Therapeutic Patient Education

Annice Heratizadeh, MD

Address

Division of Immunodermatology and Allergy Research, Department of Dermatology and Allergy, Hannover Medical School, Carl-Neuberg Str. 1, 30625, Hannover, Germany
Email: Heratizadeh.Annice@mh-hannover.de

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Opinion statement

Patient education in atopic dermatitis (AD) represents an essential therapeutic tool, which should be offered in addition to routine care, since previous studies have revealed that AD outpatients are often insufficiently treated and show severe limitations of quality of life. Considering the multifactorial pathogenesis of this chronic skin disease, the success of therapeutic patient education seems to depend on the involvement of a multidisciplinary team of professionals. The training program should include aspects on dermatology and allergy, but also on diet and nursing, as well as on disease-specific psychological issues. Synergistic beneficial effects upon interaction between affected patients or parents should be considered by performing the training in small groups. The overall aim of therapeutic patient education in AD should be an improvement of self-management strategies to finally achieve a decrease in disease severity and an increase in quality of life. For children (and their parents) and adolescents with AD, successful programs have already been developed. However, in many countries, there is still a need for official recommendations in order to regulate reimbursement for the costs of such programs. Since the preliminary results from pilot studies in adults have been promising, further large controlled trials on patient education in this age group are needed to finally improve outpatient care also in adulthood AD.

Introduction

Atopic dermatitis (AD) is a chronic inflammatory skin disease, affecting up to 20 % of children and 1–3 % of adults in Western industrialized countries. At every age, the course of the disease can be characterized by exacerbations and remissions. In particular, during periods of high disease activity, continuous medical care is indicated. Educational programs aim to improve the quality of life of affected

children and adolescents and their parents, as well as that of affected adults [1•]. Compared with the number of controlled studies on medical therapy in AD, only a few controlled trials on the effects of training programs have been performed so far. Nevertheless, because of the convincing beneficial effects, international experts on AD have argued for integration of educational programs into the therapeutic regimen. Moreover, educational

intervention has been included in the recommendations of the European guideline for treatment of AD [2].

Here, an overview is provided on the status quo regarding the results of educational programs, in particular for outpatients with AD.

Why are educational programs for AD patients necessary?

For optimal treatment, the therapeutic regimen should not only be in accordance with the patient's history and diagnostic results but should also consider the patient's experience of previous therapeutic interventions. This, in turn, necessitates a complete and often time-consuming assessment of relevant patient-specific information by specialized personnel. Moreover, the complex and multifactorial pathogenesis of AD [3] represents a challenge for both the physician and the patient. On the one hand, this implies that in many cases, patient care by an interdisciplinary team—considering medical as well as dietary or psychological aspects, for example—is advisable. On the other hand, the patients or their parents can be requested to perform a variety of therapeutic interventions. But, for organizational reasons in routine care, they often cannot be adequately instructed or informed about the ratio of beneficial effects and possible side effects of certain medications, such as corticosteroids.

Although a variety of modern preparations of topical corticosteroids is available, a high percentage of patients with AD still show fear of corticosteroids, also contributing to poor adherence [4]. Previous studies on patient-centered care focusing on the outpatient situation close to the patients' homes revealed that in this setting, AD patients are mostly insufficiently treated [5] and show more severe limitations of quality of life than those observed in many other chronic skin diseases [6, 7]. Insufficient therapy may finally result in a reduction in therapeutic adherence. Without being supervised by a specialist, patients tend to randomly undertake multiple therapeutic attempts. In fact, AD patients frequently use alternative medicine [8], although these approaches lack sufficient evidence of efficacy [9] and are—from the patients' perspective—rated lowest compared with the benefit of conventional interventions [10]. Moreover, use of complementary therapy, such as homoeopathic therapy in children with AD, is associated with higher costs, although the effects are not superior to those of conventional treatments [11]. Regarding the economic impact of the disease, an increase in disease-related costs with the severity of the disease can be observed [12, 13]. In Germany, total yearly costs of €1,425 per patient have been calculated, resulting in costs of €1.6–3.6 billion per year in society as a whole. Disease-related costs also directly affect the patients themselves or their parents. Regarding the behavior of the affected patients from the economic point of view, in particular, patients with AD are characterized by a moderate-to-high willingness to pay, as has been shown in a nationwide German study [7].

These data and the results from the studies available so far (see below) support the concept that to optimize disease management in AD, an effective

transfer of knowledge from specialists in different disciplines to the patients (or parents) is essential. The following criteria of educational programs seem to be most relevant: (1) they should be offered to all affected patients (families), irrespective of their socioeconomic status; (2) they should be conducted by a multidisciplinary team of professionals; and (3) they should be performed in (age-related) small groups.

Educational training programs for children (or their parents) and adolescents

Most controlled studies on educational programs for children and adolescents have primarily focused on their effects on quality of life [1•].

In a parallel-group study, Chinn et al. included families of children aged <4 years (n=115), as well as children and adolescents aged 4–16 years (n=120), who were instructed by a dermatology nurse during a single 30-minute session [14]. Since no significant effects on quality-of-life parameters were observable after 4 weeks nor after 12 weeks of follow-up, the authors concluded that the study population should have been larger and the disease activity higher; therefore, they proposed using additional outcome measures.

So did Shaw et al., who defined disease severity as a further outcome measure (the SCORAD [SCORing Atopic Dermatitis] index) [15]. The study population (n=106, aged 0–18 years) showed quite high disease activity, with a mean SCORAD score of ≥ 50 at baseline. Again, the intervention was a single (15-minute) session, conducted by a senior medical student. However, the educational intervention did not reveal any significant effects, compared with the control group. The authors discussed several reasons for this outcome. First, it might have been due to a high dropout rate (30 %). Second, the outcome was probably also negatively influenced by the fact that some caregivers were trained who did not primarily care for the child. Finally, individuals in the control group were receiving advice from pediatric and dermatological specialists during their routine appointments.

Grillo et al. extended the duration of the educational intervention and performed a 2-hour workshop [16]. Information on the staff conducting the workshop was not provided. In this study population, the mean disease activity of AD was also severe, with a baseline SCORAD score of ≥ 47 . Although only 58 patients (aged 0 months to 16 years) were included, 4-week and 12-week follow-up assessments both showed a significant decrease in disease severity (the SCORAD score), compared with the control group, while quality-of-life parameters did not improve.

It is well established that particularly in chronically relapsing cases, the daily life of the children and their families is severely affected by the disease—not just over a period of weeks but mostly over several months or even years. The studies cited above defined “quality of life” as a primary outcome measure. However, the content of the training sessions predominantly focused on disease-specific information in dermatology, including nursing aspects, while disease-specific psychological issues, combined with advice on successful coping strategies, were left out.

Considering established training programs for other diseases in childhood, such as asthma [17], Staab et al. performed a large (n=823) German multicenter randomized controlled trial on the effect of a structured educational program in children and adolescents with AD (aged 0–18 years) [18]. The training concept was more comprehensive, since the training sessions were performed once weekly for 2 hours over a period of 6 weeks. In order to empower the parents and patients in all relevant fields of the disease, training sessions were conducted by an interdisciplinary professional team of specialists (pediatricians, dermatologists, psychologists, and dieticians), who had previously attained a study-specific qualification. The content of each session was standardized and binding, since a training manual had been drafted. Furthermore, parents or patients were educated in small, age-related groups. The 12-month follow-up visit showed a significant improvement in AD (the SCORAD score) in all intervention groups. Moreover, in parents of children aged <7 years, all quality-of-life subscale scores were significantly ameliorated, and in parents of children aged 8–12 years, a significant improvement in 3 out of 5 subscales was observable as well. Furthermore, a greater improvement in children's coping behavior and in parents' handling of their children was observable [19]. Quality of life in children (aged 8–12 years) and adolescents (aged 13–18 years) showed a significant negative correlation with itch intensity [20]. Weber et al. also analyzed the effects on itch [21] by joining support groups. Meetings for children (lasting 90 minutes, fortnightly over 6 months) were coordinated by a child psychiatrist together with a volunteer medical student. The sessions included playing, drawing, simulations, and performances. The meetings for parents, coordinated by a senior dermatologist with two other dermatologists, were mainly for explaining and discussing different subjects. The total study population was small, with 16 patients each in the intervention group and in the control group. The authors observed an improvement in the pattern, but not the intensity, of pruritus, as well as a significant improvement in quality of life. One aspect that this program and the program established by Staab et al. [18] had in common was that the meetings were organized in small groups. In this setting, helpful communication between the participants was made possible, and they, in turn, could also provide encouragement to each other. This assumption is supported by data analysis from 73 parents, elucidating that low social support but high active problem-solving behavior are characteristics of those parents who are interested in participating in educational programs [22].

In summary, the data available on patient education for infants and children (and their parents) and adolescents with AD clearly indicate that for educational programs to be successful, it is essential that they consider the multifactorial disease concept.

After the data from the German multicenter study was published in 2006, head associations of German insurance companies recommended in 2007 that the costs of such educational programs be reimbursed by regional health insurance. Since then, participation in such programs has involved German health insurance in most cases. Remarkably, this is in contrast to the international situation. Recently, Stalder et al. offered an

overview on worldwide experiences of therapeutic patient education in AD [23••]. While in France, funding comes from regional health authorities, it comes from donations in the USA and from pharmaceutical firms in Japan and Italy [23••]. The authors therefore emphasize the need for official validated recommendations in AD programs.

Educational training programs for adult patients

Although approximately 30 % of those who have suffered from AD in childhood still have AD symptoms in adulthood, the data available on disease-specific educational programs are sparse. In their international overview of experiences in therapeutic patient education, Stalder et al. determined that patients in these programs were mainly children and adolescents [23••].

Although most affected adult patients have much experience of different therapeutic approaches, their knowledge of the pathogenesis of AD and evidence-based treatment options is often incomplete. Indeed, Dagregorio and Guillet reported that 48 % of AD patients attending an educational seminar thought that asthma could be triggered or aggravated by successful therapy for AD [24].

In 1995, Ehlers et al. performed the first randomized controlled study on an educational intervention, including 135 patients [25]. Effects in four different treatment groups were assessed: (1) dermatological education; (2) autogenic training; (3) cognitive-behavioral therapy; and (4) a combination of dermatological education and cognitive-behavioral therapy. The effects were also compared with observations in a control group receiving standard medical care. Since psychological interventions led to a significantly greater improvement in AD than dermatological education alone or treatment by routine care, the outcome of this study implied a vital need for psychological issues to also be addressed in educational programs for adults.

In Great Britain, educational intervention is mostly performed by a nurse. In a controlled trial, a practice nurse, who had received training in practical dermatology care, trained adult patients [26]. Although the training was offered as often as needed over a period of 4 months, no significant improvement in the intervention group ($n=46$), compared with the control group ($n=54$), was achieved. In this context, data from Gradwell et al. are worth noting, since they assessed the effects of providing a nurse follow-up clinic in addition to routine care by a dermatology outpatient department [27]. Because there was a significant increase in knowledge on how to apply the treatment and how to obtain disease-specific care, the authors finally stated that support from dermatology nurses can indeed be beneficial.

In a Dutch pilot study on a multidisciplinary program, nursing aspects were also part of the educational concept. Coenraads et al. performed a trial in 51 AD patients (aged 18–35 years) [28]. Small training groups of five patients received educational training from a multidisciplinary team, consisting of dermatological education and also including information on the pathogenesis of AD, dietary education, nursing aspects, and the psychosocial aspect. The duration of the program was 6 hours over a period of 10 days. This educational program revealed a significant improvement in coping strategies and disease management. Regarding the economic effects, the time needed for visits to doctors and days of inability to work were significantly reduced as well.

In a recent parallel-group study from Belgium, the intervention group ($n=21$) participated in a 12-week educational program (2 hours twice a week) given by a multidisciplinary team [29]. Despite a broad variety of issues being discussed with the patients during the lessons, no significant effects at 3 months were observable. It should be emphasized that AD patients were educated together with psoriasis patients, who did show improvements in their quality of life and skin conditions after being educated. It can be speculated that in this setting, relevant AD-specific aspects—such as pruritus and sleeplessness, for example—were neglected.

In 2010, the ARNE Study Group—consisting of a nationwide multidisciplinary team of professionals in dermatology, psychology, psychosomatics and psychotherapy, medical sociology, dietary science, ecotrophology, and health services research—initiated a German multicenter study on a new educational outpatient program for adults, with a 1-year follow-up period [30]. The first results from this trial are expected at the end of 2014.

So far, the evidence of beneficial effects of educational programs in adult AD patients is insufficient. As a consequence, reimbursement for the costs of participation in outpatient educational programs on AD seems to be unregulated. In Germany, health insurance companies pay for therapeutic outpatient education on AD in selected cases, but most applications are denied. This is in contrast to the inpatient situation in rehabilitation departments. In conclusion, further large randomized controlled studies on educational programs are needed, which should primarily aim to promote self-disease management capacity and improve the coping strategies of adult outpatients suffering from AD.

Compliance with Ethics Guidelines

Conflict of Interest

Annice Heratizadeh declares no conflict of interest.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by the author.

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