

## 7. Compliance among patients with atopic eczema

TOVE AGNER

Atopic eczema is a chronic disease with a severe impact on quality of life, and compliance is important for the course of the disease. During the last decade educational programmes have been increasingly popular, but only few randomized controlled trials evaluating the effect of educational programmes and eczema schools exist. These studies, however, indicate a high participant satisfaction and a positive influence on compliance.

### INTRODUCTION

Atopic dermatitis (AD) is a common skin disease which has a significant effect on the quality of life of sufferers. Its presence can have profound effects, disrupting family and social relationships and interfering with normal social development. Lewis-Jones and colleagues have shown that AD has a significant impact on quality of life, as measured by both the Infant Dermatology Life Quality Index (1) and by the Family Dermatitis Index.

AD is primarily a condition in small children, although it affects the whole family. Treatment is complex and comprises more than just drug taking. Due to its complexity, there are problems with adequate compliance and therapy as a whole. This is, however, essential to control the disease and minimize its adverse effect on the quality of life of the sufferer and the family.

There is clearly a need to educate patients concerning the disease and its management. Charman and colleagues surveyed over 200 patients/parents as to their ability to select whether clobetasol propionate or hydrocortisone was the more potent steroid. Although all patients had applied both steroids, only 62% were able to correctly grade clobetasol propionate as the more potent (2).

Educational programmes and attendance at 'atopic eczema schools' have become popular. They are aimed at enhancing patients'/parents' knowledge of the disease and improving patients' skills in self-management of the condition, which for example enables patients to recognize disease complications such as bacterial infections. Another aim is to improve patients'/parents' behaviour and treatment compliance, and thereby improve eczema status.

### FACTORS ASSOCIATED WITH TREATMENT ADHERENCE/COMPLIANCE

Ohya et al. sent a questionnaire to 285 mothers of children with AD in Tokyo (3). They found that the

predictors for adherence to skin care treatment included not only the severity of the disease, but also a good doctor–patient relationship. The factors influencing a good doctor–patient relationship were the mother's personality and support from her husband. The relationship between the doctors/nurses and the parents is therefore of paramount importance.

Examples of parental education are as follows:

- i) In addition to routine information, practical guidance in eczema treatment is given by a trained nurse.
- ii) Structured educational programmes covering medical, nutritional and psychological issues in group sessions.
- iii) Provision of 'eczema workshops'.

### STUDIES INVOLVING PARENTAL EDUCATION

In an open pilot study 47 mothers of children with eczema were divided into three groups receiving routine information, attendance at a parental education group or attendance at a video-aided parental education group (4). The results indicate that additional information on video-tape may be helpful.

One of the earliest studies performed involving parental education was conducted in Sweden. This was an open study involving 50 children aged up to 6 years, divided into two groups; one received routine information from the physician, the other received additional information and practical guidance from a trained nurse (5). During a follow-up period of 3 months, the nurse intervention group had a greater decrease in the patients' eczema score and an intended increased consumption of topical steroid treatment than the control group. The study concluded that information provided solely by a physician was not always sufficient. Similar results were found in another small open study involving 23 parents, where an educational programme including medical education, skin care, information on coping with itching and scratching, relaxation training and education concerning additional related problems showed benefit (6). Two further studies, both with no control group and which included quantitative assessment of eczema severity, indicated benefit of education programmes. A reduction in SCORAD from a mean of 50 to 22 (score reduced in 97% of patients) was recorded

in 40 children with a mean age of 9 years over 6 months (7). Cork et al. (8) showed a reduction in objectively assessed eczema of 89% in a group of 51 children with severe disease followed for 1 year and given repeated education and practical demonstration on steroid application and use. This study is important in that it involved primary care patients, only 5% of whom had acknowledged ever having received any information concerning their disease. In addition, only one-quarter of them had been using emollients and a similar proportion were using topical steroids inappropriately. Another significant finding from this study was that emollient use increased on average eightfold following the intervention.

Educational programmes are time-consuming and expensive to organize. Therefore, it is essential to review results from randomized controlled studies. There are two major randomized, controlled trials evaluating the benefit of educational programmes in eczema management which have been published. Staab et al. (9) included 204 families of children aged 5 months to 12 years. The programme was interdisciplinary structured, educational and included medical, nutritional and psychological issues lasting for 2 hours each. Outcome measures included SCORAD, treatments used (emollients, antiseptics, topical steroids) and their costs, quality of life assessment and coping with the disease. Outcomes were assessed after 6 months. Compared with the control group, significant beneficial differences were seen in the intervention group for treatment habits (emollient, antiseptic and topical steroid use), treatment costs and how well patients coped with the disease. No significant effect on SCORAD was observed.

Another randomized controlled study involved 235 children: 115 children aged 6 months to 4 years and 120 children aged 4–16 years. The programme involved a single dermatology nurse intervention and assessed quality of life using the Family Dermatitis Index and the Infant Dermatology Quality of Life Index (10). At follow-up after 12 months, a slight improvement was seen in the Family Dermatitis Index ( $p=0.06$ ), but not in any other parameter. This somewhat equivocal result could be due to the inclusion of patients with mild disease, and too little statistical power.

A large intervention programme is ongoing involving over 1000 parents of children with at least moderate to severe AD aged up to 6 years, parents and children with AD aged 6–12 years and youths with AD aged 13–18 years (11). Preliminary results indicate its overall benefit in terms of improved SCORAD, which importantly lasts for at least 1 year after participation.

#### GENTOFTE ECZEMA SCHOOL AND ITS EVALUATION

The Gentofte Eczema School is specifically aimed at parents of infants and small children with AD. In

addition to a dermatological consultation, information on treatment is given by a trained nurse, and written information as well as a 15-minute video-tape are provided to take home. Direct telephone access to a trained nurse is an option. The information given is consistent and checked against a standard list. A group educational session involving around 25 participants lasts one evening for three and a half hours. The programme's aim is to improve knowledge, 'self-management' skills and compliance with treatment. Sessions focus on practical management and treatment of the disease. They also include background information on its aetiology, epidemiology and the results of recent research. This covers clinical features of AD and its complications, particularly infections and exacerbating factors including allergens. Particular emphasis is placed on disease management including use of moisturizers, medical treatment, avoiding exacerbating factors, the risk of developing hand eczema in adulthood, quality of life and social factors. Questions often raised by the parents include allergens, foods, side effects of topical steroids and herbal remedies.

The impression gained to date is that the eczema school improves patient/parent–physician contact, clinical visits are shorter and there is improved treatment compliance and less concern about using topical steroids. Interaction with other sufferers and their families appears to be beneficial.

We conducted an open evaluation of our eczema school using a questionnaire at the initial attendance and after 1 month. Results concerning the attitude to treatment and knowledge of the disease from 31 parents who have completed the study demonstrated high participant satisfaction with the eczema school, increased knowledge about AD, and a positive influence on behaviour as regards the disease and its management. A particular improvement was seen in patients' understanding of the disease itself, the increased risk of developing hand eczema and in concern about its treatment.

#### CONCLUSION

There is high participant satisfaction with AD educational programmes. They increase the knowledge of the disease in patients and parents of children with AD and seem to have a positive influence on patients' behaviour as regards the disease and its treatment.

#### DISCUSSION

*Leung:* Whenever we see a patient whose eczema is the worse it ever has been, we ask them to show us how they use their treatment. Quite often patients do not do as instructed, even when this is done well. We get nurses to demonstrate how to apply medications and when they return get them to show us.

*Agner;* It is very important to ensure treatments are used correctly.

*Taieb;* Yes, we do the same. We also found that when patients grade the quality of the information given to them, the information from the doctor is the most important. Patients appreciate the time given by doctors.

*Leung;* The main reason for poor compliance is patients do not believe that treatment works. However, if you can convince them to apply the treatments correctly, this can be overcome.

*Diepgen;* Enrolment in our study is now complete at 1000 patients with moderate eczema according to SCORAD (at least 20). A problem is that some of our patients in the 'Waiting group' do not want to wait and try to get information from others. Overall, the SCORAD was improved significantly and the effect is maintained for some time, indicating the long-term value of eczema schools. An economic evaluation is under way as the costs increase with the school, greater use of steroids, nurse time, etc.

*Thestrup-Pedersen;* Are patient organizations such as the Eczema Society in the UK important?

*McFadden;* In the hierarchy of health care in UK the majority of patients are managed in primary care. Compliance is essential and the three main problems at least in the UK are inadequate use of emollients, steroid phobia leading to inadequate use and the single antigen concept can mislead patients if they have an endogenous or multifactorial problem. Steroid phobia is a major problem. It can stem from negative comments from relatives and press scares, which are generally sensationalized. Patient groups can be very important here.

*Diepgen;* What proportion of patients on steroids request alternative non-steroidal topical therapies?

*McFadden;* In the UK a high proportion.

*Agner;* Similar in Denmark, at least half our patients have tried herbal remedies.

*Diepgen;* It is important to demonstrate that the eczema schools are cost-effective. This is particularly important when health costs are covered by insurance companies. Whilst eczema schools increase some costs they may

diminish others, for example alternative medicines, but the important aspect is: Are they cost effective?

*Taieb;* Alternative medicine costs are high.

*Agner;* The eczema schools also increase the quality of life of the clinicians!

## REFERENCES

1. Lewis-Jones M, Finlay A, Dykes P. The Infants' Dermatitis Quality of Life Index. *Br J Dermatol* 2001; 144: 104–110.
2. Charman CR, Morris AD, Williams HC. Topical corticosteroid phobia in patients with atopic eczema. *Br J Dermatol* 2000; 142: 931–936.
3. Ohya Y, Williams H, Steptoe A, Saito H, Iikura Y, Anderson R, et al. Psychosocial factors and adherence to treatment advice in childhood atopic dermatitis. *J Invest Dermatol* 2001; 117: 852–857.
4. Niebel G, Kallweit C, Lange I, Folster-Holst R. Direct versus video-based parental education in the treatment of atopic eczema in children. A controlled pilot study. [Direkte versus videovermittelte elternschulung bei atopischem ekzem im Kindesalter als ergänzung fachärztlicher behandlung. Eine kontrollierte Pilotstudie.] *Hautarzt* 2000; 51: 401–411.
5. Broberg A, Kalimo K, Lindblad B, Swanbeck G. Parental education in the treatment of childhood atopic eczema. *Acta Derm Venereol* 1990; 70: 495–499.
6. Gieler U, Kohnlein B, Schauer U, Freiling G, Stangier U. Counselling of parents with children with atopic dermatitis. [Eltern-Beratung bei Kindern mit atopischer Dermatitis.] *Hautarzt* 1992; 43(Suppl 11): 37–42.
7. Chavigny JM, Adiceom F, Bernier C, Debons M, Stalder JF. Assessment of an educational program in an "Atopic School": pilot study in 40 patients. [Ecole de l'atopie, evaluation d'une experience d'education therapeutique chez 40 malades.] *Ann Dermatol Venereol* 2002; 129: 1003–1007.
8. Cork MJ, Britton J, Butler L, Young S, Murphy R, Keohane SG. Comparison of parent knowledge, therapy utilization and severity of atopic eczema before and after explanation and demonstration of topical therapies by a specialist dermatology nurse. *Br J Dermatol* 2003; 149: 582–589.
9. Staab D, von Rueden U, Kehrt R, Erhart M, Wenninger K, Kamtsiuris P, et al. Evaluation of a parental training program for the management of childhood atopic dermatitis. *Pediatr Allergy Immunol* 2002; 13: 84–90.
10. Chinn DJ, Poyner T, Sibley G. Randomized controlled trial of a single dermatology nurse consultation in primary care on the quality of life of children with atopic eczema. *Br J Dermatol* 2002; 146: 432–439.
11. Diepgen TL, Fartasch M, Ring J, Scheewe S, Staab D, Szczepanski R, et al. Education programs on atopic eczema. Design and first results of the German Randomized Intervention Multicenter Study. *Hautarzt* 2003; 54: 946–951.