

## INVESTIGATIVE REPORT

# Itch Intensity Evaluated in the German Atopic Dermatitis Intervention Study (GADIS): Correlations with Quality of Life, Coping Behaviour and SCORAD Severity in 823 Children

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**The German Atopic Dermatitis Intervention Study (GADIS), which includes 823 children and adolescents, showed that age-related educational programmes are effective in the long-term management of atopic dermatitis. We investigated whether the itch severity obtained in the scoring of atopic dermatitis (SCORAD) correlates with quality of life and coping behaviour in children and parents. There were significant but low correlations between the severity of atopic dermatitis and the itch intensity. Itch and sleeplessness were significantly correlated. Significant correlations of itch with the coping behaviour and quality of life in parents of children with atopic dermatitis were measured. The coping and itching behaviour of children (8–12 years) and adolescents (13–18 years) had higher significant correlations with the itch compared with the parents' answers. Quality of life in children (8–12 years) and adolescents (13–18 years) showed a significant negative correlation with itch intensity. Quality of life, itch intensity and coping strategies should be considered when treating patients with atopic dermatitis. Key words: itch; atopic dermatitis; coping behaviour; quality of life.**

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Atopic dermatitis (AD) is one of the most common inflammatory skin diseases and has an increasing prevalence. In approximately 70% of cases it starts during infancy or early childhood (1). Its course is chronic or chronically relapsing. There is strong evidence for a multifactorial aetiology with interplay of several factors such as genetic, environmental, lifestyle and psychological factors (1, 2). AD is often referred to as the “itch” that “rashes” (3). Itching is often reported to be the most “bothersome” aspect of AD and is one of the first symp-

toms of an impending AD flare (4). The symptoms, such as itching, scratching and sleeplessness, can be a burden on the whole family (5), causing irritability and stress, not only for patients, but also for caregivers and other family members (5, 6). An association between scratching habits and “night awakening” was found (7). Itching in AD is not only the most frequent symptom but also a parameter of quality of life (QoL), as it has been shown that itch, its severity and, respectively, QoL are correlated (8). Itching has a highly negative impact on the affected patients' QoL (9). It is often the dominant reason for patients seeking professional help, especially in AD. In addition, scratching causes further itching, leading to the so-called itch-scratch cycle. Itching is a subjective sensation that shows great intra- and inter-individual variations and is difficult to assess. The process of documentation of itching and scratching includes the clinical inspection of skin lesions (e.g. erythema, papules, excoriations in acute pruritus, e.g. prurigo nodules, hyper- and hypopigmentation, scarring, atrophy in chronic pruritus), questionnaires, visual analogue scale (VAS), rating box, wrist activity monitoring and video camera documentation (10–14). The SCORAD (SCORing Atopic Dermatitis) is an index combining evaluation of extent, intensity of skin lesions and subjective symptoms (daytime pruritus, sleep loss) (15). It is the most extensively tested severity index (16). The validity and reliability of SCORAD have been demonstrated, as has its sensitivity in clinical trials. However, problems with inter-observer variations have occurred, but significant inter-observer variability has been shown only for lichenification and excoriations but not for itching (17).

The German Atopic Dermatitis Intervention Study (GADIS) was set up to develop standardized interventions for AD self-management, and to address their effects, focusing particularly on itching behaviour. It showed that age-related educational programmes are effective in the long-term management of AD in children and adolescents. The GADIS study has been described

in detail elsewhere (18, 19). Further analyses of the GADIS data presented here investigated the correlation of itching, AD severity and coping behaviour, including the objective SCORAD items and the subjective itch intensity obtained by a visual analogue scale (VAS).

## MATERIALS AND METHODS

The German Task Force on Education Programmes for Atopic Dermatitis (AGNES) for children, youths and parents was founded in 2000. ([www.neurodermitisschulung.de](http://www.neurodermitisschulung.de)) In a randomized prospective controlled trial (GADIS study) the effectiveness of AD group intervention programmes in parents of children with AD aged 0–7 years (A), parents of children with AD aged 8–12 years (B) and adolescents with AD aged 13–18 years (C) were studied compared with a control group (19) (Table I). The teaching programmes (6 × 2 h once weekly) comprised basic medical information about AD including the itch-scratch cycle, coping with scratching and sleep disturbances, basic information about topical and systemic treatment modalities, food allergy and food intolerance. The SCORAD index was used for scoring the disease severity of AD in the treatment groups A, B and C before and after the education programme and in the control group (without any teaching programme). This also comprised rating of itch (VAS scale ranging from 0 to 10) and sleep loss (VAS scale ranging from 0 to 10) included in the SCORAD. Additional questions focused on coping with itching, aggressions from scratching, and QoL parameters. We used the baseline data of the GADIS study for these analyses.

### Severity of eczema

The SCORAD scale was used to grade the severity of AD (15). The SCORAD scale is based on the extent of eczema, the morphology of lesions, and the 2 subjective parameters “sleep disturbance during the night” and “itch”. The objective SCORAD is the total SCORAD without the scales “itch” and “sleep disturbances during the night” related to subjective items. For statistical analyses, the intensity of itch was measured using the VAS integrated in the SCORAD. The subjective itch intensity was obtained by the investigator according to the patient’s rating. In the age group 0–7 years the VAS was performed by the investigator according to the parents’ rating.

### Quality of life in parents of children younger than 13 years with atopic dermatitis

Parents’ QoL was measured with the German questionnaire “Quality of life in parents of children with atopic dermatitis”. This questionnaire was developed as part of the Berlin public health study, “Evaluation of an educational programme for parents of children with atopic dermatitis” and has been validated (20). It comprises 26 items that can be divided by factor analysis into 5 clearly interpretable subscales: psychosomatic well-being; effects on social life; confidence in medical treatment;

Table I. Demographic data of the study population

Demographic data	0–7 years	8–12 years	13–18 years	Total
Age, mean (SD)	2.4 (1.9)	9.6 (1.6)	14.8 (1.7)	5.9 (5.1)
Participants, <i>n</i>	518	185	120	823
Gender (% male)	52.1	43.8	39.2	48.4
Itch, mean (SD)	5.4 (±2.4)	5.1 (±2.2)	5.2 (±2.3)	

SD: standard deviation.

emotional coping; and acceptance of the disease. The convergent validity of this scheme has been tested. The questionnaire also highlights differences between parents of children with various degrees of disease severity, which is a prime indicator of clinical relevance. The questionnaire has demonstrated high intra-class coefficients for re-test reliability. The reliability for the subscales was medium to high, which was expressed by a Cronbach’s alpha for the subscales between 0.57 and 0.90. The intercorrelations of the dimensions are moderate (0.20–0.63), which demonstrates that each dimension gives independent information on the respective aspects of QoL.

### Coping behaviour in parents of children (FEN) with atopic dermatitis

The coping behaviour of parents of children with AD was measured using a standardized questionnaire with 22 items on 4 scales: aggression with respect to scratching; protective behaviour; control of scratching; and negative treatment experience (21). The German version of the questionnaire has been well validated in several studies focusing on coping behaviour in parents of children with AD showing coping problems of parents (22) (Table IIa).

### Coping and itching behaviour in children and adolescents aged 8 years and older with atopic dermatitis

Itching behaviour was measured using standardized questionnaires (“JUCKKI” with 15 items for children aged 8–12 years, and “JUCKJU” with 18 items for adolescents aged 13–18 years) (Table IIb). The final versions of these 2 questionnaires were tested in a group of 204 children and 168 adolescents. Two-

Table II. Questionnaires for atopic dermatitis (AD) for parents (a) and for children (b). Number of items and range of scales used in this study.

a)		
Questionnaire for parents with children with AD	Number of items (range)	
<i>Coping for parents of AD infants/children (FEN) (22)</i>		
Aggression in regard of scratching	8 (8–40)	
Protective behaviour	7 (7–35)	
Control of scratching	4 (4–20)	
Negative treatment experience	3 (3–15)	
<i>Quality of Life (20)</i>		
Psychosomatic well-being	9 (9–45)	
Effects on social life	6 (6–30)	
Confidence in medical treatment	5 (5–25)	
Emotional coping	4 (4–20)	
Acceptance of the disease	2 (2–10)	
b)		
Questionnaire for children with AD	Number of items (range)	
	8–12 years	13–18 years
<i>Coping for children with AD (COPEKI; COPEJU) (23)</i>		
Depressive mood/social anxiety	10 (0–40)	8 (0–32)
Itching-scratching circle/stress from the disease	8 (0–32)	10 (0–40)
<i>Itching behaviour for children with AD (JUCKKI; JUCKJU) (23)</i>		
Catastrophisation	9 (0–36)	9 (0–36)
Coping	6 (0–24)	9 (0–36)
<i>Quality of life for children with AD (24)</i>		
Quality of life	15 (15–75)	15 (15–75)

Table III. Correlations of itch with coping behaviour and quality of life in parents of children with atopic dermatitis (AD) aged 0–7 years ( $n = 518$ ) and 8–12 years ( $n = 185$ )

	Age group		Age group	
	0–7 years ( $n = 518$ )		8–12 years ( $n = 185$ )	
Correlation of itch with:	Mean (SD)	Spearman's $\rho$ ( $p$ -value)	Mean (SD)	Spearman's $\rho$ ( $p$ -value)
<i>Coping for parents of AD infants/children (FEN) (22)</i>				
Aggression with regard to scratching	16.7 (6.0)	0.22 (<0.001)	17.0 (6.0)	0.17 (0.027)
Protective behaviour	16.3 (5.7)	0.28 (<0.001)	17.7 (6.1)	0.13 (0.110)
Control of scratching	10.5 (2.9)	0.20 (<0.001)	10.6 (3.0)	0.18 (0.023)
Negative treatment experience	8.7 (3.0)	0.19 (<0.001)	9.0 (3.2)	0.15 (0.052)
<i>Quality of life of parents (20)</i>				
Psychosomatic well-being	29.2 (7.6)	-0.20 (<0.001)	31.4 (7.2)	-0.25 (0.002)
Effects on social life	24.6 (4.3)	-0.23 (<0.001)	25.8 (4.5)	-0.18 (0.024)
Confidence in medical treatment	16.0 (4.2)	-0.05 (0.262)	17.2 (4.0)	-0.17 (0.033)
Emotional coping	14.0 (3.3)	-0.16 (<0.001)	14.1 (3.3)	-0.29 (<0.001)
Acceptance of the disease	7.0 (1.9)	-0.14 (0.002)	7.3 (1.8)	-0.22 (0.005)

SD: standard deviation; FEN: questionnaire for parents of children with atopic dermatitis.

factorial scale solutions resulted for both questionnaires. The 2 factors covered the areas "catastrophization" and "coping". The internal consistence can be rated "satisfactory" to "good" showing values between 0.72 and 0.91 (23).

#### *Quality of life in children and adolescents aged 8 years and older with atopic dermatitis*

The QoL in children and adolescents suffering from AD were assessed by a short questionnaire that was established by Warschburger (24) and validated in a recent study regarding coping behaviour (25).

#### *Data analysis*

Data entry and storage was performed using Microsoft Access 2000. Data analysis was performed with SAS® Version 9.1 WIN. Categorical data were summarized by means of absolute and relative frequencies (counts and percentages). Quantitative data and scores were summarized by means of arithmetic mean and standard deviation. Spearman's rank correlations were calculated to evaluate possible correlations. Graphical data are presented as scatter plots.  $p$ -values less than 0.05 were considered statistically significant.

## RESULTS

Comparison of trained and non-trained patients with AD in all age groups including their parents (groups A and B) showed significant improvement of all physical and psychological parameters (19). The current analysis focused on the correlations of itch with AD severity measured with the objective SCORAD, coping behaviour and parents' QoL of children with AD in the age groups 0–7 years and 8–12 years and coping behaviour, coping with itch and QoL in patients with AD aged 8–12 and 13–18 years. The subjective itch measured by VAS in the SCORAD correlated with nearly all investigated variables of AD (severity and coping aspects significantly). There were different levels of significant correlations. The coping behaviour of parents correlated much more in children aged 0–7 years ( $r = 0.19$ – $0.28$ ) than in those aged 8–12 years ( $r = 0.13$ – $0.18$ ) (see Table III). QoL showed no significant correlation in the scale "confidence in medical treatment" and low significant

Table IV. Correlations of itch with coping and itch behaviour of children with atopic dermatitis (AD) aged 8–12 years ( $n = 185$ ) and adolescents aged 13–18 years ( $n = 120$ )

	Age group		Age group	
	8–12 years ( $n = 185$ )		13–18 years ( $n = 120$ )	
Correlation of itch with:	Mean (SD)	Spearman's $\rho$ ( $p$ -value)	Mean (SD)	Spearman's $\rho$ ( $p$ -value)
<i>Coping for children with AD (COPEKI; COPEJU) (23)</i>				
Depressive mood / social anxiety	13.4 (8.8)	0.35 (<0.001)	17.4 (6.4)	0.40 (<0.001)
Itch-scratch cycle / stress from the disease	14.3 (6.5)	0.43 (<0.001)	12.5 (7.2)	0.23 (0.011)
<i>Itching behaviour for children with AD (JUCKKI, JUCKJU) (23)</i>				
Catastrophization	13.6 (8.4)	0.41 (<0.001)	16.4 (8.2)	0.40 (<0.001)
Coping	7.6 (4.9)	0.10 (0.183)	14.6 (7.5)	0.05 (0.597)

SD: standard deviation; COPEKI: coping with disease questionnaire for children; COPEJU: coping with disease questionnaire for adolescents; JUCKKI: itching questionnaire for children; JUCKJU: itching questionnaire for adolescents.

Table V. Correlations of itch with the quality of life scale and the objective SCORAD (SCORing Atopic Dermatitis) in children with atopic dermatitis (AD) aged 0–7 years ( $n = 518$ ) 8–12 years ( $n = 185$ ) and adolescents aged 13–18 years ( $n = 120$ )

Correlation of itch with:	Age group					
	0–7 years ( $n = 518$ )		8–12 years ( $n = 185$ )		13–18 years ( $n = 120$ )	
	Mean (SD)	Spearman's $\rho$ ( $p$ -value)	Mean (SD)	Spearman's $\rho$ ( $p$ -value)	Mean (SD)	Spearman's $\rho$ ( $p$ -value)
Quality of life in children with AD (23)	–	–	47.0 (7.9)	–0.42 (<0.001)	46.4 (7.2)	–0.33 (<0.001)
Objective SCORAD	32.0 (13.7)	0.32 (<0.001)	33.3 (13.7)	0.30 (<0.001)	34.0 (12.1)	0.38 (<0.001)

SD: standard deviation.

correlations in the other 4 scales (Table III). As demonstrated in Table IV, higher correlations could be found between itch and coping in any of the age groups. To a lesser extent, negative correlations were found between itch and QoL (Table V). This was also shown when correlations of QoL and itch intensity were tested (Fig. 1). The analysis of the correlation between the objective SCORAD (extent and severity) and the subjective itch intensity showed positive significant correlations to a low extent (Table VI). The correlations of itch with “sleeplessness” were much higher (Fig. 2). The Spearman's rank correlation coefficients are presented for different age groups (Figs 1 and 2).

## DISCUSSION

As demonstrated in the Tables and Figures, there are different positive correlations between itching, SCORAD, sleeplessness, coping behaviour and QoL parameters in the investigated age groups. Measuring itch in a VAS scale of the last 7 days (in the SCORAD questionnaire) is difficult and is limited by subjective variations of the children and the parents. This is striking because it is a well-known fact that night-time pruritus is a particular and frequent problem described by patients with AD (7). In addition, day-time itching and scratching differ from night-time itching because it is influenced by daily activities. Additionally, the results obtained in children of different age groups who attended an AD teaching programme showed that there is a remarkable correlation of the itch intensity recorded in the SCORAD and QoL parameters as well as coping behaviour.

Differences in correlations are very interesting. There are high correlations between subjective itch in the VAS

scale and coping behaviour in parents of children with AD aged 0–7 years as well as the QoL in parents. The correlations in children with AD aged 8–12 years are much lower. There are high and significant correlations between itch and coping behaviour, coping with itch, QoL and sleeplessness in children with AD aged 8–12 and 13–18 years, wherever the significant correlations between the objective SCORAD and subjective itch is not that high. In conclusion, QoL parameters and coping behaviour seem to play a major role in the subjective impairment of itch, especially in patients aged 8–12 and 13–18 years. The same result can be demonstrated when looking at the QoL and coping behaviour in parents of children with AD aged 7 years and younger.

Measuring itch and scratch in children is still a challenge. A recent experimental study showed that children aged 4–5 years discriminated between saline and histamine prick tests but not between different histamine concentrations. Children aged 6–12 years were able to discriminate between different histamine-induced itch stimuli in a dose-dependent way (26). Studies using limb-worn digital accelerometers and infrared video analyses demonstrated that children with AD showed 2–3 times as much scratching or restlessness activity as control subjects (13). Scratching and restlessness were highly correlated. There was little correlation between parental assessment of scratch and objective measured scratch (13). This was confirmed in another study investigating measurement of itch using actigraphy in children with AD. It showed that the correlation between subjective measures and objective recorded measures of disease severity was imperfect and may not be straightforward (12). Others found a lack of correlation between subjective symptoms (pruritus, sleep loss) and objective parameters (extent and intensity of AD) obtained by

Table VI. Spearman Correlation Coefficients (significance) of itch in the different age groups in comparison to extent, severity and sleeplessness in the SCORAD (SCORing Atopic Dermatitis)

	0–7 years ( $n = 518$ )	8–12 years ( $n = 185$ )	13–18 years ( $n = 120$ )
Extent in SCORAD	0.165 (<0.0002)	0.303 (<0.0001)	0.232 (<0.0001)
Severity in SCORAD	0.329 (<0.0001)	0.284 (<0.0001)	0.398 (<0.0001)
Objective SCORAD (extent + severity)	0.320 (<0.0001)	0.299 (<0.0001)	0.381 (<0.0001)
Sleeplessness (VAS-scale in SCORAD)	0.450 (<0.0001)	0.523 (<0.0001)	0.499 (<0.0001)

VAS: visual analogue scale.

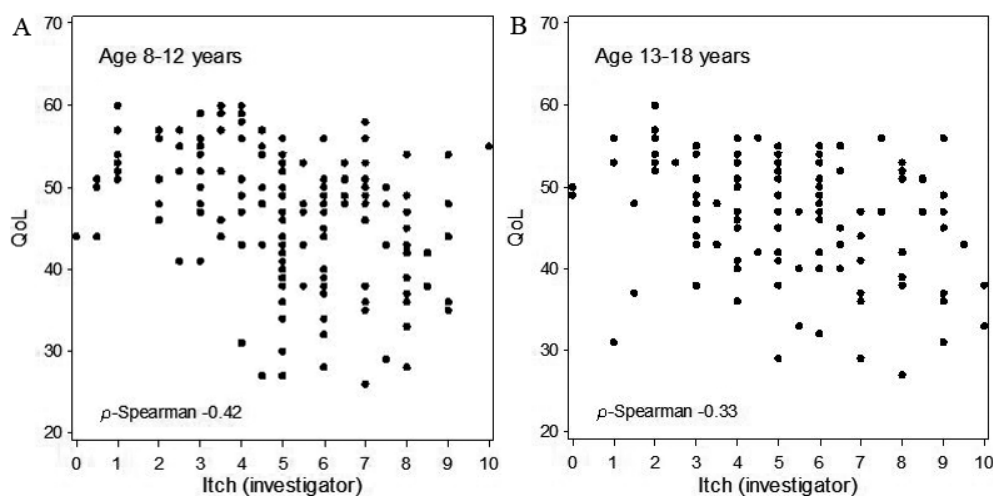


Fig. 1. Correlations between quality of life (QoL) and itch in (A) children with atopic dermatitis aged 8–12 years and (B) children aged 13–18 years.

SCORAD in children with AD (14, 27). These results were supported by another study (28). It demonstrated that wrist activities measured by DigiTrac are closely correlated with the objective clinical scores and levels of peripheral blood chemokine markers for AD but are not correlated with the reported symptoms of pruritus and sleep loss. It was concluded that itch and sleep-loss components of the SCORAD should be substituted by wrist activity documentation (28).

Our results emphasize that the recording and measurement of itching require separate appreciation and validation. Subjective symptoms such as itch are frequently assessed fragmentarily even in well-established index systems such as the SCORAD index. There is a likelihood that even well-appreciated index systems for scoring the severity of AD underestimate the problem of itch. Further studies are needed, not only for improving the assessment of itch in children in a practical way, but also to fill the gap between objective and subjective symptoms, including parental assessment of subjective symptoms in AD.

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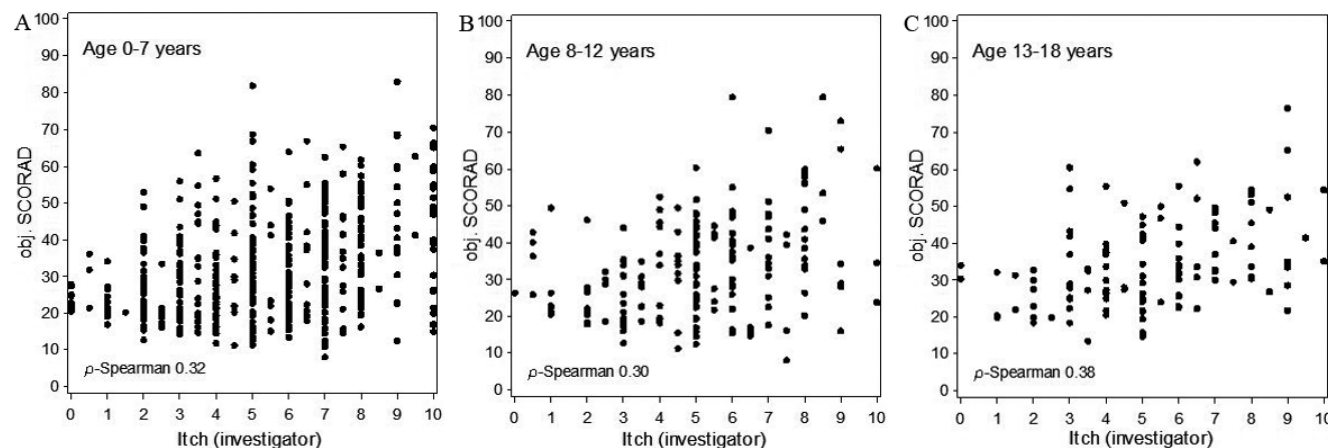


Fig. 2. Correlations between objective SCORAD (SCORing Atopic Dermatitis) and itch in AD children: (A) aged 0–7 years; (B) aged 8–12 years; and (C) aged 13–18 years.

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