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Structured education program improves the coping with atopic dermatitis in children and their parents—a multicenter, randomized controlled trial☆

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Abstract

Objective: The objective of this study was to prove training-specific effects in children with atopic dermatitis (AD) and their parents concerning coping with the disease after their participation in a training program. In the 1-year follow-up, the changes in the training group were compared to the changes in a waiting control group while controlling the effects of the changes in severity scores. **Methods:** One hundred eighty-five children aged 8–12 years and their parents participated in the study. Complete data sets at the 1-year follow-up were available for 185 parent-child pairs (102 training group; 83 waiting control group). In addition to the severity of the AD [measured with the Scoring Atopic Dermatitis (SCORAD)], data on children's itching-scratching cognitions and coping behavior and on parents handling their affected children were used in the analysis. To study whether the intervention group experienced an additional psychological benefit, which is not due to the SCORAD values, analyses of covariance with repeated measures with standardized residual change scores of the SCORAD as covariate were calculated. **Results:** The intervention group showed greater improvement in children's coping behavior and in parents' handling their affected children. Additional effects of the training program not due to somatic improvement could be seen in the scales of itching-scratching cognitions and in three of four scales on parents dealing with their affected children. **Conclusion:** The training program, which was tested in the German Atopic Dermatitis Intervention Study, had effects on almost all explored psychological variables. Therefore, additional psychological benefit in the training group does not only depend on the greater improvement of SCORAD values in this group.

Keywords: Atopic dermatitis; Children; Coping; Education program; Parents; Randomized controlled trial

☆ Ethics approval: The study was approved by the Ethics Committee of the Humboldt University in Berlin. All participants (parents and adolescents) gave written informed consent.

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Introduction

Atopic dermatitis (AD), a chronic pruritic skin disease, poses a large psychosocial burden on children and their families [1] and reduces quality of life in children, adolescents, and adults [2,3]. AD affects about 15–20% of school-aged children, frequently beginning in infancy or early childhood [4]. Parents of children with a higher severity of the disease reported a significantly higher impact on family functioning, a greater financial burden, and a higher level of disease management [1]. Parental disease management can be predicted by the familial situation, their personal well-being and the severity of childhood AD [5]. A subjective lack of support from medical professionals can lead to suboptimal management of the disease including increased utilization of the medical system and multiple unconventional therapies [1].

However, "all children and young people who are ill or thought to be ill or injured, should have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness" [6]. Thus, educational programs must aim at supporting children and their families in dealing with problems arising from chronic diseases [7]. Until now, different studies have focused on educational programs [8,9] or psychotherapy [10] for adult AD patients, but only a few have focused on educational interventions for children and their parents. The realized studies [11] except the German Atopic Dermatitis Intervention Study (GADIS, [12]) did not use a randomized controlled multicenter trial design.

In the first study that was published on GADIS [12], we could show that the somatic severity of AD in children aged 8–12 years and most aspects of quality of life in their parents improved significantly in the intervention group compared to the control group in the 1-year follow-up. Additionally, in this age cohort the dimensions "catastrophizing" and "coping" of itching behavior revealed significantly greater improvements in the intervention group compared to the control group in the follow-up.

However, the previous study published on GADIS [12] did not focus on the following two questions which we examine now:

- Is the parental disease management (FEN [13]) and the coping behavior of children (COPEKI [14]), which have not been studied in the previous study [12], significantly improved through the intervention in the training group compared to the control group?
- Can additional psychological benefits in the intervention group compared to the control group be found while controlling the differences between Scoring Atopic Dermatitis (SCORAD) at T0 and the 1-year follow-up concerning the itching-scratching cognitions (JUCKKI [14]), the coping behavior (COPEKI [14]) of the children and the parental disease management (FEN [13])?

Methods

Participants and intervention

Two hundred fourteen parents of children with AD were assessed for eligibility to take part in the study. Eight parents and their children were excluded (not meeting inclusion criteria or refused to participate). Two hundred six parents of affected children were randomized to the two groups [105 intervention group (IG); 101 waiting control group (CG)] after giving their informed consent. After taking into account the losses during the follow-up, data sets of 185 parents and their children aged 8–12 years were available (IG=102, CG=83). There were no significant differences in any characteristics (clinical and outcome measures) at baseline between participants that were lost to the follow up and those completing the study. However, the first GADIS study already revealed a considerably greater number of participants lost to the follow-up in the control group compared to the intervention group. That can be explained through different reasons, e.g., lost interest or no sufficient response [12]. Thus, sample size differences between the two groups that are shown here just reflect a well known greater adherence of an intervention group to the study than that of the control group.

The study was performed as a randomized controlled interventional multicenter study (seven centers) with a waiting control group design. The treatment program included six weekly group sessions (with 5–8 participants) that lasted 2 h each. The patients and parents in the intervention and waiting control groups were investigated until 12 months after the intervention took place. The treatment program is described in detail in another article [15]. In short, parents of affected children aged 8–12 years and the children attended different educational sessions depending on their needs. The sessions covered medical, nutritional, and psychological issues and were carried out by a multiprofessional team of dermatologists or pediatricians, psychologists, and dieticians, who had undergone a previous training program to qualify as trainers. Sessions also intended to encourage participants to share personal experiences and to try out newly studied skills. All patients and their parents in the waiting control group were given the opportunity to take part in the same structured education program as the intervention group after the 1-year follow up.

For the present study, the data of 102 children and their parents in the IG and 83 children and their parents in the CG were assessed. The groups did not differ significantly regarding age, gender, and duration of disease at time T0, before the intervention took place (Table 1).

Measures

Somatic outcome measures

The SCORAD index (scoring atopic dermatitis, [16]) was recorded as somatic severity before starting the training