

Compliance Difficulties in Atopic Children, Reflections from an Eczema School in Sweden

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Abstract

Atopic dermatitis in children is common. However, where many patients only have minor symptoms, in children seen in departments of dermatology the majority often have widespread dermatitis for longer periods of time. Both the disease, with repetitive flares, and the treatment are often a cause of concern for both patient and parents. Compliance in the group varies and in the patients seen in the eczema school this is often a problem.

Keywords: Atopic dermatitis; Contact allergy; Eczema school; Compliance

evident but can be major obstacles for a team trying to reach a patient with atopic dermatitis or the parents.

Introduction

Although 20% of all children in the western world at the age of about 6 have or have had atopic dermatitis [1-3], living with eczema and learning how to treat the skin is still for many patients and their parents considered very difficult [4,5]. As a treating physician, often the major obstacle is not finding a suitable treatment but finding a way to reach the patient and parent in order to have a good understanding of the disease and its treatment and good adherence [6-8]. It is well known that education [9-15] as seen in eczema schools and not only for diseases such as eczema [16] but also other educational measures [15,17,18] at least temporarily enhances compliance. How the eczema school works in different countries and cities depend often on the local clinicians, the facilities found and cultural differences [13,19-21].

Since 2003 in Malmö had eczema for school children in the age of 0-16 years. The eczema school is team-based with a dermatologist that, at first visit, decides on any needed investigations, diagnosis and gives the initial information about the disease and treatment. The nurse then gives hands-on information on how treatment should be done practically and then has a follow-up visit to implement knowledge and care. A social well fare officer is connected to the team and is present sometimes already at the initial visit or the patient/parents are given the opportunity to meet the social well fare officer if there is need for this. Thus, the patient/parent should actually only need 2 visits in the eczema school. However, as in many eczema schools, this is not actually the case, and also the reason for having the eczema school, many patients/parents need several visits in order to implement knowledge of the disease, its tendency for flare-ups and how to treat the dermatitis and minimise these. In the case reports below we have wanted to highlight some of the clinical and social problems, including the fact that as an immigrant in a new country a diagnosis of eczema may be more difficult to handle, due to social and cultural differences, and where the families often have not had a history of dermatitis in their home country. Some of these problems are often not initially

Case I: Girl 14 Years Old

Presents on referral from a general practitioner who had seen the patient with a flare of atopic dermatitis involving most of the body and especially the face. Does not come for first visit due to the fact that she had so much facial dermatitis that she did not want to show herself outdoors. Finally shows up with her mother.

History

Atopic manifestations observed in the family but no one except for the patient with atopic dermatitis. Has had dermatitis since infancy. Last years flexural dermatitis, hand dermatitis and facial dermatitis especially around the eyes. The actual reason for referral is that the patient no longer goes to school when her facial dermatitis flares. Several years of sleep disturbances due to dermatitis. Better in summertime and when on holiday. The mother and daughter had sought different doctors for several years, everyone prescribing local corticosteroids. This treatment option was by the mother considered to have too much many side-effects and therefore was not used. Sometimes the mother admitted the use of a mild corticosteroid on dermatitis on legs and arms when the sleep disturbances were too much to bear. The mother had sought other treatment options for her daughter such as yoga and dance therapy. Nothing had had lasting effect. The patient has, when seen in clinic, a totally untreated and widespread dermatitis with excoriations and lichenifications in flexural areas, prurigo nodularis pattern on legs and arms and a facial flare. Dry and excoriated skin observed everywhere.

Care

The patient gets careful information on treatment options and regimes with her mother. UVB therapy and group III local corticosteroids are prescribed for the body and milder corticosteroids for the face. Emollient was given several times daily. Initial treatment is given in the out-patient clinic and the patient has a quick follow-up

with the eczema school within a week. The mother and patient come back after 6 weeks of UVB treatment. The patient quickly heals. The family can see the quick effect of the local corticosteroids and the benefit from the treatment, the patient has the opportunity to treat herself and sees that she can by this prevent flare-ups. Compliance is good and after follow up with the doctor the family can leave the eczema school.

Case 2: Girl 5 Years Old

Referred from nurse. Comes with her mother. Atopic dermatitis on most of the body and a dermatitis round the eyes which is infected.

History

Has had atopic dermatitis since infancy. In family eldest of two children's were sufferings from atopic dermatitis. Father has lived in Sweden 8 years and mother has come to Sweden 5 years ago. Mother learns Swedish, father unemployed.

Care

Treatment was given with antibiotics, local corticosteroids and emollients. The patients are treated several times but the dermatitis relapses after just a couple of weeks. The family gets to see the social welfare officer. There are financial problems and the family gets support for this. Still the dermatitis constantly relapses; there is no adherence when the patient is recommended light therapy. Often when seen in clinic, the patient is in such a bad condition that the treating clinician suggests hospitalization. The family doctor is contacted. There are several social problems in the family. The family stops coming. Family problems as well as a problematic economic situation have prevented compliance. The social service is contacted. The patient comes with the mother for a follow up visit. Gets information on treatment once more and the social well fare officer ensures that the family has money to buy medications. Since then has had no problem with relapsing uncontrolled dermatitis.

Case 3: Boy 3 Years Old

Referred from the paediatric department after having been seen in the emergency for widespread dermatitis and secondary infection.

History

One of three children lives with both parents, but father traumatized in war in homeland. He has come to Sweden several years ago. He was always only seen with mother, who speaks very good Swedish. Has atopic dermatitis since infancy. Huge problems with relapsing eye dermatitis, widespread eczema on legs and arms.

Care

Is put on local corticosteroids, emollients and given oral antibiotics. The patient is seen after one week and is healed but then does not come to eczema school. Comes several time as an emergency patient. Patient does not adhere to any plan that clinician, nurse and mother agreed on at previous visit. Every time the patient is seen has relapsing eye dermatitis often so bad that the eyes are swollen with restricted sight and secondary signs of infection. The family is seen by the social well fare officer. The family situation is more restrained than the team had first realized. The mother has three different works to be able to

support her family. She leaves home at 3 o'clock for her morning shift. The older children go to school themselves but the patient is taken to school by a neighbour. Therefore no proper treatment is given in the mornings. The mother collects the boy at kindergarten so late that there often comes to argument on whether treatment should be given at home. This is the reason for the family not being able to adhere to treatments. By help of the social service the mother can get other working hours and can also be on sick leave for a time in order to give the patient proper treatment. The treatment is started with hospitalization under which the patient heals totally. The patient has had relapses but the family has managed to understand and, by help from the eczema school where there is now understanding on the living conditions, manages to adhere to treatment.

Case 4: Girl 8 Years Old

Dermatitis is mostly seen in face, round eyes and mouth, but sometimes in flexural areas. It was treated with local hydrocortisone for months but it never really healed. So it is referred to eczema school because of this.

History

Suffering from atopic dermatitis since infancy and other atopic manifestations are observed in the family.

Care

The patient seemed to have adhered well to treatment. Due to the history and clinical picture, when seen in the eczema school, the patient is referred to patch testing. The patient is patch tested with the baseline series and found contact allergic to tixocortol pivalate. Treatment is changed and the patients now heals when on treatment and manages to stay healed with local corticosteroid treatment 2 weekly.

Discussion

In our eczema school we annually see more than 200 patients (2014; the number was 226, ♂ 127, ♀ 99). In all, on an annual basis we have more than 480 visits, ie there will be a majority of patients coming several times. The majority of patients are in the age of 0-5 years (2014, 0-5 years: 283, 6-10 years: 147 and 11-16 years: 54). The examples above are cases typical for the patient group that tends to need help over a prolonged period of time. We know that of patients with atopic dermatitis the majority of the patients symptoms disappear in early teens [22,23] but for those with more severe atopic dermatitis many will have ongoing clinical symptoms also as adults [24-26] and it is important that clinical, social or cultural reasons for frequent relapses are considered.

Malmö is a city with many structural problems, the city has a large population being first generation immigrants, many of whom have difficulties with the language (in our clinic we use interpreters on a daily basis, but many of the patients speak Swedish in a manner that make them want to be independent, however language difficulties are experienced from the physician in almost 1/3 of the patients). The immigration from countries with more sun than in Sweden and from countries with different medical care makes the diagnosis of atopic manifestations from the home country difficult and even more difficult for the patient/parent to realize that genetic background might have a part in a disease that "strikes" the family once in Sweden. Rhinitis and

atopic eczema might not have been obvious or diagnosed in the former home country. This makes adherence to treatment and understanding of the disease more difficult. Fear of corticosteroids as seen in case I is something that is still very common and where knowledge among nurses and the pharmacies that often give advice to the patients is still lacking. A large part of the population, both Swedish and first generation immigrants are unemployed causing economic problems, this and social problems within the families that are not communicated to the team treating the patient, is a third factor that might be a major obstacle for adherence to treatment. Case 4 illustrates the importance to always, when problems with compliance are suspected, re-evaluate the diagnosis. One important differential diagnosis when treatment seems inadequate is of course contact allergy to the local treatment used, tixocortol pivalate as such is not found in dermatological preparations but it is a marker for hydrocortisone allergy [26].

Conclusion

It is of the utmost importance that patients with atopic eczema get a correct diagnosis.

The contact with the family and considering different social, cultural and economic aspects that might impede treatment is important. When treatment fails apart from these factors, of course, a differential diagnosis or a diagnosis that might aggravate the atopic dermatitis, such as contact allergy, must be excluded.

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