

## Age related, structured educational programmes for the management of atopic dermatitis in children and adolescents: multicentre, randomised controlled trial

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### Abstract

**Objective** To determine the effects of age related, structured educational programmes on the management of moderate to severe atopic dermatitis in childhood and adolescence.

**Design** Multicentre, randomised controlled trial.

**Setting** Seven hospitals in Germany.

**Participants** Parents of children with atopic dermatitis aged 3 months to 7 years (n = 274) and 8-12 years (n = 102), adolescents with atopic dermatitis aged 13-18 years (n = 70), and controls (n = 244, n = 83, and n = 50, respectively).

**Interventions** Group sessions of standardised intervention programmes for atopic dermatitis once weekly for six weeks or no education (control group).

**Main outcome measures** Severity of eczema (scoring of atopic dermatitis scale), subjective severity (standardised questionnaires), and quality of life for parents of affected children aged less than 13 years, over 12 months.

**Results** Significant improvements in severity of eczema and subjective severity were seen in all intervention groups compared with control groups (total score for severity: age 3 months to 7 years - 17.5, 95% confidence intervals - 19.6 to - 15.3 v - 12.2, - 14.3 to - 10.1; age 8-12 years - 16.0, - 20.0 to - 12.0 v - 7.8, - 11.4; - 4.3; and age 13-18 years - 19.7, - 23.7 to - 15.7 v - 5.2, - 10.5 to 0.1). Parents of affected children aged less than 7 years experienced significantly better improvement in all five quality of life subscales, whereas parents of affected children aged 8-12 years experienced significantly better improvement in three of five quality of life subscales.

**Conclusion** Age related educational programmes for the control of atopic dermatitis in children and adolescents are effective in the long term management of the disease.

### Introduction

Although several educational interventions have been developed for adults with atopic dermatitis, the literature on educational programmes for children and their parents is sparse.<sup>1</sup> In addition, studies have not used the

type of standardised, structured intervention that is proving highly beneficial in the management of other chronic atopic conditions in children.<sup>2</sup> Our study was set up to develop standardised interventions for the self management of atopic dermatitis and to assess their effects.

We determined the long term effect of age related, structured educational programmes on the control of moderate to severe atopic dermatitis in childhood and adolescence by assessing changes in disease severity, itch, and parents' quality of life over 12 months.

### Participants and methods

The three participating groups were parents of children with atopic dermatitis aged 3 months to 7 years and 8-12 years and adolescents with atopic dermatitis aged 13-18 years (see [bmj.com](http://bmj.com)). Participants were recruited from seven hospitals in Germany. The inclusion criteria were diagnosis of atopic dermatitis according to predefined criteria,<sup>3</sup> eczema duration of at least three months, and a severity of eczema of at least 20 points on the scoring of atopic dermatitis scale.<sup>4</sup>

The study was designed as a randomised, controlled intervention study. Randomisation was carried out by an independent study centre using computer generated random numbers. The treatment programme consisted of six, weekly group sessions (5-8 participants), lasting two hours each. Patients were drawn consecutively from the seven study centres. The patients and their parents in the intervention and control groups were followed up at six (data not shown) and 12 months. See [bmj.com](http://bmj.com) for details of sample size calculation.

### Interventions

The educational programme was standardised to provide theme centred group training. Parents of children aged 3 months to 7 years received education with con-

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tent based on reported work.<sup>5</sup> The parents of children aged 8-12 years attended separate sessions. Adolescents aged 13-18 years attended sessions tailored to their needs.<sup>6</sup> These sessions covered medical, nutritional, and psychological issues, and were carried out by a multiprofessional team (see bmj.com).

**Outcome measures**

The primary end points were the differences in severity of eczema and parents' quality of life over 12 months.

We graded the severity of eczema using the scoring of atopic dermatitis scale.<sup>4</sup> This scale is based on the extent of eczema, the morphology of the lesions, and the two subjective items of sleep disturbance during the night and itch. The objective scoring of atopic dermatitis is the total score on the scoring of atopic dermatitis scale minus the scores related to both subjective items.

The subjective severity of eczema was measured using the "skin detective"; parents compared their child's skin lesions with those of illustrations evaluated by experts.<sup>7</sup>

We used two standardised questionnaires to measure itch: JUCKKI for 8-12 year olds and JUCKJU for 13-18 year olds.<sup>8</sup> Two factors covered by the questionnaires were catastrophisation (negative thoughts on pain that have got out of control) and coping.

The quality of life for parents of children aged less than 13 years was measured with the validated questionnaire "Quality of life in parents of children with atopic dermatitis."<sup>9</sup> Its 26 items can be divided into five subscales: psychosomatic wellbeing, effects on social life confidence in medical treatment, emotional coping, and acceptance of the disease.

**Statistical analysis**

For statistical tests we used non-parametric methods. We used analyses of covariance to compare values at baseline with those at 12 months between the study arms.

**Results**

In total, 992 of 1010 patients eligible for the study were randomised: 645 parents of children with atopic dermatitis aged 3 months to 7 years, 214 parents of children aged 8-12 years, and 151 adolescents aged 13-18 years (see bmj.com). Outcome measures at baseline in all age groups did not differ significantly between the intervention and control groups (see bmj.com). After losses during follow-up, the number of participants in the intervention arms was 274 for children aged 3 months to 7 years; 102 for children aged 8-12 years; and 70 for adolescents aged 13-18 years (control groups 244, 83, and 50), respectively.

**Severity of eczema**

At baseline the mean score for severity of eczema was greater than 40 points in the intervention and control groups (table 1). At 12 months the score had decreased in all groups, but the decrease was significantly greater in the intervention arms. The subjective severity score for eczema decreased significantly more in the intervention groups.

**Itching behaviour in 8-12 year olds and 13-18 year olds**

In the 8-12 year olds, significantly greater improvements were shown for itch in the intervention group for the subscales catastrophisation (intervention, -7.0, 95% confidence interval -8.9 to -5.1; control, -1.8, -3.5 to -0.2; P<0.0001) and coping (1.0, -0.3 to 2.3 v -0.4, -1.6 to 0.8; P<0.05; table 1). In adolescents only the subscale catastrophisation showed a significantly greater improvement.

**Quality of life for parents of children aged less than 13 years**

Improvement in quality of life for mothers of children aged 3 months to 7 years was significantly greater in the intervention group for all five subscales of the

**Table 1** Outcome variables using analysis of covariance at baseline and 12 months' follow-up for groups receiving an educational programme in atopic dermatitis or no education

Outcome by age group	Intervention			No intervention			No intervention minus intervention Difference (95% CI)	P value
	Baseline	12 months	Mean (95% CI) difference	Baseline	12 months	Mean (95% CI) difference		
3 months to 7 years: n=274								
Total severity score*	41.1 (16.6)	23.7 (16.7)	-17.5 (-19.6 to -15.3)	40.6 (15.2)	28.4 (16.5)	-12.2 (-14.3 to -10.1)	-5.2 (-8.2 to -2.2)	0.0002
Objective severity score*	32.5 (14.3)	19.5 (13.9)	-13.0 (-14.8 to -11.2)	31.4 (13.0)	22.6 (13.4)	-8.7 (-10.5 to -7.0)	-4.2 (-6.8 to -1.7)	0.0009
Subjective severity	8.3 (3.8)	4.8 (3.4)	-3.3 (-3.9 to -2.8)	8.3 (3.8)	6.1 (3.6)	-2.2 (-2.7 to -1.6)	-1.1 (-1.9 to -0.3)	<0.001
8-12 years: n=102								
Total severity score*	41.8 (16.6)	25.8 (17.7)	-16.0 (-20.0 to -12.0)	40.4 (15.1)	32.6 (16.5)	-7.8 (-11.4 to -4.3)	-8.2 (-13.6 to -2.8)	0.003
Objective severity score*	34.0 (14.1)	21.7 (15.1)	-12.3 (-15.6 to -8.9)	32.5 (13.1)	26.9 (14.2)	-5.6 (-8.7 to -2.5)	-6.7 (-11.2 to -2.1)	0.005
Subjective severity	8.5 (3.9)	4.9 (2.9)	-3.7 (-4.6 to -2.7)	8.6 (3.5)	7.0 (3.8)	-1.6 (-2.5 to -0.7)	-2.1 (-3.4 to -0.8)	<0.001
Itching behaviour								
Catastrophisation†	13.6 (8.5)	6.6 (6.5)	-7.0 (-8.9 to -5.1)	13.6 (8.2)	11.8 (8.6)	-1.8 (-3.5 to -0.2)	-5.2 (-7.7 to -2.7)	<0.0001
Coping	7.7 (5.1)	8.8 (5.4)	1.0 (-0.3 to 2.3)	7.6 (4.6)	7.2 (5.0)	-0.4 (-1.6 to 0.8)	1.5 (-0.3 to +3.2)	0.047
13-18 years: n=70								
Total severity score*	43.1 (14.7)	23.4 (12.6)	-19.7 (-23.7 to -15.7)	40.4 (13.9)	35.2 (15.2)	-5.2 (-10.5 to 0.1)	-14.5 (-21.2 to -7.9)	<0.0001
Objective severity score*	34.4 (12.4)	19.5 (11.1)	-15.0 (-18.4 to -11.6)	33.4 (12.0)	28.3 (12.0)	-5.1 (-9.5 to -0.6)	-9.9 (-15.5 to -4.3)	<0.0001
Subjective severity	8.9 (3.2)	5.8 (3.4)	-3.1 (-4.1 to -2.2)	8.8 (3.5)	8.1 (4.0)	-1.0 (-2.1 to 0.1)	-2.1 (-3.5 to -0.7)	<0.0022
Itching behaviour								
Catastrophisation†	16.6 (7.9)	9.8 (8.1)	-6.8 (-8.6 to -5.0)	16.9 (8.6)	14.9 (9.0)	-2.0 (-3.9 to -0.2)	-4.7 (-7.3 to -2.2)	0.0002
Coping	15.4 (7.8)	15.2 (8.2)	-0.2 (-1.9 to 1.5)	14.0 (7.0)	14.5 (7.0)	0.4 (-1.2 to 2.1)	-0.6 (-3.0 to +1.7)	0.875

\*Scoring of atopic dermatitis scale.

†Negative thoughts on pain that have got out of control.

quality of life questionnaire (table 2). Improvement in quality of life for mothers of children aged 8-12 years was significantly greater in the intervention group for three of the subscales. The improvement in the subscales for confidence in medical treatment, emotional coping, and acceptance of the disease were significantly greater in the intervention group. The subscales for psychosomatic wellbeing and effects on social life did not differ significantly between the intervention and control groups.

## Discussion

Age related educational programmes for the control of atopic dermatitis in children and adolescents are effective in the long term management of the disease. Over a 12 month period statistically significant benefits were seen in the intervention groups for severity of eczema, subjective severity, and effect on parents' quality of life. One important feature of our study was the inclusion of a control group, since improvements in outcomes are also observed in the absence of education. The educational intervention is probably complex as it can have a range of specific and non-specific effects and interactions between such effects. The benefit may not be attributable solely to the interventions in the absence of a controlled group that has simple non-directive group work with no education. We assumed that patients in the control groups were highly motivated and tried to optimise therapies. We monitored treatments by questionnaire and found no major imbalances between study arms. The effect of education on long term improvements of disease severity was noticeable and compares favourably with drug intervention alone.

It is well known that patients with an identical composite score on the scoring of atopic dermatitis scale may differ greatly in the measures of individual items. To our knowledge, however, even a 5 point improvement in the score might be clinically relevant for an individual patient.

The design of the programme, developed by the German atopic dermatitis intervention study, differs from previous psychosocial interventions. The educational programme comprises a 40 hour training work-

### What is already known on this topic

Atopic dermatitis is a chronic skin disease with a high prevalence and high burden

Lack of information and lack of confidence in medical treatment lead to suboptimal management of the disease

### What this study adds

Age related educational programmes improve the long term management of atopic dermatitis

Both parents of affected young children and adolescents reported reduced severity of eczema and improved quality of life

shop for teachers qualified in atopic dermatitis. The programme is offered by institutions with national certification for the education of children and adolescents with the disease. One new and notable aspect of the educational programme is the promotion of cooperation between professionals from different disciplines with highly diverse approaches.

A strategy that maximises patient and parent education can complement a symptom oriented therapeutic approach.<sup>10</sup> Such an approach is appropriate for atopic dermatitis, when psychological and nutritional factors and a combination of topical and systemic therapies may need to be considered to tackle the underlying multifactorial pathophysiology of this chronic disease.<sup>11</sup> In addition to treating the symptoms of atopic dermatitis in childhood and adolescence, giving parents educational support is an important factor in achieving a positive long term outcome.<sup>5</sup>

Although the value of programmes for the prevention of atopic dermatitis is recognised, this approach is usually used when basic therapy and expert attention have failed. We included in our study only families of children diagnosed as having moderate to severe atopic dermatitis. However a study that evaluated educating adult patients about atopic dermatitis showed that those patients with less severe symptoms derived greater benefit.<sup>12</sup>

**Table 2** Results using analysis of covariance of parental quality of life questionnaire at baseline and 12 months for groups receiving an educational programme in atopic dermatitis or no education

Outcome by age group	Intervention			No intervention			No intervention minus intervention	P value
	Baseline	12 months	Mean (95% CI) difference	Baseline	12 months	Mean (95% CI) difference	Difference (95% CI)	
3 months to 7 years: n=274								
Psychosomatic wellbeing	29.3 (7.6)	33.7 (7.0)	4.4 (3.6 to 5.2)	29.1 (7.7)	32.1 (7.1)	3.1 (2.2 to 3.9)	1.4 (0.2 to 2.5)	0.0040
Effects on social life	24.9 (4.0)	26.7 (3.4)	1.8 (1.4 to 2.3)	24.5 (4.4)	25.5 (4.1)	1.0 (0.6 to 1.5)	0.8 (0.2 to 1.4)	<0.0001
Confidence in medical treatment	16.0 (4.0)	20.0 (3.5)	4.0 (3.5 to 4.5)	15.8 (4.4)	17.8 (4.2)	1.9 (1.4 to 2.4)	2.1 (1.4 to 2.8)	<0.0001
Emotional coping	13.7 (3.2)	16.8 (2.9)	3.1 (2.7 to 3.5)	14.2 (3.4)	15.4 (3.2)	1.1 (0.7 to 1.6)	1.9 (1.3 to 2.5)	<0.0001
Acceptance of disease	7.1 (1.9)	8.2 (1.7)	1.1 (0.8 to 1.3)	7.0 (1.9)	7.5 (1.8)	0.5 (0.3 to 0.8)	0.6 (0.2 to 0.9)	<0.0001
8-12 years: n=102								
Psychosomatic wellbeing	31.5 (7.9)	34.7 (6.0)	3.2 (1.9 to 4.5)	31.2 (6.1)	33.8 (7.0)	2.6 (1.4 to 3.8)	0.6 (-1.2 to 2.4)	0.360
Effects on social life	25.8 (4.2)	27.0 (3.8)	1.1 (0.4 to 1.8)	26.3 (4.0)	27.2 (3.5)	0.9 (0.2 to 1.6)	0.2 (-0.8 to 1.2)	0.940
Confidence in medical treatment	17.0 (4.0)	20.1 (3.2)	3.1 (2.2 to 3.9)	17.4 (3.9)	17.5 (4.4)	0.1 (-0.7 to 1.0)	2.9 (1.7 to 4.1)	<0.0001
Emotional coping	13.7 (3.3)	16.4 (2.8)	2.7 (2.0 to 3.4)	14.7 (3.2)	15.6 (3.4)	0.9 (0.2 to 1.6)	1.8 (0.9 to 2.8)	0.002
Acceptance of disease	7.3 (1.9)	8.1 (1.5)	0.8 (0.4 to 1.2)	7.4 (1.7)	7.7 (1.8)	0.2 (-0.2 to 0.6)	0.6 (0 to 1.2)	0.031

In conclusion an age related educational programmes for the control of atopic dermatitis in children and adolescents were significantly effective in the long term management of the disease.

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## Commentary: The double benefits of educational programmes for patients with eczema

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Stabb et al's study clearly shows that educational programmes for the management of atopic dermatitis in children and self management in adolescents greatly improve control of the disease.<sup>1</sup> What they fail to say, however, is why the programmes are so effective, or that they could be a valuable resource in primary care (where most patients with atopic dermatitis are seen) as well as in secondary care.

Poor adherence to therapy is a major reason for treatment failure in patients with atopic dermatitis. The most important cause is lack of knowledge about the disease and its treatment.<sup>2</sup> People with eczema and their carers have several educational needs that must be met if they are to be enabled to take control of the disease. They need to understand the nature of the condition—that it is a chronic and relapsing disorder with no cure at present, but that it can be managed effectively; they need the opportunity to try a range of treatments to find those that suit them best; they need reassurance that the treatments are safe and effective; they need to be shown how best to apply topical treatments; and they need to be motivated to continue treatment, albeit usually in a modified form when the disease is in remission.

All this takes time—a scarce resource in most healthcare systems. In Britain an appointment with a general practitioner typically lasts 10 minutes,<sup>3</sup> nowhere near sufficient time to provide the education necessary for effective management of atopic dermatitis. The problem is exacerbated by the suboptimal training of general practitioners in dermatology.<sup>4</sup>

One factor that is often ignored but which can and should be addressed in educational programmes for atopic dermatitis is the need for patients to be able to choose their topical treatments. Treatments for almost all non-dermatological diseases are taken orally or injected. Most treatments for atopic dermatitis are

topical and must be “worn” by patients in much the same way as women wear make-up. If a topical treatment is cosmetically unacceptable to a patient, he or she will not use it, resulting in waste, poor clinical outcomes, and patient dissatisfaction.

A further common and significant factor in non-adherence to treatment regimens for atopic dermatitis is “steroid phobia.”<sup>5</sup> Patients—and especially the parents of small children—need to be educated about the safety and efficacy of topical corticosteroids and their use.

Patients also need to be educated about the quantities of topical treatments used and to be shown how to apply those treatments. At present in Britain this is often made more difficult for patients by the under-prescribing of emollients.<sup>2</sup>

The potential benefits that educational programmes for atopic dermatitis have to offer patients and carers are matched by their benefits to health professionals. Good education is time consuming, and although individual tuition may be ideal it is unlikely to be practicable. Institutes dedicated to eczema, as with those pioneered in Germany, are neither difficult nor expensive to run and offer the opportunity to educate groups of patients.

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