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Evaluation of a parental training program for the management of childhood atopic dermatitis

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Atopic dermatitis (AD) in childhood is a common disease with prevalence rates as high as 20%. Its early onset in infancy and its chronic relapsing course puts a special burden on families. Supporting parents in dealing with the management of AD presents a challenge for physicians. The objective of this study was to determine the effect of a structured parental training program on managing AD in children. Two-hundred and four families participated in a prospective, randomized controlled trial. Children (5 months to 12 years in age) had suffered from moderate-to-severe AD for at least 4 months. They were randomly assigned to either the intervention group or a waiting, control group who could participate in the training program 1 year later. The intervention was an inter-disciplinary, structured educational program which covered medical, nutritional, and psychological issues in six group sessions of 2 h each. The families were assessed at the beginning of the study and 1 year later. Main outcome measures were: severity of eczema (SCORAD); treatment habits; treatment costs; quality of life; and coping strategies. Significant effects were shown regarding treatment behavior, such as regular use of emollients, use of antiseptics and topical steroids in the event of exacerbation, and a reduction in the use of unconventional therapies. Satisfaction with medical treatment was improved, and rumination as an ineffective coping strategy was reduced. Finally, significant reduction of treatment costs was achieved. We conclude that structured training programs for parents of children with AD is a helpful adjunct to dermatological treatment.

Doris Staab, Ursula von Rueden, Rainer Kehrt, Michael Erhart, Kerstin Wenninger, Panagiotis Kamtsiuris and Ulrich Wahn
Department for Pediatric Pneumology and Immunology, Children's Hospital Charité Campus Virchow, Humboldt-University, Berlin, Germany

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Dr Doris Staab, Clinic for Pediatric Pneumology and Immunology, Children's Hospital Charité, Campus Virchow, Augustenburger Platz 1, D-13353 Berlin
Tel.: +49-30-8002-2205
Fax: +49-30-8002-2278
E-mail: doris.staab@charite.de

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Atopic dermatitis (AD) is one of the most common chronic diseases in western industrialized countries, with prevalence rates as high as 20% for primary school children (1,2). Recent European studies suggest that this frequency is increasing (3). As AD mostly starts in infancy or early childhood, its chronic course, with frequent relapses, puts a special burden on the children and their caregivers and may affect the whole family (4,5). As it is an extremely pruritic condition with continuous scratching, which may aggravate inflammation of the skin, the behavioral component of the disease is especially problematic.

To improve long-term outcome in the management of childhood AD, it is important to support parents in dealing with the chronic disease of their child, in addition to treating the symptoms. Data suggest that symptom severity of children with AD is related to stress and family environment (6). Lack of information, lack of confidence in the treatment, feelings of helplessness, and strain may lead to ineffective management of the disease. As shown in the management of other chronic diseases in childhood (7,8), health education programs for parents, addressing medical as well as psychological issues, can make an important contribution to supporting the families and improving long-term treatment outcome.

While a number of educational programs and behavioral interventions have been developed for adult patients with AD (9,10), the literature on educational interventions for parents and children is sparse (Table 1). Some preliminary work by McSkimming et al. (11) suggests that time-limited support groups for parents may be helpful in reducing feelings of anxiety, helplessness, and loneliness. Furthermore, single cases have been reported (12) where an intervention focusing on a conflictual parent–child relationship contributed to an improvement of the skin condition. Another educational program for parents, including medical information as well as psychological issues such as stress reduction and coping with itching, was described by Gieler et al. (13). Parents were trained in individual counselling sessions in self-monitoring of itching and scratching, and practised relaxation techniques. The majority of parents reported that their confidence in managing their child's chronic disease increased with their participation in the program. Likewise, ≈ 80% of parents who participated in a group education program described by Schmidt-Grüber et al. (14) felt that the program was helpful overall in a 6-month follow-up assessment. This program was conducted in co-operation with a self-help organization and included, besides medical and psychological information, the opportunity for extensive sharing of personal experiences in managing the child's AD. In the only controlled study on parent education, Broberg et al. (15) demonstrated the therapeutic effect of a 2-h consultation with a nurse. Parents participating in the session received additional, general information about AD as well as information on topical treatment and on factors known to aggravate the disease. The control group received routine information given by the physician during the medical visit. In a 2-month follow-up assessment, the decrease in the total eczema score was significantly greater in the intervention group than in the control group. In summary, there is preliminary evidence that parental education is helpful in addition to the dermatological treatment of childhood AD. We aimed to provide a proper evaluation of a parental training program in a prospective, controlled design with adequate sample size.

Subjects and methods

Study design and subjects

A total of 240 families were recruited, of which 204 met the inclusion criteria: a physician-confirmed diagnosis of AD of a duration of at least 4 months, and moderate to severe symptoms (SCORAD score $>$ 20 points) of AD. These families were assessed with a clinical examination of the child to verify the diagnosis [according to the diagnostic criteria of Hanifin & Rajka (16)] and to assess the severity of the eczema. Parents were asked to complete a questionnaire consisting of a structured medical history concerning treatment behaviors and costs, and, for fathers and mothers separately, a quality-of-life (QoL) questionnaire (disease-specific and generic) and a coping questionnaire. After assessment the families were randomized to either an intervention group or a waiting control group. Finally, 93 families participated in the program and 111 families were assigned to the control group. After 1 year, 72 families of the intervention group (77%) and 73 families of the control group (66%) were available for recruitment to the second evaluation (Fig. 1). The group of families who dropped out of the study did not differ significantly from the participants according to demographics or severity of disease.

Outcome measures

The SCORAD index (17) was used to assess disease severity.

The questionnaire on medical history, treatment behaviors, and treatment costs was designed together with health economists.

A disease-specific questionnaire on the quality of life of parents of children with AD was developed and pretested; the psychometric validation process on reliability, construct, and clinical validity and sensitivity to change was finalized in the

Table 1. Publications on parental education in childhood atopic dermatitis (AD)

Author	Publication (year)	n	Control group	Intervention
D. H. Williams	Arch Dermatol (1951)	53	No	Single counselling
J. McSkimming	Australas J Dermatol (1984)	11	No	Group intervention
C. S. Koblenzer	Arch Dermatol (1988)	8	No	Single counselling
A. Broberg	Acta Derm Venereol (1990)	41	Yes	Single counselling
U. Gieler	Hautarzt (1992)	23	No	Single counselling
C. Schmidt-Grüber	Sozialpädiatrie (1996)	102	No	Group intervention

present study (18). The QoL questionnaire consists of 26 items representing five dimensions: psychosomatic well-being, effects of disease on social life, confidence in medical treatment, emotional coping, and acceptance of the disease. As a generic QoL instrument we applied 'Daily life' (19), a German questionnaire used in a wide variety of diseases and healthy population.

To assess coping strategies we used a German questionnaire, 'The Trier Scales of Coping' (20). This is a questionnaire with 37 items in five dimensions: rumination, seeking information about the disease, seeking social support, minimizing disease-related threat, and seeking support in religion.

Intervention

The parental training program consisted of six units of 2 h each. The sessions were carried out once a week in the evening over a total time-period of 6 weeks. The inter-disciplinary team included pediatricians, psychologists, and nutritionists. Medical, psychological, and nutritional topics were covered with the particular aim of transferring the knowledge to daily life at home (Table 2). Besides presentation of information, the group was encouraged to share personal experience and to exercise newly learned skills. The program and its theoretical background have been described in detail previously (21).

Statistical analysis

Differences between groups were tested using Pearson's chi-squared test. The follow-up analysis examined the effect of the intervention on treatment behavior and costs by logistic regression, adjusted for SCORAD and age of the child as the major covariates. Because duration of disease did not explain more of the changes than age of the child, we show only the results of SCORAD and age in addition to the effect of educational intervention. The results are presented as odd's ratios with 95% confidence intervals. Effects on QoL and coping were analyzed with MANOVA regarding effects of time and intervention. Probabilities of <0.05 were considered statistically significant. Data analysis was performed using spss for Windows, version 7.5 (SPSS, Chicago, IL, USA).

Results

Baseline characteristics of the families

Results are presented from the 145 patients who participated at both baseline and the 1-year evaluation. At baseline, the severity of eczema was similar in both groups: SCORAD index=44, standard deviation (SD)±17 in the intervention group; and SCORAD index=42, SD±15 in the control group. The mean age of the children was 3.4 years in the control group and 2.7 years in the intervention group, the difference being not statistically significant ($p= 0.075$), and the mean duration of disease was 2.4 and 2.1 years, respectively. There was no significant difference in any of the socio-demographic parameters.

Effects of the education program

Severity of AD. As described above, children displayed a wide range of disease severity, as indicated by their SCORAD index. At the 1-year follow-up assessment, disease severity had markedly decreased in both groups. The average decrease in the SCORAD index in the intervention group was 20 points. In the control

Table 2. Structure and content of the education program

Session	Trainers	Topics
1	Pediatrician and psychologist	Introduction round Basic medical information about AD Introduction of a relaxation technique
2	Pediatrician	Recognition and avoidance of trigger factors Daily skin care
3	Psychologist	Stress management Dealing with itching and scratching, and sleep disturbances
4	Pediatrician	Stage-related treatment of symptoms Unconventional therapies
5	Dietician	General child nutrition Food allergies in AD Different forms of diets
6	Pediatrician and psychologist	Issues of coping Self-management plan Problems in transfer to daily routine

AD, atopic dermatitis.

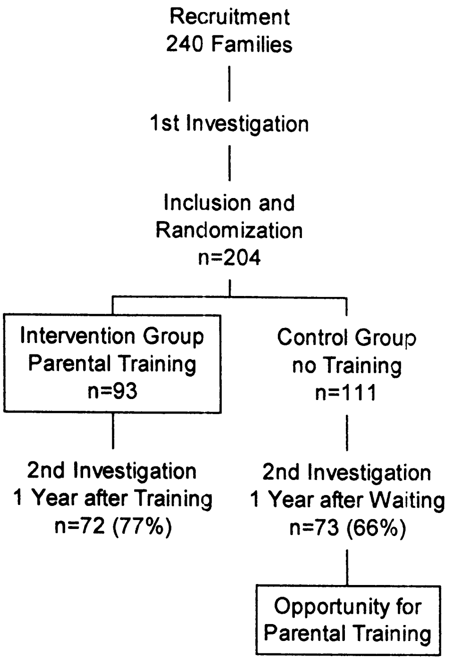

Fig. 1. Atopic dermatitis. Parental training: study design.

group, the average decrease was 16 points. This difference was not significant (p = 0.43).

Treatment behavior. At baseline, 88% of the intervention group and 89% of the control group stated regular use of skin care products. After 1 year, 82% of the intervention group and only 67% of the control group still used regular skin care (p = 0.041) (Fig. 2). As skin care is highly dependent on disease severity, logistic regression was performed using education, SCORAD index, and age of the child as predictors. It was shown that education was the strongest predictor followed by SCORAD index (Table 3). Age did not have any influence.

Treatment adaptation to severity of the skin condition is one of the main topics for self-management of the disease. In this regard the program showed highly significant effects. The use of antiseptics for weeping and suppurating wounds rose from 10% to 19% in the intervention group and fell from 19% to 7% in the control group, the difference between groups being highly significant (p = 0.025) (Fig. 2).

Topical steroids were used at baseline by 35% of the intervention group and 33% of the control group. After the educational program, inflammation of the skin was treated with steroids by 65% of the intervention group in contrast to 38% of the control group (p = 0.001) (Fig. 2). Again, logistic regression was performed, as the use of steroids depends mainly on disease severity. The effect of the educational program was highly significant (Table 3).

Seeking help in the broad field of unconventional medicine is a common phenomenon in patients with AD. At baseline, more than 50% of the parents (56% in the intervention group and 64% in the control group) reported trying at least one kind of unconventional treatment in the previous year. In the year after participation in the educational program this proportion was reduced to 26% in the intervention group, while it

Table 3. Changes in treatment behavior: logistic regression analysis

Behavior	Predictor	OR	CI	p-value
Emollients	Education	2.25	0.97–4.9	0.049
	SCORAD	1.03	1.00–1.05	0.024
	Age	0.91	0.77–1.07	0.26
Antiseptics	Education	3.94	1.32–11.76	0.014
	SCORAD	1.03	1.00–1.05	0.062
	Age	0.90	0.70–1.15	0.40
Topical steroids	Education	3.80	1.79–8.25	0.0005
	SCORAD	1.04	1.02–1.07	0.0003
	Age	0.99	0.84–1.17	0.92
Unconventional therapies	Education	2.97	1.46–6.05	0.0028
	SCORAD	1.0	0.98–1.02	0.9500
	Age	1.04	0.89–1.21	0.63
Dietary restriction	Education	3.09	1.55–6.18	0.0014
	SCORAD	1.0	0.98–1.02	0.86
	Age	1.02	0.87–1.19	0.82
Arbitrary diets	Education	6.54	2.28–18.75	0.0005
	SCORAD	0.98	0.96–1.0	0.066
	Age	1.0	0.83–1.21	0.99
Removal of pets	Education	3.23	1.16–9.02	0.025
	SCORAD	0.99	0.96–1.02	0.38
	Age	1.04	0.84–1.29	0.74

CI, confidence interval; OR, odds ratio.

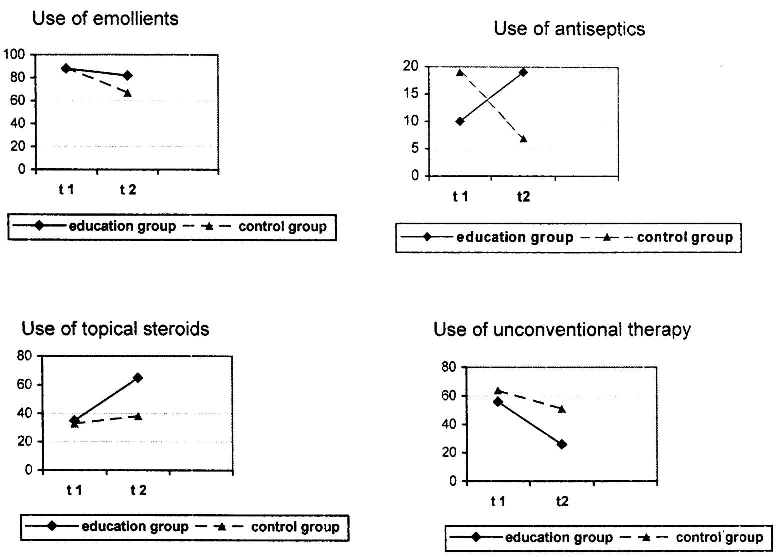

Fig. 2. Changes in treatment behavior. *y*-axis values represent the % of families. t1, baseline; t2, 1-year follow-up time-point.

remained at 51% in the control group (p = 0.003) (Fig. 2). Again this effect was influenced by education, with no influence of SCORAD index and age (Table 3). This implies that the program was able to promote confidence in medical treatment and the capability of self-management.

Behavior regarding allergen exposure

Dietary restriction. The role of nutritional factors in the exacerbation of AD symptoms is frequently over-estimated. Parents are confronted with multiple recommendations on dietary management of AD. At baseline, 49% of the intervention group and 41% of the control group had tried some kind of dietary restriction. Transient diets without proven allergy had been used by 19% vs. 27% of the intervention and control groups, respectively, at baseline. One year later, overall dietary restriction remained nearly unchanged in the control group (40%) compared to 67% in the intervention group. However, there was a significant decrease in arbitrary dietary restriction without proven food allergy in the intervention group. Only 7% of the intervention group tried diets without proven allergy vs. 33% of the control group (p = 0.001).

Indoor allergen reduction. One possibility of secondary prevention could be reduction of indoor allergens such as house dust mites and pets. Regarding house dust mites, we could not change behavior at home by education. However, there was an effect on dealing with pets. At baseline investigation, 11 families (15%) of the intervention group and 10 families (14%) of the control group indicated that they had removed a pet from their household because of the AD of their child. After 1 year, 22% of the intervention group vs. 8% of the control group had removed a pet from their household because of the AD of their child; the difference was now significant (p = 0.019).

Quality of life. As mothers were the primary caregivers in most families, the impact of disease was more severe for mothers than for fathers. For this reason, results are presented only from mothers. At baseline, the health-related QoL of mothers, as measured using the generic instrument, was impaired compared to a healthy population. The differences reached significance in all sub-scales. After 1 year, there was significant improvement in the sub-scale psychic and somatic well-being, daily life, joy of life, and satisfaction with medical treatment. No changes were found in the sub-scale social life. With this generic instrument no differences were detected between the groups. In the disease-specific health-related QoL questionnaire, there was a trend towards a greater increase in the education group regarding confidence in medical treatment as compared to the control group (p = 0.016, alpha level set as 0.01 after correction for the number of scales). This indicates that the program was able to reassure parents in dealing with the disease.

Coping. Group comparisons with regard to changes in coping style revealed that at the 1-year follow-up assessment, there was a trend towards a greater decrease in rumination in the intervention group than in the control group (p = 0.013, alpha level set as 0.01 after correction for the number of scales). Rumination represents a coping style that is characterized by withdrawal and cognitive avoidance of actual problems in managing the disease. High scores on this scale mean that the mother is oriented towards the past and may brood about things she may have done wrong. No group differences were found with regard to changes in seeking information about the disease, seeking social support, minimizing disease-related threat, or seeking support in religion.

Treatment costs. In this study only direct costs of treatment during the previous 6 months were assessed at baseline and after 1 year. At baseline, the mean costs consisting of medical consultation and prescriptions were 269 over 6 months. They diminished after 1 year to 177. Cost reduction was greater in the intervention group (119 vs. 65 in the control group, p = 0.043). These values represent only the costs covered by public health insurance; costs for treatments such as unconventional medicine have to be funded by the family.

Discussion

This program has been developed to assist parents with the management of AD of their child. As an inter-disciplinary program, developed and carried out by pediatricians, psychologists, and dieticians, it meets the standards for health education programs. Its evaluation in a controlled clinical trial showed certain benefits. Treatment behaviors could be directed towards better regular skin care, even with improved skin condition. Parents demonstrated a better capability of modulating treatment intensity according to severity of inflammation, as shown by increased use of antiseptics and anti-inflammatory steroids. Reduction of unconventional treatments suggested improved confidence in medical treatment and personal capabilities of managing the disease, and a reduction in the feelings of helplessness or strain. Although the percentage of families who tried diets increased overall in the education group, the use of arbitrary diets without proven food allergy was significantly reduced. As shown in Table 3, all these changes were independent of the child's age. Changes in the use of emollients and topical steroids were not only predicted by the educational intervention but also by severity of disease, as measured using the SCORAD index. Certain aspects of health-related QoL and coping strategies were influenced favorably. In particular, the reduction of rumination suggests that the program may encourage an active rather than a passive coping style, which is helpful in establishing self-management of disease. As all families showed improvement over time, both in skin condition of the child and in the psychosocial impact of the disease on the family, the importance of evaluating psychosocial interventions in a controlled study design is clearly demonstrated. Following on from this preliminary work, a multicentre study is now starting to evaluate the practicability of this program at various dermatologic and pediatric-allergologic centres in Germany, together with newly developed modules on behavioral training for children and adolescents.

The effect of reduced costs of treatment after 1 year can only partly be explained by the decrease of disease severity in both groups. Other factors such as disease management seem to play an important role as the reduction was greater in the education group. This greater reduction in the education group is surprising in view of the increased use of prescribed medication such as emollients, antiseptics, and steroids. It may be explained by a reduced number of consultations resulting from better self-management. Parents seem to feel more confident in how to deal with the disease, as indicated by less rumination about issues around the disease and more confidence in the medical treatment. Results on costs of treatment are preliminary and more detailed data on factors explaining changes in costs over time need to be collected in future research. Also, in our analyses only costs covered by health insurance were taken into account. If costs for unconventional therapies that have to be paid by parents were included, the group difference may become even more substantial, as help-seeking in the field of unconventional medicine was reduced only in the education group.

In summary, an education program for parents of children with AD (as presented in this study) contributes towards a comprehensive, family-oriented management of childhood AD and is a helpful adjunct to dermatological treatment.

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