDLQI cover six areas of daily activities including symptoms and feelings, leisure, school or holidays, personal relationships, sleep, and treatment. Each question is answered on a 4-point Likert scale scored from 0 to 3. These are added to give a minimum score of 0 and maximum score of 30. Higher scores indicate a poorer quality of life. In order to facilitate the clinical interpretation of the CDLQI scores a banding system (consisting of 5 bands) was validated. According to this system, a CDLQI score 0-1=no effect at all on patient's life; a CDLQI score of 2-6=small effect on patient's life, a CDLQI score of 7-12=moderate effect on patient's life, a CDLQI score of 13-18=very large effect on patient's life, and a CDLQI score of 19-30=extremely large effect on patient's life (18).

The DFI also consists of 10 questions scored 0-3 and a maximum score of 30, investigating the following areas: housework, food preparation and feeding, sleeping, family leisure activity, shopping, expenditure, fatigue, emotional distress, and relationships (13). The higher the score, the more quality of life is impaired in both questionnaires.

Data on validation of original (English) and Ukrainian versions of the CDLQI (12,19) and the DFI (13,19-21), the Italian version of the DFI (22), and initial validation of the Czech version of the DFI (23) questionnaires was published previously.

**Table 1.** Age, Scoring of Atopic Dermatitis (SCORAD), overall Children's Dermatology Life Quality Index (CDLQI) and Dermatitis Family Impact (DFI) of children with atopic dermatitis (AD) (mean±SD)

	Singapore (n=35)	Czech Republic (n=50)	Italy (n=38)	Ukraine (n=44)
Age	10.60±2.56	12.0±3.73	6.58±1.93	9.86±2.91
SCORAD	50.27±27.22	19.32±14.22	36.54±20.24	23.50±14.89
CDLQI	9.89±6.14	8.58±5.26	5.37±5.44	12.89±7.82
DFI	6.51±6.16	8.26±7.11	5.58±25.52	15.59±6.05

### Disease severity assessment

Disease severity was estimated using the “classic” SCORAD (Scoring Atopic Dermatitis) index – a clinical disease severity instrument that combines information on the involved area of skin, as well as objective and subjective symptoms in patients with AD (15). AD with a SCORAD higher than 40 was regarded as severe, whereas AD with a SCORAD 20-39 was regarded as moderate and AD with a SCORAD below 20 was regarded as mild (24).

### Statistical analysis

Spearman nonparametric correlation was used. The results were considered significant if  $P < 0.05$ .

### RESULTS

Data on the age of children, disease severity (SCORAD), overall self-assessed QoL, and family QoL are presented in Table 1.

Data on separate CDLQI and DFI items are presented in Table 2 and Table 3.

CDLQI scores correlated significantly with DFI scores in Czech, Italian, and Ukrainian patients ( $r=0.67, 0.78, \text{ and } 0.68$ , respectively;  $P < 0.0001$ ) and did not correlate significantly in patients from Singapore ( $r=0.04; P=0.84$ ). Correlations of disease severity with CDLQI, DFI, and the age of patients are presented in Table 4.

Correlations of CDLQI and DFI scores with patient age are presented in Table 5.

SCORAD significantly correlated with all separate CDLQI items in Ukrainian children ( $P < 0.05$ ), with all items ( $P < 0.01$ ) except the item “how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?” in Czech children, with 4 items (“how embarrassed or self conscious, upset or sad have you been because of your skin?”  $r=0.62, P < 0.0001$ ; “how much have you changed or worn different or special clothes or shoes because of your skin?”  $r=0.49, P < .001$ ; “how much has your skin trouble affected going out, playing, or doing hobbies?”  $r=0.34, P < 0.05$ ; and “how much did your skin problem affect your school work?”  $r=0.43, P < 0.01$ ) in children from Singapore and did not correlate significantly with any CDLQI item in Italian children.

Correlations of disease severity with separate DFI items were significant for 7 items (except “food preparation and feeding”, “time spent on shopping for the family”, and “expenditure”) in Ukraine ( $P < 0.01$ ), 8 items (except “sleep of others in family” and “emotional distress”) in the Czech Republic ( $P < 0.01$ ), one item (“tiredness or exhaustion in your child’s parents/carers”  $r=0.34, P < 0.05$ ) in Singapore, and two items (“expenditure”  $r=0.44, P < 0.01$  and “emotional distress”  $r=0.37, P < 0.05$ ) in Italy.

Age of children correlated with three CDLQI items (“how much has your skin trouble affected going out, playing, or doing hobbies?”  $r=0.45, P < 0.01$ ; “how much did your skin problem affect your school work?”

**Table 2.** Data on separate Children’s Dermatology Life Quality Index (CDLQI) items of children with atopic dermatitis (AD) (mean±SD)

CDLQI Items	Singapore (n=35)	Czech Republic (n=50)	Italy (n=38)	Ukraine (n=44)
How itchy, “scratchy”, sore or painful has your skin been?	1.49±0.66	1.62±0.81	1.61±0.79	1.55±0.93
How embarrassed or self conscious, upset or sad have you been because of your skin?	0.89±0.87	1.18±0.98	0.66±0.94	1.23±1.10
How much has your skin affected your friendships?	0.57±0.65	0.30±0.65	0.26±0.60	0.80±0.95
How much have you changed or worn different or special clothes or shoes because of your skin?	1.00±0.94	0.68±0.79	0.13±0.34	1.98±1.02
How much has your skin trouble affected going out, playing, or doing hobbies?	1.06±1.00	0.72±0.95	0.24±0.71	1.16±1.06
How much have you avoided swimming or other sports because of your skin trouble?	1.09±0.95	0.88±1.04	0.42±0.98	1.07±1.11
How much did your skin problem affect your school work/interfered with your enjoyment of the holiday?	0.86±0.97	0.90±0.95	0.36±0.74	1.20±0.90
How much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?	1.17±0.87	0.44±0.64	0.32±0.77	0.95±0.91
How much has your sleep been affected by your skin problem?	1.17±1.22	1.02±0.94	0.74±0.95	1.34±0.86
How much of a problem has the treatment for your skin been?	1.09±1.04	0.84±0.71	0.64±0.95	1.59±1.02

**Table 3.** Data on separate Dermatitis Family Impact (DFI) items of children with atopic dermatitis (AD) (mean±SD)

DFI Items	Singapore (n=35)	Czech Republic (n=50)	Italy (n=38)	Ukraine (n=44)
Helping with treatment	0.54±0.95	1.04±1.03	0.68±1.0	1.57±0.82
Relationships	0.29±0.62	0.92±1.05	0.55±0.80	2.16±0.91
Emotional distress	0.57±0.95	0.68±0.94	0.68±0.90	1.20±0.79
Tiredness or exhaustion	0.74±1.16	1.04±1.07	0.21±0.47	1.14±0.88
Expenditure	0.29±0.62	0.50±0.74	0.37±0.67	1.82±1.04
Time spent on shopping	1.26±1.07	1.00±0.95	1.08±1.10	1.98±0.98
Leisure activities	0.94±0.97	0.78±0.93	0.74±0.83	1.50±0.85
Sleep of others	0.89±0.87	0.88±0.92	0.47±0.73	1.36±0.84
Food preparation and feeding	0.43±0.65	0.44±0.79	0.26±0.50	1.36±0.84
Housework	0.63±0.97	1.02±0.96	0.55±0.72	1.50±0.82

$r=0.44, P<0.01$ ; "how much has your sleep been affected by your skin problem?"  $r=0.38, P<0.01$ ) significantly in Czech children, one ("how much trouble have you had because of your skin with other people calling you names, teasing, bullying, asking questions or avoiding you?"  $r=0.38, P<0.05$ ) in children from Singapore, and none in Ukrainian children. In Italian children one separate CDLQI item "how much have you changed or worn different or special clothes or shoes because of your skin?" negatively correlated with their age ( $r=-0.40, P=0.01$ ). Only one separate DFI item on housework significantly correlated with age of children in Czech Republic ( $r=0.34, P<0.05$ ). No other significant correlations of the DFI items with age of children were found.

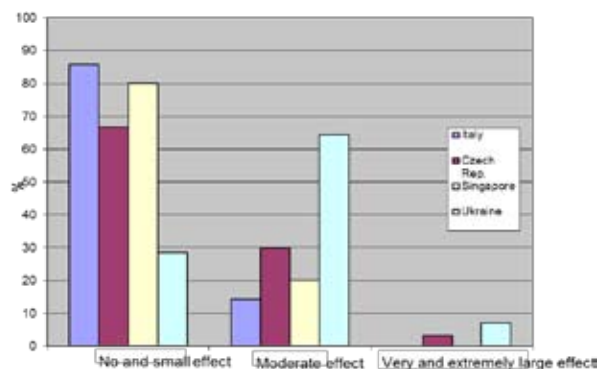
The percentage of children with mild, moderate, and severe AD according to SCORAD who reported no or small effects, moderate effects, very large, or extremely large effects on the child's life according to CDLQI stratification by Waters *et al.* (18) are presented in Figure 1, Figure 2, and Figure 3.

No significant gender differences were found between boys and girls in CDLQI and DFI results (Table 6).

## DISCUSSION

In most cases the parent who filled in the DFI questionnaire was the mother. However, it was previously shown that the gender of parent who filled in the DFI cannot significantly influence the results of clinical studies (19).

We found that self-assessed HRQoL of children with AD was in most cases better correlated with disease severity than family QoL results. However, there was a high level of correlation between self-assessed



**Figure 1.** Children's Dermatology Life Quality Index (CDLQI) banding results in children with mild atopic dermatitis (AD) according to Scoring of Atopic Dermatitis (SCORAD).

**Table 4.** Correlations of disease severity (Scoring of Atopic Dermatitis (SCORAD) with the overall Children's Dermatology Life Quality Index (CDLQI) and Dermatitis Family Impact (DFI) results and age of children with atopic dermatitis (AD)

	SCORAD (Spearman r)			
	Singapore (n=35)	Czech Republic (n=50)	Italy (n=38)	Ukraine (n=44)
CDLQI	$r=0.48 P<0.01$	$r=0.88 P<0.001$	$r=0.37 P<0.05$	$r=0.83 P<0.001$
DFI	$r=0.24 P=0.17$	$r=0.56 P<0.001$	$r=0.40 P<0.05$	$r=0.63 P<0.001$
Age	$r=0.16 P=0.36$	$r=0.34 P<0.05$	$r=0.41 P<0.05$	$r=0.02 P=0.92$

**Table 5.** Correlations of the age of patients with the Children’s Dermatology Life Quality Index (CDLQI) and Dermatitis Family Impact (DFI) results.

	Age (Spearman r)			
	Singapore (n=35)	Czech Republic (n=50)	Italy (n=38)	Ukraine (n=44)
CDLQI	r=0.17 P=0.34	r=0.39 P<0.01	r=0.09 P=0.60	r=0.02 P=0.90
DFI	r=0.06 P=0.75	r=0.23 P=0.10	r=0.15 P=0.36	r=-0.05 P=0.76

and family QoL in all countries except Singapore. The assistance of a parent or guardian to fill in the questionnaire is allowed by the authors of the CDLQI (12). However, this influence bring into question the level of interaction between children and parents during QoL assessment and explain the adult-child concordance reported for some proxy-ratings (9). Additional study on this issue is important.

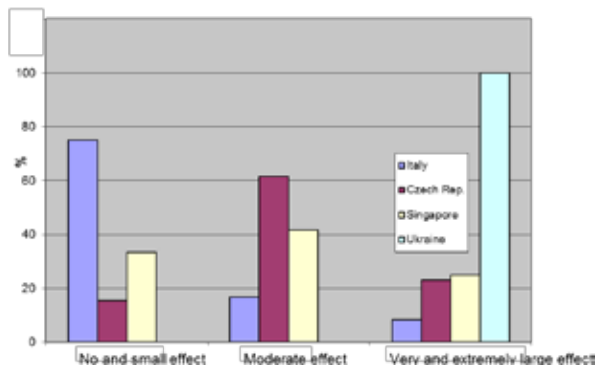
Disease severity increased with the age in Italian and Czech children. It is likely that elder children with not as severe AD less frequently apply for dermatologic consultation. Only in Czech children were the overall CDLQI results correlated with their age.

Older children from Czech Republic and Singapore had more problems related to their social life. Older Czech children also had more sleep problems. Older Italian children reported fewer problems related to wearing of special clothing. It is likely they mostly avoided wearing it to conform.

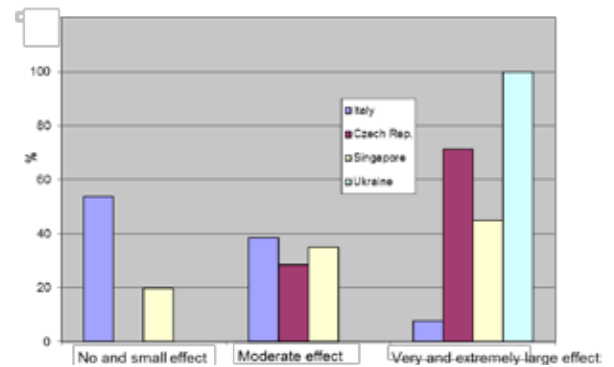
Only the family QoL item on housework problems in Czech families correlated significantly with the age of children. This means that family problems do not increase in conjunction with the duration of AD in any of the four countries.

Despite the hypothesis that the parents of younger AD children seemed to have a poorer QoL (7), mean family QoL scores of children less than 4 years of age from the Czech Republic and Ukraine (8) were lower than family QoL results of older children in our present study (7.43±5.86 and 8.26±7.11 for the Czech Republic and 9.44±5.69 and 15.59±6.05 for Ukraine, respectively).

The highest and the lowest scored CDLQI items were quite similar but not identical in different countries. The question on symptoms was one of the three highest scored items and the question on affected friendship was one of the three lowest scored items in all four countries. Meanwhile, the question on ex-



**Figure 2.** Children’s Dermatology Life Quality Index (CDLQI) banding results in children with moderate atopic dermatitis (AD) according to Scoring of Atopic Dermatitis (SCORAD).



**Figure 3.** Children’s Dermatology Life Quality Index (CDLQI) banding results in children with severe atopic dermatitis (AD) according to Scoring of Atopic Dermatitis (SCORAD).

**Table 6.** Mean overall data of the Children’s Dermatology Life Quality Index (CDLQI) and Dermatitis Family Impact (DFI) of boys and girls with atopic dermatitis (AD)

	Italy		Czech Republic		Singapore		Ukraine	
	Boys (n=19)	Girls (n=19)	Boys (n=19)	Girls (n=31)	Boys (n=20)	Girls (n=15)	Boys (n=17)	Girls (n=27)
CDLQI	6.32±6.57	4.42±3.96	9.16±5.33	8.23±5.28	10.0±6.71	9.73±5.51	12.59±8.20	13.07±7.73
DFI	6.58±6.52	4.58±4.23	9.68±7.67	7.39±6.73	6.10±6.03	7.07±6.49	15.53±5.06	15.63±6.69



penditures was one of the three highest scored DFI items and the question on relationships between the main carer and partner or between the main carer and other children in the family was one of the three lowest scored items in all countries. This is similar to the DFI results of small children with AD from different countries (8). However, in the present study only parents from Singapore reported "emotional distress" and parents from Italy and Singapore reported "tiredness and exhaustion" among the three highly scored items. Thus, parents of school children with AD are generally less stressed, tired, and exhausted than parents of preschool children.

Much more children from Ukraine and the Czech Republic reported a very large and extremely large effect of AD on their life. A comparative study on the impact of skin diseases on children in the UK and Bulgaria assessed using the CDLQI was published previously (26). The impact of AD was also more severe in children from the Eastern European country of Bulgaria. Total HRQoL results were quite similar in younger Ukrainian and Czech children with AD in a comparative study using the Infants Dermatitis Quality of Life Index (27). However, in our study Ukrainians showed more severe self-assessed and family QoL impairment. We hypothesize that the ability to assess HRQoL and family QoL in Ukrainians in this study was influenced by non-HR factors caused by political and subsequent military conflict.

We did not find gender differences either in the overall DFI or in the overall CDLQI results. However, it has been shown that such gender differences can be adequately studied only in scrupulously matched groups when each child in the group of boys is matched to a corresponding child in the group of girls whose age in months and SCORAD value are almost identical (28).

Self-assessed HRQoL of children with AD in our study correlated better in most cases with disease severity than family QoL results. AD symptoms and expenditures related to AD were highly scored in all countries. Impact of AD on friendship and relations between family members were among the lower scored items, and family problems did not increase in proportion with duration of AD in any of the four countries. These are very optimistic results for families with children with AD who did not recover until adolescence. Self-assessed HRQoL and family QoL results of children with AD from 5 till 16 years of age showed more heterogeneous results than proxy-assessment of HRQoL and family QoL results of younger children than was reported in a previous publication (8). Further international study on the influence of

treatment methods on the CDLQI and DFI results may be important to confirm common tendencies of self-assessed and family QoL changes under successful therapeutic intervention.

## CONCLUSION

Our study showed that the highest and the lowest scored CDLQI items were quite similar but not identical in different countries. Self-assessed health-related QoL of children with AD in our study correlated better in most cases with disease severity than family QoL results. Parents of school children with AD were generally less stressed, tired, and exhausted than parents of preschool children. These data together with results showing that duration of AD in children does not affect relations between parents and other family members is optimistic news for families with children with AD who did not recover until adolescence.

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