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# Structured parent education in the management of childhood atopic dermatitis: The Berlin model

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#### **Abstract**

Childhood atopic dermatitis (AD) is a common disease with the prevalence rates increasing. Its chronic course with frequent relapses puts a special burden on both children and their parents. To maximise positive long-term outcome in the management of AD it is important to support parents in dealing with the chronic condition of their child in addition to treating symptoms. In the present article, we describe in detail the goals, structure, and content of the Berlin education program for parents of children with AD. The program aims to contribute towards a comprehensive, family-oriented management of childhood AD. Its objective is to improve parent's self-management skills with regard to their child's disease and to positively impact the course of the disease as well as the family's quality of life. Medical, nutritional and psychological issues are covered in six group sessions which are conducted by a multiprofessional team of paediatricians, psychologists and dieticians. Preliminary data show that the program has a desirable effect on aspects of quality of life and coping. © 2000 Elsevier Science Ireland Ltd. All rights reserved.

Keywords: Parental education; Health education; Atopic dermatitis; Self-management

#### 1. Introduction

Atopic dermatitis (AD) is an extremely common disease in the western industrialised countries with prevalence rates as high as 20% for elementary school children [1]. Recent European studies bear evidence that this frequency is increasing [2]. As AD

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often starts in infancy or early childhood, its chronic course with frequent relapses puts a special burden on the children and their caregivers and may impact the whole family [3]. Since it is an extremely pruritic condition with continuous scratching often maintaining or exacerbating inflammation of the skin, the behavioural 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 [4]. Lack of information, overstrain, and cognitive-emotional factors such as lack of confidence in the treatment or feelings of helplessness may lead to suboptimal management of the disease. Health education programs for parents addressing medical as well as psychological issues can make an important contribution to supporting the families and maximising long-term treatment outcome. The trend in chronic illness management diverges from an emphasis on compliance toward self-management [5,6]. In the present paper, we describe a health education intervention for parents of children with AD promoting self-management skills in dealing with their child's chronic disease. The effectiveness of the program with regard to an improvement of medical parameters and variables reflecting the family's overall quality of life is currently under evaluation. Preliminary results will be reported.

While a number of educational programs and behavioural interventions for adult patients with AD have been developed [7,8], the literature on interventions addressing parents is sparse. Some preliminary work by McSkimming et al. [9] has suggested that time limited support groups for parents may be helpful in reducing feelings of anxiety, helplessness and loneliness. Furthermore, single cases have been reported [10] where an intervention fostering insight of parents into a conflictual parent-child relationship contributed to an improvement of the skin condition. Broberg et al. [11] demonstrated in a controlled study the therapeutic effect of a 2-h educational session 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 which was based on the type, intensity and distribution of the skin lesions was significantly greater in the index group than in the control group. A more comprehensive educational program for parents including not only medical information but also issues such as stress reduction and coping with itching was described by Gieler et al. [12]. In three 2-h individual counselling sessions on dermatological and psychological issues, parents were trained in self-monitoring of itching, scratching and its preceding triggers, and practised relaxation training. In addition, they received written material on the topics discussed during the sessions. The majority of parents reported that their confidence in managing their child's chronic disease increased from their participation in the program. Likewise, about 80% of parents who participated in a five-session education program described by Schmidt-Grüber et al. [13] evaluated the program as overall helpful in a 6month follow-up assessment. This program was conducted in co-operation with a self-help organisation and included, besides medical and psychological information, the opportunity for extensive sharing of personal experiences in managing the child's AD. In summary, there is preliminary evidence that parental education is an important adjunct to the dermatological treatment of childhood AD and may be helpful in preventing or reducing distress within the family. The present paper provides a detailed description of a structured education program for parent groups that specifically aims at increasing the parents' self-management skills. Such a theory-based program which is evaluated in a controlled study with adequate sample sizes has been missing to date.

### 2. Berlin parental education program

#### 2.1. Theoretical framework

Health behaviour theories aim at explaining the process by which people adopt and maintain desired health behaviours. Social Cognitive Theory, also referred to as Social Learning Theory (SLT) [14,15], is frequently being used as a theoretical basis for explaining health behaviour and for planning health education programs focused at promoting self-management of chronic illness [5,6,16]. While a second major theoretical orientation based on the Health Belief Model [17] has been criticised as static and unidirectional [18], an important advantage of SLT is the conceptualisation of behaviour as a consequence of a reciprocal interaction among cognitive, behavioural, and environmental determinants. Another strength of the model is its cognitive approach which

stresses the importance of cognition as mediator. One clear implication of the model is the recognition that education interventions focusing solely on an increase in knowledge are insufficient to induce behaviour change.

SLT states that behaviour is determined by expectancies and by consequences of the behaviour as they are relevant to the person. Three types of expectancies influence future behaviour: (a) expectancies regarding situational outcome without the person taking action (e.g. what will the course of disease be without following the medical regimen), (b) outcome-expectancies regarding the behaviour in question (e.g. how will the course of disease be influenced by following the regimen), and (c) selfefficacy expectancies, (e.g. one's perceived competence to perform the specific behaviour leading to a desired outcome). Outcome beliefs are postulated to be important in intention formation. Self-efficacy beliefs are thought to affect both, intention formation and action control, i.e. the effort made and the persistence, how long a person tries, particularly in the face of obstacles and setbacks [19]. According to SLT, the capability to carry out a behaviour is a necessary prerequisite, but it is not sufficient to guarantee that the action is performed. Behavioural capability refers to the knowledge of what the desired self-management behaviour is, and the skills to perform it [20].

The different components of the SLT model have extensively been researched. In reviewing the literature, Schwarzer [18] found that self-efficacy has proven to be a very powerful determinant of health behaviour. He concluded that "by summing up direct and indirect effects, it can be stated that the total effect of self-efficacy on health behaviour exceeds the effects of any other single variable" (p. 223). For planning health care interventions it is therefore important to ask how self-efficacy beliefs are formed and how they can be promoted. According to SLT, sources of self-efficacy beliefs are previous mastery experiences, indirect experience through the observation of models, and verbal persuasion.

The implications of SLT for the design of self-management programs have been outlined by several authors [16,20]. Tobin et al. [16] have formulated three principle therapeutic goals in SLT through which self-management of chronic illness is

achieved: (a) cognitive and behavioural coping skills that can be used to meet changing demands during the course of the disease need to be trained. In the case of an AD parental education program, such training may include skills for observing environmental triggers, monitoring the skin condition, monitoring one's behaviour in reaction to scratching or sleeping problems, and reacting properly to symptom exacerbation. (b) As a second goal, the enhancement of expectations of success or personal efficacy is emphasised. One approach in promoting self-efficacy beliefs is to plan small steps in behavioural change to increase the likelihood of mastery experiences. Also, in a group intervention program, social modelling is provided by the group leader as well as by the other members of the group. (c) The final goal of a health intervention program based on SLT is the person's management of stimulus conditions in the social and physical environment. Participants are encouraged to exert control over their environment, e.g., in an AD parental education program, parents may be trained to avoid identified environmental and nutritional triggers of exacerbation. They may also be encouraged to seek a supportive social environment.

#### 2.2. Goals of the program

The objective of the Berlin parental education program for parents of children with AD is to improve the parents' self-management skills in dealing with their child's disease. Self-management of a chronic illness can be defined as those behaviours that minimise the frequency and severity of symptoms and dysfunction caused by the disease, and promote optimum participation in normal activities [21]. The term puts an emphasis on competent and flexible active coping rather than on merely following the recommended therapeutic regimen. Self-management not only includes the parents' management of the child's care but also the age appropriate transfer of responsibilities to the child in managing his or her own care [5]. Improved self-management is assumed to positively impact the child's skin condition as well as the overall family's quality of life. Quality of life has been suggested in the literature [22] as an outcome variable in coping with chronic diseases.

The program endeavours to improve self-manage-

ment by influencing the following SLT construct: behavioural capability as a prerequisite to performance of new behaviours (which includes increasing knowledge), and outcome and self-efficacy beliefs as important cognitive mediators in health behaviour. A number of educational techniques based on SLT have been suggested to facilitate these goals [20]. We selected the following techniques for implementation in our program:

- skills training (this includes goal setting by the parents and breaking the desired behaviour down into small steps)
- modelling and positive reinforcement (modelling, reinforces such as praise or validation of personal experiences, and encouragement are not only provided by the trainer but can also be offered by the other parents during group discussions)
- monitoring of relevant behaviours and environmental triggers.

#### 2.3. Structure of the program

The Berlin parental education program consists of six 2-h group sessions conducted at weekly intervals. Group sizes are limited to a maximum of eight couples. Both fathers and mothers as well as other primary care givers (if involved) are invited to participate. However, in our experience in the majority of the cases only mothers attend the sessions. Groups are composed of parents with children in a comparable age range to ensure that the topics of interest within the group are not too diverse.

The interdisciplinary team of trainers includes paediatricians, psychologists and dieticians. Team supervision by a psychologist who is not involved in the program take place on a regular basis to discuss individual cases or problems in conducting the sessions and to reflect on group dynamics.

In the first session, the outline of topics for each session is presented to the parents. This outline can be modified according to which issues are especially relevant to the members of the specific group, e.g., parents of newly diagnosed children have a greater need for basic information on AD than experienced parents. Issues around sleeping problems are often of special interest to parents of young children, whereas parents of older children often express interest in

topics such as stigmatisation or independence of the child. At the end of each session, parents receive written material on the issues discussed. Additional information handed out to parents include a list of books on medical as well as psychological aspects of AD and nutrition, and a list of relevant addresses. Homework assignments are given to promote the transfer of what is learned in the sessions into everyday family life.

In conducting the groups, trainers are challenged to find a balance between structured presentation of information, skills training, and group discussions where parents have the opportunity to share their personal experiences. As a second dimension, trainers need to carefully balance between specific needs of the individual participants and the interests of the group as a whole. As individual needs arise that are beyond the frame of the group session, referral addresses are given for further information or counselling.

#### 2.4. Content

The Berlin education program for parents of children with AD consists of three components covering medical, nutritional, and psychological issues. A detailed outline of the topics of the six sessions is given in Table 1.

- (A) Medical issues discussed in the sessions include:
- basic information on AD (definition, epidemiology, symptoms and course of the disease, basic pathophysiological mechanism, multifactorial model of triggers, diagnostic tests for allergies)
- skin care (structure and biological and social functions of skin, AD specific skin characteristics, composition and ingredients of skin care products, recommendations for daily cleaning and care of skin)
- dealing with environmental triggers (allergens, climatic, chemical and physical triggers)
- treatment of symptoms (indication, therapeutic and side effects of different agents, dealing with exacerbation, discussion of unconventional therapies)

The depth of discussion of these issues depends on

Table 1
Table of content of the Berlin parental education program

Session no.	Trainers	Topics	Homework Assignments
1	Paediatrician and Psychologist	Introduction: getting to know each other Basic information on AD Introduction to stress management: muscle relaxation	Keeping symptom diary including triggers Practising relaxation Bringing skin care products to next session
2	Paediatrician	Daily skin care Recognition of and dealing with triggers	Paying attention to what situations increase scratching behaviour of child and monitoring own reactions to scratching
3	Psychologist	Stress management Managing sleep problems Dealing with itching and scratching	Bringing prescribed therapeutics into next session
4	Paediatrician	Treatment of symptoms Unconventional therapies	paying attention to nutritional factors in symptom exacerbation
5	Dietician	General nutrition Alternative forms of nutrition Food allergies in AD Different forms of diets	Going through information material and writing down all remaining questions for last session
6	Paediatrician and psychologist	Issues of coping with the disease Summary: self-management plan	-

the special interests and the level of pre-information of parents. Information given by the trainer is limited to knowledge that is relevant for parents when making decisions in the daily management of their child's disease. This relation between knowledge and behaviours is least obvious for general information on AD, such as information on pathophysiology. However, a basic understanding of pathophysiological mechanisms is assumed to be indirectly related to self-management behaviours in the way that it increases parents' understanding of therapeutic strategies. Besides increasing parents' motivation for regular skin care and treatment, goals of the education on medical issues are threefold: First, parents are trained to recognise and avoid triggers of exacerbation to prevent relapses, e.g., as a homework assignment, parents are asked to fill out a symptom diary including triggers that precede changes in skin condition or in the intensity of itching. Ways to avoid potential triggers such as using mattress encasings protecting against dust mite allergen are discussed in detail in the sessions. Second, parents' behavioural repertoire in attending to the special needs of their child's sensitive skin is broadened by an extensive exchange of experiences regarding skin care issues

within the group. Ground rules for skin care are given by the paediatrician, and parents have the opportunity to try out different skin care products. Finally, it is the goal of this component of the education program to enable parents to make competent and flexible decisions regarding treatment of symptom exacerbation. This includes adequate treatment of skin inflammation as well as recognising superinfections such as staphylococcal impetigenisation or herpes infection that cannot be managed by the parents and require a visit at the clinic or the physician's office. As a summary in the last session of the program, parents fill out their own individualised multi-step self-management plan outlining behavioural options for managing different stages of disease severity.

- (B) The following nutritional issues are covered by the program:
- recommendations for general nutrition (optimally balanced diet containing all essential nutrients, minerals and vitamins, age appropriate food plan)
- risks of alternative forms of nutrition and nonindividualised diets (such as pure wholefoods or an animal protein free diet)

- basic information on nutritional allergies in AD (epidemiology, frequent allergens, nutritional irritants, pseudo-allergies)
- different forms of diets (preventive, diagnostic and therapeutic diets, double blind placebo controlled food challenge)

The role of nutritional factors in the exacerbation of AD symptoms is frequently overestimated by parents. There is indication that food allergies are present in only about one third of the cases of childhood AD [23]. One of the goals of this part of the education program is to help parents see nutritional factors in AD in relative terms, i.e. as one possible component in the multifactorial model of symptom triggers.

This part of the program is conducted by a dietician. At the beginning of the session the habits of the parents in feeding their child are assessed, and whether any allergic reactions to certain foods were observed. The issues outlined above are then discussed depending on their relevance to the parents. Special emphasis is put on the necessity of a balanced diet containing all essential nutrients, minerals and vitamins. Dietary restrictions are only recommended when allergic reactions to specific foods were observed. Risks of restrictive diets without specific indication are discussed to prevent malnutrition and unnecessary restrictions in the child's nutrition. It is important to allow enough time for parents to share their own experiences on nutritional issues. Parents report that they are frequently confronted with recommendations for diverse dietary restrictions for their child by non-professionals such as friends of the family or in magazines. Through the information given by the nutritionist and group discussions it is intended to increase parents' competence as well as self-confidence regarding their own judgement of those dietary recommendations. Also, they are trained to recognise potential nutritional triggers for symptom exacerbation. Again, they are encouraged to keep a symptom diary including food information to identify the role of nutritional factors. Parents are educated about the different ways of diagnosing food allergies including hospital stays for controlled provocation tests. Finally, parents learn about therapeutic diets with a specific indication, and have the opportunity in the session to try different hypoallergenic food products for infants.

- (C) Psychological issues raised in the sessions include:
- stress management (relaxation training, ways of dealing with sleep problems, other stress management strategies for parents and children)
- dealing with itching and scratching (vicious circle of itching, scratching, and skin lesions, prevention of itching, alternatives to scratching)
- coping of the child (promoting a positive self- and body-image of the child, dealing with refusal of skin care or treatment by the child, transfer of responsibilities for self-management as the child develops)
- coping with the disease within the family (family dynamics related to having a chronically ill child)

As psychological issues are raised in the sessions, it is emphasised that they are not seen as etiological factors in the disease but as potential consequences from the special burden put on the patients as well as their families in dealing with a chronic and frequently relapsing disease. Psychological issues arise secondary to the development of the disease and play a role in the maintenance or exacerbation of symptoms rather than being a causal factor. The view that a disturbed mother-child relationship precedes and is responsible for the onset of childhood AD is outdated and was not supported by empirical research. It is important to stress this point in the sessions because parents frequently report they are confronted with prejudices against their parenting skills. They may be blamed by others for visible eczema symptoms of their child which may lead to feelings of guilt and shame.

Goals of the parental education program with regard to psychological issues are threefold: first, reducing parents' overall level of disease related stress; second, increasing parents' ability to support their child in coping with the illness; and third, increasing parents' awareness of how chronic illness of the child may effect the whole family. Ideas for how to change maladaptive family dynamics are given by the psychologist and in group discussions.

As one strategy of stress management, relaxation skills are practised in the sessions. Parents are trained in progressive muscle relaxation by Jacobson. Furthermore, since sleeping problems of the child are often a major stressor for parents, sleep training is

discussed in detail. After the parents have set their own goals for changes in the sleep habits of their child, the psychologist develops a plan with the parents for conducting an age appropriate sleep training which takes disease specific factors such as itching attacks during the night into account. Other stress management strategies for the parents as well as their child are discussed. The list of references handed out to the parents includes story books for children that incorporate relaxation and problem solving instructions. Another major issue usually raised by the parents is dealing with itching and scratching. In addition to a group discussion of this topic, specific instructions are given on how alternative behaviours to scratching can be practised with the child. In summary, this part of the program offers the opportunity for parents to discuss a broad variety of disease related psychological issues, general questions regarding the upbringing of their child, and family issues. At the same time, the trainer carefully balances between the individual group members' needs and the overall goals of the program. Parents are offered referral addresses if further counselling seems to be indicated.

## 3. Evaluation of the program: preliminary results

The Berlin parental education program is currently being evaluated in a controlled study including medical outcome variables as well as questionnaires on quality of life and coping. Changes in the costs of treatment are assessed in an economical evaluation of the program. Baseline data were obtained from 204 families recruited from the Berlin area. Inclusion criteria were the confirmed diagnosis of AD with a minimum SCORAD-Score [24] of 20 and a duration of eczema of at least 3 months. Families were randomly assigned to the intervention group and a 1-year waiting control group. Before entering the program, each family was seen individually in the clinic for diagnostic procedures and an assessment of disease severity. An interview was conducted, and parents filled out a number of questionnaires covering medical history as well as information on psychosocial variables such as ways of coping with the disease and current level of stress in the family. The same procedure was carried out 1 year after the intervention. At present, complete longitudinal data are available from 63 families who participated in the intervention and from 66 control families. The following preliminary results are based on the data of these 129 complete cases. Mothers and fathers filled out separate questionnaire packages. So far, only data of mothers as the primary care givers have been analysed.

The ages of the children ranged from 5 months to 9 years, with a mean age of 3.1 years (SD = 2.2 years). Mothers ages ranged from 25 to 44 years (mean = 32.7 years, SD = 3.9 years). Mothers had completed an average of 11.4 years of school education (SD = 1.6 years). Forty percent held a college or a university degree. Fifteen percent were single parents. The intervention and the control group did not differ significantly on any of the demographic variables.

Children displayed a wide range of disease severity as indicated by their SCORAD scores. At baseline, the SCORAD scores ranged from 20 to 85 (mean = 43.3, SD = 16.5). Groups did not differ with regard to the child's disease severity. At the 1-year follow-up assessment, disease severity had markedly decreased in both groups. The average decrease in SCORAD scores in the intervention group was 20.5 points. In the control group, the average decrease was 16.2 points. This difference was not significant  $(t_{(127)} = 1.27, P = 0.21)$ .

Health related quality of life (HRQOL) was assessed by the disease specific questionnaire 'Fragebogen zur Lebensqualität von Eltern neurodermitiskranker Kinder' (Quality of life in parents of children with AD) [25]. The instrument contains five subscales reflecting different domains of HRQOL: psychosomatic well-being, effects of the disease on daily life, confidence in their medical treatment, emotional coping, and acceptance of the disease. A multivariate group comparison (MANOVA) with differences between the follow-up and the baseline scores on the five subscales as dependent variables revealed a group difference just below significance  $(F_{(5,122)} = 2.22, P = 0.057)$ . As indicated by univariate analyses, this trend is mainly accounted for by a marked increase in confidence in the medical treatment in the intervention group as compared to the control group  $(F_{(1,126)} = 7.96, P < 0.01)$ . For mothers of children age three or younger, the multivariate group comparison on the five HRQOL dimensions reached significance ( $F_{(5,65)} = 2.85$ , P < 0.05).

The German questionnaire 'Trierer Skalen zur Erfassung der Krankheitsbewältigung' (Trier scales for measuring coping with disease) [26] was administered to assess different coping styles. Group comparisons with regard to changes in coping style revealed that, at the 1-year follow-up assessment, the decrease in rumination was significantly greater in the intervention group than in the control group  $(t_{(127)} = 2.44, P < 0.05)$ . Rumination represents a coping style that is characterised 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, minimising disease related threat, or seeking support in religion.

The final results of the outcome study will be reported elsewhere after analysis of the complete data set.

#### 4. Conclusion and practice implications

In the present article, we have described in detail the goals, structure, and content of the Berlin education program for parents of children with AD. The objective of the program is to assist families with the management of and adjustment to their child's chronic disease. The program which was developed by a team of paediatricians, psychologists, and dieticians meets the standard of multidisciplinary for health education programs. Another requirement that needs to be met before the implementation of a health care intervention is its evaluation in a controlled clinical outcome study. Preliminary results from a sample of 129 mothers indicate that aspects of health related quality of life and coping were influenced by the program in a desirable direction. A reduction in rumination, cognitive avoidance and orientation towards the past suggests that the program may be successful in encouraging an active rather than a passive coping style by teaching problem solving and self-management skills. No conclusion can be drawn at this point regarding the

programs impact on the course of the disease, since a marked decrease in disease severity over the course of 1 year was observed in both the intervention and the control group.

The advantage of a group intervention compared to individual sessions is its economy regarding time and staff resources which allows to establish the program on a broader basis and in different health care settings. However, before the general implementation of a health education program in the management of childhood AD, standards need to be developed for the qualification of trainers. The team should be multiprofessional and trainers should undergo a special training that includes didactical aspects of running parent groups. Team supervision is desirable to discuss difficult cases and to reflect on group dynamics.

The program presented in this article contributes towards a comprehensive, family-oriented management of childhood AD. Educational interventions addressing the child directly, such as the behavioural training described by Scheewe et al. [27], still need to be integrated and evaluated together with parental education.

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