

# Educational and Medical Programme for Young Children Affected by Atopic Dermatitis and for Their Parents

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## Key Words

Atopic dermatitis · Children · Educational programme · Psychological and medical approach

## Summary

**Background:** Atopic dermatitis (AD) is a chronic inflammatory skin disease particularly prevalent during the first years of life. The chronic course of AD is a serious problem for affected children and their families. Since the condition provokes extreme itching with continuous scratching that often maintains or exacerbates the inflammation of the skin, the behavioural component of the disease is especially problematic. Moreover, the chronic course and the frequent relapses that characterise AD are a particular burden for the children and their caregivers. To improve long-term outcome in the management of childhood AD, it is important to give parents support in dealing with the chronic disease of their child in addition to medical treatment.

**Objective:** The aim of our programme was to inform families of children with AD about the course of the disease, to improve the family management and to offer them an opportunity for a more open and wide medical dialogue. **Methods:** Our educational programme consisted of six 2-hour group sessions, conducted at weekly intervals. Sessions were managed by a multidisciplinary team composed of a paediatrician-allergist, a psychologist and a dermatologist. The following issues were covered in the sessions: epidemiology, natural history of the disease, diagnostics and treatment, stress management, psychological counselling on sleeping problems and itching-scratching. **Results:** Parents reported that the programme well improved the quality of life of their family, particularly thanks to better knowledge and understanding of the disease. **Discussion:** The programme may encourage an active rather than a passive coping style in the families involved. During routine clinical care it is difficult to recognize and deal with all family troubles and doubts, which are for the most part caused by a poor knowledge of the disease.

## Schlüsselwörter

Atopische Dermatitis · Kinder · Trainingsprogramm · Psychologischer und medizinischer Ansatz

## Zusammenfassung

*Patientenschulungs- und medizinisches Behandlungsprogramm für kleine Kinder mit atopischer Dermatitis und ihre Eltern*

**Einleitung:** Atopische Dermatitis (AD) ist eine chronisch-entzündliche Hautkrankheit, die hauptsächlich in den ersten Lebensjahren auftritt. Der chronische Verlauf von AD ist ein großes Problem für die betroffenen Kinder und ihre Familien. Da die Erkrankung extremen Juckreiz mit ständigem Kratzen auslöst, der die Entzündung der Haut aufrechterhält oder verschlimmert, ist die Verhaltenskomponente bei AD besonders problematisch. Darüber hinaus sind der typische chronische Verlauf und die häufigen Rückfälle eine besondere Belastung für die Kinder und deren Betreuungspersonen. Um ein langfristig erfolgreiches Krankheitsmanagement bei kindlicher Neurodermitis zu fördern, ist es wichtig, zusätzlich zur medikamentösen Behandlung die Eltern beim Umgang mit der Erkrankung ihres Kindes zu unterstützen. **Methoden:** Ziel unseres Programms war es, Familien mit einem Neurodermitis-kranken Kind über den Verlauf der Krankheit zu informieren, das Familienmanagement zu verbessern und eine Gelegenheit für einen offeneren und breiteren medizinischen Dialog anzubieten. Unser Trainingsprogramm bestand aus 6 je 2-stündigen Gruppensitzungen, die wöchentlich stattfanden. Die Sitzungen wurden von einem multidisziplinären Team bestehend aus einem Pädiater-Allergologen, einem Psychologen und einem Dermatologen geleitet. Folgende Themen wurden in den Sitzungen behandelt: Epidemiologie, Entstehung der Krankheit, Diagnose und Behandlung, Stressmanagement, psychologische Beratung zu Schlafstörungen und Jucken/Kratzen. **Ergebnisse:** Die Eltern berichteten, dass sich das Programm positiv auf die Lebensqualität ihrer Familie ausgewirkt habe, insbesondere durch mehr Wissen über und ein verbessertes Verständnis der Krankheit. **Diskussion:** Das Programm kann bei den betroffenen Familien einen aktiven im Gegensatz zu einem passiven Bewältigungsstil begünstigen. Im dermatologischen Behandlungsaltag ist es schwierig, familiäre Probleme und Unsicherheiten zu erkennen und zu behandeln, die hauptsächlich auf mangelndes Krankheitswissen zurückzuführen sind.



## Introduction

Atopic dermatitis (AD) is a common chronic inflammatory skin disease that typically begins in the first years of life. AD has an estimated incidence of 10–15% of the paediatric population under 5 years of age and its prevalence has markedly increased over the past 3 decades.

The chronic course of AD is a serious problem for affected children and their families. Many trigger factors can provoke AD, including food and inhalant allergens, climatic factors, chemical or physical irritants, microbes and psychological factors [Gieler et al., 2000]. The link between AD and emotional disturbances has been well documented over a period of 50 years as recently reviewed by Wenninger et al. [2000].

Since AD provokes extreme itching with continuous scratching that often maintains or exacerbates the skin inflammation, the behavioural component of the disease is especially problematic [Howlett, 1999]. Moreover, the chronic course and frequent relapses that characterise the disease are a particular burden for the children and their caregivers [Fegert, 1995].

Clinicians who work with children affected by AD are well aware of the psychological life-style problems caused by AD, and it has been claimed that of all skin diseases in children, AD is among those with the highest impact on the child's quality of life [Lawson et al., 1998]. Its impact is higher than that of psoriasis and equivalent to that of other serious medical conditions such as early onset of diabetes mellitus [Su et al., 1997]. An Australian study found that looking after a child with moderate or severe AD is significantly more stressful than looking after a child with insulin-dependent diabetes mellitus [Kemp, 1999]. Two further studies evidenced that AD has a significant impact on quality of life in both children [Lewis-Jones et al., 2001] and adults [Hanifin, 2002].

## Atopic Dermatitis and Family Life

The strong negative impact of AD on the life of the family and the child has recently been well documented by Lawson et al. [1998] with the Dermatitis Family Impact Questionnaire that aims to understand the family aspects most affected by the disease. The results of this study showed that 74% of parents described a general burden of extra care, for example relating to household cleaning and washing, preparing meals and shopping; 71% of parents described psychological pressures including feelings of guilt, exhaustion, frustration, resentment and helplessness; night-time itching and scratching caused delay in getting the child to sleep and led to parental frustration and exhaustion in 64%. Furthermore, 66% of families said they did not live a 'normal' family life because of the child's disease.

Pauli-Pott et al. [1999] described mothers of children with AD as more helpless, depressed, and overprotective than a group of mothers of healthy children, sometimes leading to ineffec-

tive management of the disease. Moreover, Lawson et al. [1998] reported that 63% of children with AD had current sleep problems, and most had had sleep disturbances at some time. Patients with AD scratch more during sleep than patients with other chronic dermatologic diseases [Savin et al., 1975]. Dahl et al. [1995] showed that sleep problems of children with AD correlate with their AD symptoms and that sleep disruption was notable in many AD patients without eczema at the time of the study.

## Educational Programme

The first educational programmes for patients with chronic diseases were developed for diabetics [Kohle and Hitzler, 1986] and soon after for asthma patients [Petermann et al., 1997]. Squyres [1980] has defined patient education as a method to assist persons who are or have been ill to change their behaviour in such a way that their health is improved.

To improve long-term outcome in the management of childhood AD, it is important to give parents support in dealing with the chronic disease of their child in addition to medical treatment [Wenninger et al., 2000]. Support may also help decrease feelings of anxiety, helplessness and tiredness in families with children affected by AD. However, no conclusion can be drawn regarding the impact of programmes on the course of the disease. A marked decrease in disease severity over the course of 1 year was observed in both the intervention and the control group [Wenninger et al., 2000].

A preliminary study by Mc Skimming et al. [1984] suggested that short-term support groups for parents of children with AD may be helpful in decreasing feelings of anxiety, discouragement and loneliness. Further studies have shown the relevance of a parents' educational programme that comprised medical interventions and psychological counselling to offer parents the means to face the chronic course of the disease and to teach them relaxation techniques [Gieler et al., 1992; Schmidt-Gruber et al., 1996]. Preliminary data of a recent study have highlighted an improvement in the quality of life and in the strategies adopted to face the chronic nature of the disease in parents of children affected by AD. This improvement was the consequence of a 6-week educational programme offered by a multidisciplinary team composed of a clinician, a nutritionist and a psychologist with groups of parents matched for the age of their children [Wenninger et al., 2000].

Broberg et al. [1990] demonstrated the therapeutic effect of a 2-hour educational session with a nurse. In fact, there was a more significant decrease in the total eczema score in the index group than in the control group.

Gieler et al. [2000] also reported that the majority of parents involved in an educational programme had more confidence in their ability to manage their child's chronic disease since their participation in the programme.



**Table 1.** Medical, psychological and behavioural issues of AD covered in the programme

*Epidemiology*

Definition, prevalence and incidence in Western industrialised countries, natural history

*Diagnostics*

Diagnostic tests (skin prick test, patch test, RAST test, challenge test)

*Nutritional Aspects in Children with AD*

Importance of food allergy and clinical aspects

*Food Allergy and Subsequent Development of Inhalant Allergy in Children with AD*

Early strategies of prevention

*Treatment of Symptoms*

*Stress Management*

Schultz relaxation training (autogenic training)

*Infant Massage*

A way to relax parents together with child and to promote a positive self and body-image of the child

*Itching and Scratching*

Management of the child with AD

*Sleep Disturbances in Children and Their Families*

Thus, preliminary evidence suggests that parental education is an important adjunct to the clinical treatment of childhood AD and may be useful in preventing or reducing distress in family life.

To reduce family distress and to prevent parental discomfort, it seems important to encourage parents to manage the disease more actively and positively and to increase their confidence in clinical treatment. A quiet acceptance of the chronicity of the disease and an appropriate use of techniques to face it may promote a parents' psychological well-being and bring about an improvement in the relationship with the child.

## Patients and Methods

*Aims of the Programme*

The general aim of our programme was to inform families of children with AD about the natural course of the disease, to improve their management of AD and to offer them the opportunity of a more open and wide medical dialogue.

The psychological aim was to decrease the parents' level of disease-related stress, to offer a space where they can express, share and digest the emotional strain caused by the disease, particularly by sleeping problems and the almost continuous itching and scratching. Parents are given advice how to support their child in coping with the illness and how to improve the family's quality of life.

*Participants*

All families participating in the programme were asked for their informed consent. The families of 17 children with AD, 16 Caucasians and 1 Afro-Caucasian, ranging in age from 5 months to 48 months (mean age

18 months) were admitted to the study. 10 children had no brothers or sisters. Parents were of average social class, the fathers' mean age was 37 years, the mothers' mean age was 35.

AD was evaluated using the SCORAD index: AD was considered moderate when SCORAD index was >20, severe when >40.

The families were divided into three groups, consisting of a maximum of 6 families.

*Study Plan*

Before the start of the programme the psychological status of the parents was evaluated by a conversation with a psychologist to obtain social and anamnestic data about pregnancy, birth, breast-feeding, weaning, sleeping, mother-father-child relation and troubles linked to the disease. In addition, at the beginning and at the end of the programme families were given a short and easy questionnaire to evaluate any possible psychological suffering: the Fava-Kellner Symptom Questionnaire [SQ; Fava and Kellner, 1982], with a 92-item self-rating scale that yields four scales of distress (anxiety, depression, somatization and hostility-irritability) and four scales of well-being (relaxation, contentment, physical well-being and friendliness). Scores in the distress scales may range from 0 to 17; in the well-being scales from 0 to 6. At the end of the programme, parents were also requested to fill out a 'Satisfaction Questionnaire' to evaluate how effective the programme had been. Each item was evaluated on a 5-point scale: 1 = not at all, 2 = a little, 3 = moderately, 4 = a lot, 5 = very much. We considered 4 and 5 to be positive scores, 1 and 2 negative, and 3 not significant.

*Structure of the Programme*

Our educational programme consisted of six 2-hour group sessions, conducted at weekly intervals. We designed our educational programme on the basis of the 'Berlin Parental Education Programme' based on six 2-hour group sessions [Wenninger et al., 2000] with some adjustment to our local conditions. Both parents were invited to participate.

Sessions were managed by a multidisciplinary team composed of a paediatrician-allergist, a psychologist and a dermatologist.

Part of the medical team was to give more information about the disease: an overall 'picture' of the disease was presented to parents in terms of epidemiology, pathogenesis, development. Particular attention was given to the 'allergic' component of the disease and to the clinical problems of diagnostics, diet, and atopic skin care.

During the meetings the psychologist had a constant role of active listening and observation of parents. It was also the psychologist's task to give suggestions and instruments to improve the parents' capacity to face the difficulties related to the disease.

In the first session, the topics of each session were outlined to the parents who were encouraged to talk openly about their worries and to ask questions regarding the daily management of their child's disease. At the end of each session, parents received written information on the issues discussed and homework assignments to promote the transfer of what was learned in the sessions into everyday family life. The second session started with the description and the discussion of the experiences and problems that the families had had in the past week.

*Content of the Programme*

The medical, psychological and behavioural issues covered in the sessions are listed in table 1. The medical approach focused on the natural history of the disease with a picture of AD at different ages and its evolution over the years. Allergic and non-allergic AD were regarded with particular interest in diet problems of allergic children. Diagnostic techniques were explained to parents, focusing on skin prick test, atopy patch test, RAST test, challenge test. Skin management and therapy were largely discussed. Our strategy included techniques of relaxation and itching-scratching control for children of very young age, i.e. infant massage techniques, and counselling for sleep disturbances in the first years of life.



Particular attention was given to introducing the parents to the infant massage technique of the International Association of Infant Massage adapted to the child with atopic dermatitis [Field, 1995]. Many important aspects of this technique were emphasised, such as the stimulating, relaxing and psychological effects. The massage allows the relaxation of the child through a decrease of itching and a pleasant touch sensation.

The psychological aspects of the programme referred to the knowledge, communication and confidence between child and parent. They aimed to facilitate the exchange of emotional messages, and focused on body scheme knowledge, and self-imagine training.

The question of itching was also covered and alternative strategies were proposed to eliminate the vicious circle of itching, scratching, lesions.

Behavioural techniques were used to deal with sleep problems. Suggestions given to the parents aimed to modify the many erroneous habits contracted during the first months of life and enforced by the presence of the disease.

An important medical aspect was the possible development of an inhalant allergy: Parents were trained to adopt preventive measures for house dust-mite early in childhood.

Moreover, each family received a tape for autogenic training [Schultz, 1999] in a simplified version proposed by Langen [1998] to experiment with relaxation training at home.

Satisfaction was evaluated in 2 ways, directly with a questionnaire at the end of the course, and indirectly by evaluating the percentage of participation, and finally the number of questions asked during the group meetings.

## Results

The psychological evaluation of well-being (SQ) is reported in table 2.

Participants were mostly satisfied with the programme: only 1 family expressed dissatisfaction, the remaining 16 families were very interested. Participation rate was 95%: Half of the sessions were attended by both parents, the remaining meetings were attended mainly by mothers.

The first group was composed by 12 parents; 6 mothers and 1 father participated in all sessions, the remaining 5 fathers could only participate at intervals because of working problems. The second group comprised 12 parents: the 6 mothers were always present, the 6 fathers were discontinuous. The third group was composed by 10 parents: 5 mothers and 1 father participated in all of the meetings, the remaining 4 fathers in every other session.

Parents were interested in the issues and actively took part by explaining their troubles and asking questions: The number of questions rose from 2–3 in the first sessions to 8–9 in the last. The parents were particularly concerned about problems related to sleep, nutrition and itching-scratching, and were interested in therapies. Our approach therefore focused on how to decrease parents' anxiety about these problems.

The Satisfaction Questionnaire that was administered to the parents at the end of the programme was filled out by 14 out of 17 families. It revealed that the majority of participants considered the programme satisfactory (79%); their attitude towards the disease was described as more tranquil (79%). 11 families (79%) registered an improvement in their relation

**Table 2.** Distress and well-being in mothers of children with AD, according to the SQ (n = 17).

	SQ score		Normal value <sup>1</sup>
	before the training	after the training	
<i>Distress</i>			
Anxiety	5.8	4.8	2.10 ± 2.1
Depression	4.0	3.3	1.75 ± 1.6
Somatization	4.2	3.2	3.25 ± 3.3
Hostility	4.4	3.3	2.20 ± 2.2
<i>Well-being</i>			
Relaxation	2.4	1.8	1.40 ± 1.5
Contentment	1.4	1.3	1.40 ± 1.9
Physical well-being	3.0	2.1	1.95 ± 1.9
Friendliness	1.2	0.6	0.90 ± 1.2

<sup>1</sup>Normal values refer to the control group of the Symptom Questionnaire Italian validation study.

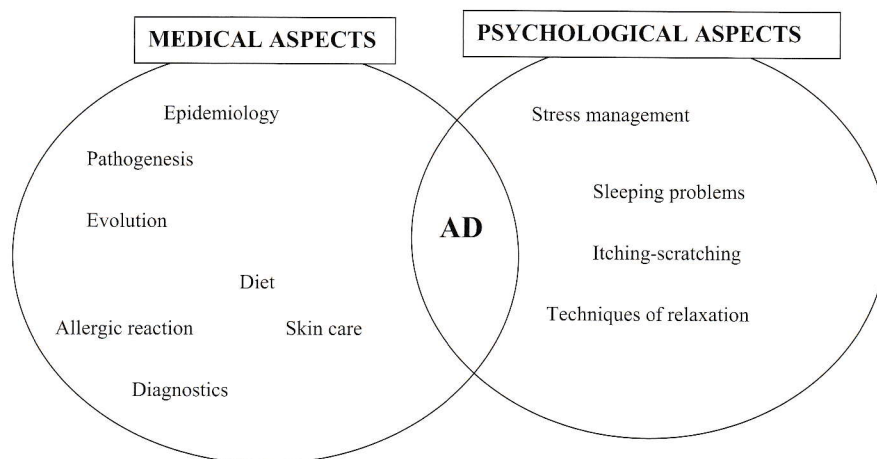
with the child and 7 (50%) in the communication with the partner. 4 families (30%) observed less frequent itching in the child, and 6 families (43%) benefited from a more stable sleeping-waking rhythm. Suggestions related to infant massage had a positive effect in 6 families (43%); only 3 families (21%) used the relaxation training techniques.

## Discussion

The profound impact of AD on families is well known [Su et al., 1997]. Management of atopic eczema in children is potentially complex and costly, often requiring a carefully planned multidisciplinary approach for optimal care [Su et al., 1997]. Appropriate counselling may be offered to patients on who AD exerts a pronounced psychological impact [Ellis et al., 2003]. In recent guidelines, Hanifin et al. [2004] said that psychotherapeutic approaches to the treatment of AD are supported for a combination of educational and psychological interventions.

A significantly higher impact on family scores for children less than 6 years old with moderate or severe eczema has been reported [Su et al., 1997]. The approach used in our educational programme therefore focused on families of very young children, and hence the strategies used are particularly suitable for younger patients.

Due to the importance of the programme and the difficulties involved in its management, the course could only be offered to a small number of selected families, i.e. those with more seriously affected children and a continuous history of severe and not easily controlled AD in the months before our clinical examination. Groups had to be small in order to permit an easy and effective dialogue between the clinicians and the participants: For this purpose, a greater number of educational



**Fig. 1.** Aspects involved in the care of children affected by AD according to a multi-disciplinary approach.

group programmes may have been desirable, but this would have required a larger number of medical forces and more time in addition to the normal clinical treatment.

We believe that the programme can help improve the quality of life of families with children affected by AD and ameliorate the clinical manifestations of the disease. The feelings of isolation and discouragement often experienced by families of children with AD can be reduced if they can share their problems with others who face the same situation. A recent review on AD [Leung, 2003] focused on the disease as an important cause of distress, anxiety, embarrassment, poor self-esteem, social isolation, lack of self-confidence; the discomfort that arises from itchy skin leads to significant sleep disruptions and impaired performance of daily activities. We therefore consider it important that the caring of children with AD be based on a multidisciplinary approach (fig. 1).

However, due to the small number of children involved and the short time that has elapsed since the sessions, no conclusion can yet be made about the impact of the programme on the course of the disease: the clinical and psychological status

of the children and their parents will be reevaluated in a 6-month follow-up.

At the end of the programme lower levels of anxiety especially in the mothers could be observed. We noticed in fact that mothers were particularly engaged in the programme. Only 2 fathers participated in all meetings. However, this should not be considered statistically significant because of the small number of participants studied so far.

The programme may be successful in encouraging an active rather than a passive coping style in the families involved. During routine clinical examination, in fact, it is difficult to recognize and deal with all family troubles and doubts that arise to a large extent from poor knowledge of the disease.

At the end of the sessions, parents reported a good influence of the programme on the quality of life of their family, especially thanks to an improved knowledge and understanding of the disease. The relaxation training was the only activity that was not much appreciated by the families: parents considered it too demanding in terms of time and energy. This aspect of the programme will be removed from the next courses.

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