

ORIGINAL ARTICLE

Improvement of pruritus and quality of life of children with atopic dermatitis and their families after joining support groups

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Keywords

atopic dermatitis, psychodermatology, quality of life, support groups

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Received: January 2006, accepted December 2006

DOI: 10.1111/j.1468-3083.2008.02697.x

Abstract

Introduction Atopic dermatitis places a large burden on patients and their families, with greater risk of emotional disorders and behavioural problems. Preliminary evidence suggests that support groups and educational programs are helpful in reducing stress, disease and pruritus severity and improves quality of life (QoL).

Objectives To evaluate the intensity of pruritus and the QoL in children with atopic dermatitis and their families after joining support groups.

Material and methods Subjects were randomly assigned to intervention or control group and completed the Children's Dermatology Life Quality Index (CDLQI) and Family Dermatitis Impact (FDI). Pruritus was evaluated by the Yosipovitch's questionnaire for pruritus. Each patient/family unit was considered as one 'patient'. Participants were divided into two different groups: one with children under 16 years and the second with patients' relatives. Each unit was accompanied during 6 months.

Results Thirty-two patients and their relatives completed the questionnaires satisfactorily. After intervention, pruritus intensity was similar ($P = 0.42$), but the pattern of pruritus improved in the intervention group. Overall QoL for CDLQI instruments improved significantly ($P < 0.01$) and, when specific domains were analysed, personal relationships ($P = 0.02$) and leisure ($P = 0.04$) showed marked enhancement. FDI scores failed to demonstrate differences in the QoL of patients' relatives after treatment.

Conclusion The improvement on pruritus and QoL showed that atopic dermatitis patients had benefits with the attendance to support groups. We consider that these non-pharmacological approaches can be a very effective accessory tools in the management of recalcitrant forms of the disease.

Introduction

Atopic dermatitis (AD) is a chronic and recurrent dermatose characterized mainly by pruritus and skin dryness. Its prolonged evolution, intensity of symptoms and discomfort cause serious implications in the patients and their family's life.¹⁻³ In Brazil, there are few specific data related to AD epidemiology, but a study conducted by Solé *et al.* in 2006 presented data showing that the disease

is a major problem in Brazilian children and adolescents, with an incidence of 13%.⁴

Among dermatological diseases that affect children, AD is the one with the greater impact on patients and their families, similar to type 1 diabetes.² The level of its burden is similar to other severe systemic diseases because the necessity of skin daily care and the attention to avoid exacerbating factors demands the patients and their caregivers to be in constant alert during daily activities.^{2,5}

Pruritus is the main complaint of AD patients, and its perception can be compared with pain or choking sensations when the symptom is serious.⁶ Sleeping alterations are common in preschool children, reaching scores of 10% to 30%. Atopics are particularly affected (up to 60%) mainly when the pruritus increases during the night; anxiety and depression can also influence the symptom.⁷

Some AD emotional aspects are as follows: difficulty in psychosocial adjustment, embarrassment at school and interruption of leisure and sport activities.⁵ The family structure is deeply affected by the disease.⁵ Some unpleasant feelings toward their children, sleeping disturbances of all the house members, high incidence of adults work absences and even compromising of school performance of other siblings are other significant parallel consequences. The family and community expenses involve medication, hospital admissions and work absence because the disease occurs mainly when parents are still responsible for their children's care.^{8,9}

There is an established relationship among psychological factors and various dermatoses, especially AD. Atopics are often described as insecure, dependent, sensitive, uneasy, hyperactive individuals with repressed emotions.¹⁰⁻¹² However, there are few evidences supporting the existence of a specific atopic personality, but it is clear that setback flares can be caused by psychological variables and that these aspects influence the disease course.¹³ Besides, AD patients have a tendency to consider that the health care team does not deal adequately with them or their disease, leading to disillusion feelings toward treatments and physicians.¹⁴ Explaining the disease characteristics emphasizing that there is neither cure nor a unique ideal treatment and trying to obtain a greater adhesion to the treatment are basic precepts that must be followed when treating AD patients. Anxiety, frustration, shame, depression in relation to the disease and changes in life quality can be treated through support groups, family therapies or individual follow-up.¹⁵⁻¹⁸ The family of chronically diseased individuals is often deeply involved with the disease; they usually do not follow treatment recommendations properly and, frequently, pass on the responsibility they should have in relation to their children's disease.^{18,19}

Non-pharmacological psycho-cutaneous treatments can be useful for various dermatological diseases and generally work as adjuncts, reducing stress and the amount of medications.²⁰ AD support groups and group therapy techniques for AD can improve the patient's symptoms mainly for those with serious manifestation or uncontrollable pruritus. Those groups would be part of the so-called total care scheme, proposed by Eugene Farber in 1997.²¹ Studies with educational groups have shown improvement in the quality of patients and their families'

lives after their participation in these meetings as well as a better adhesion to treatment, reducing its cost.^{14,19,22-27}

Individual feelings about the disease and its improvement are presently evaluated by specially developed questionnaires for different disorders, including AD.²⁸⁻³²

In 2005, Beattle and Lewis-Jones, evaluating children younger than 4 and their parents, showed a significant improvement on both quality of life (QoL) and clinical severity after two appointments in which specific instructions about the dermatitis were given. The aspects that showed better improvement were the time children spent to start sleeping and feeding habits; for parents, the better result were related to tiredness and emotional factors.³³

The objective of this study is to evaluate pruritus and QoL in atopic children and their families after joining support groups.

Method

Patients

Individuals of both sexes, ageing from 2 to 16 years, with AD defined by the Hanifin and Rajka's³⁴ criteria as moderate or severe. These criteria include the body surface area with eczema, pruritus intensity and the history of the disease. Scores between 4.5 and 7.5 are classified as moderate disease, and scores between 8 and 9 are classified as severe disease. Patients with these criteria and that did not respond appropriately to conventional treatments were included in the study. The duration of the inclusion was 1 year³⁴. Patients were randomized to intervention group (IG) or control group (CG), each one composed of 18 subjects. The duration of the attendance for the IG group was 6 months, with a minimum audience of 75% of the fortnightly meetings. Each patient/family unit was considered as one 'patient'.

Patients

Individuals of both sexes, ageing from 2 to 16 years, with AD defined by the Hanifin and Rajka's²¹ criteria as moderate or severe and that did not respond appropriately to conventional treatments.

Variables studied

Age, gender, pruritus and QoL.

Instruments

All patients answered Children's Dermatology Life Quality Index (CDLQI) and Family Dermatitis Impact (FDI) questionnaires in the beginning and after completing

follow-up. These questionnaires are validated for Brazilian Portuguese.³⁵ Pruritus was analysed by questionnaire based on the McGill pain questionnaire adapted from Yosipovitch 2002.³⁶

Dynamics of the children's group meeting

The meetings were coordinated by a child psychiatrist (PTLFN) and volunteer medical students (NGM, BB) who acted as assistant therapists. The meeting started allowing 30 min for free playing to relax and stimulate the interrelationship. Afterwards, a brief educational approach about disease, and treatment was introduced followed by a discussion about the theme. Finally, a structured playful activity was proposed where children would perform a task related to the subject. The activities were as follows: playing, drawing, simulations and performances. At the end of the proposed 90 min, children joined the parents' group and presented the performed activities.

Dynamics of the parents' group meeting

This group was coordinated by a senior dermatologist (MBW) with two other dermatologists (CP and MS) who acted as facilitators. Initially, the subject selected for the day was explained, with the addition of a writing text to stimulate discussion. Afterwards, parents report their experience about situations related to the proposed subject. The meeting coordinators interfere when necessary, with explanations considering the doubts that brought up. Other subjects could also be discussed during the meeting, when considered relevant by the group.

Statistical analysis

Continuous variables with normal distribution were expressed in mean \pm standard deviation and categorical variables through frequency and percentage. The variable analysis at the beginning of the treatment was established by the *t*-test for the quantitative variables and chi-square for the qualitative ones. The temporal difference analyses in the life quality scores was tested in models of analysis of variance for the repeated measures establishing a $P < 0.05$. The final summary of the differences observed among groups, considering the life quality scores, in children and parents was expressed by means of standardized mean difference (SMD). The statistical analysis was made using the SPSS program, 12.0 version.

Ethical consideration

The study was approved by the Ethics and Research Committee of the HCPA and considered of minimum risk,

Table 1 Distribution of variables: pruritus effects and quality of life in both groups, before the intervention

	Intervention (n = 16)	Control (n = 16)	P
Pruritus effect			
Mood	6.94 \pm 3.28	6.44 \pm 3.76	0.69
Feeding	2.50 \pm 2.92	2.19 \pm 3.43	0.78
CDLQI	11.37 \pm 7.26	11.75 \pm 5.36	0.86
DFI	7.56 \pm 4.94	12.87 \pm 8.59	0.04

The data are presented as mean \pm standard deviation.

as support groups are not psychotherapy groups but educational ones. All patients and their responsible freely agreed to participate and signed an informed consent. Patients designated for the control group received the opportunity to participate on the SG after the observation period.

Results

Thirty-six AD patients were included in the study, and 32 of them completed the follow-up, during a 24-month period. Five patients (31.2%) from the intervention group and 9 patients (56.2%) from the control group were female ($P = 0.28$). The average age of the IG members was 79.31 \pm 49.82 months and in the CG was 79.44 \pm 53.86 months ($P = 0.99$). The disease average time for the IG patients was of 61.25 \pm 42.84 months and for the CG was 56.25 \pm 51.59 months ($P = 0.77$). At the beginning of the evaluation period, both groups were similar regarding to pruritus effect on child's mood and feeding habits, CDLQI and DFI (Table 1).

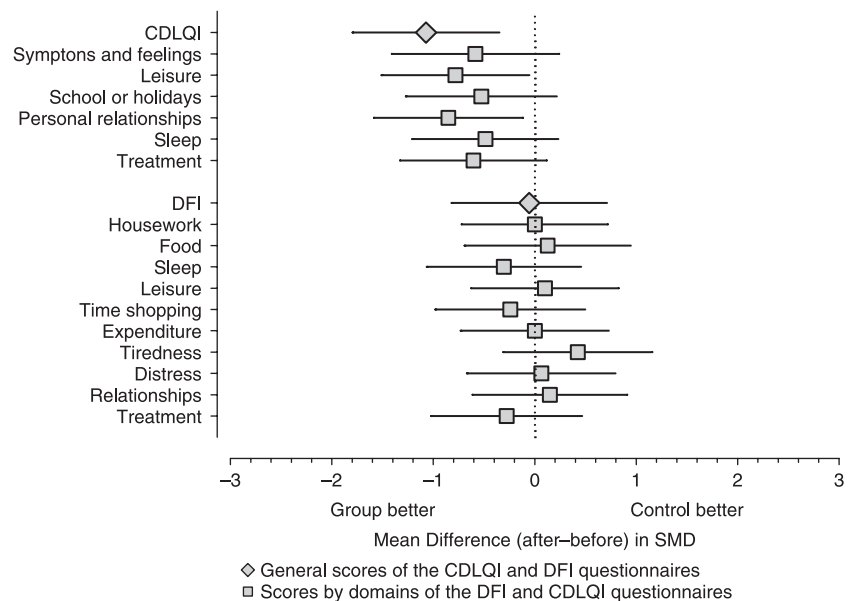
Evaluation of the pruritus improvement

Initially, there was no difference in pruritus frequency between the groups, with 15 patients referring daily pruritus in the studied group and 12 in the control group ($P = 0.31$). However, there was a significant difference in the pattern of pruritus after the intervention, with a larger number of patients from the IG referring only weekly pruritus ($P = 0.023$), in comparison with daily itch at the beginning.

After the intervention, children presented a significant change on the influence of pruritus over their mood. Considering values from 0 to 10 to analyse this influence (measured by the visual analogous scale), the support group participants indicated values of 3.63 \pm 3.30 and the control patients of 6.19 \pm 3.54 ($P = 0.03$).

In relation to influence on feeding, the significance was borderline ($P = 0.52$).

fig. 1 Described results presented as variation average difference (before-after) of the life quality score values between the groups in SMD. The negative values in the graph represent a life quality improvement, as in the QoL score of the CDLQI and DFI lower results mean better life quality. This way, an after-before difference, with a negative result represents a final score lower than the initial one, showing an improvement in the life quality during this time.



Evaluation of the QoL improvement

According to CDLQI questionnaire in the beginning of the study the difference between the groups did not show significant differences ($P = 0.86$) in QoL. Nevertheless, there was a noticeable improvement in the intervention group in relation to controls, in the questionnaire evaluation as a whole ($P < 0.01$). There was also clear improvement of the QoL in the leisure and personal relationship domains ($P = 0.04$ and $P = 0.02$, respectively) as shown in fig. 1.

FDI scores failed to show differences in the QoL of patients' relatives after treatment.

Discussion

Nowadays, the best concept for the treatment of individuals is to consider both, the patient physical and emotional aspects and the impact of the disease in the personal and familiar contexts. A better understanding of the individual as a whole facilitates the physicians-patient relationship and the adhesion to proposed treatments.

Non-pharmacological interventions, such as support groups, improve the understanding of the disease, so patients can better control their illness.³⁷

AD is a chronic disease of variable severity and susceptible to acute flares. In well-informed patients, the control over the disease is reflected by better response to treatments and reduction of flares.

Support groups, also called 'eczema schools', have been reported for many years as a new proposal for the guidance of AD patients and their families^{25,26} showing a

significant improvement in the subjective and objective symptoms of the disease.³⁸ Educational programs involve the participation of dermatologists, paediatricians, psychiatrists, nurses and psychologists.

In Germany and France, the 'atopy schools' are part of the patient public assistance.^{23,25,26} In Brazil, this form of intervention for atopic patients is not available yet. However, programs aimed to help obese children showed a defined influence on the handling of weight problems.³⁹

Pruritus is one of the main symptoms of AD; patients have a lower threshold to symptom, when compared with healthy children, and it could be triggered by minimum stimuli.^{11,40} Psychological interventions can reduce the intensity of pruritus, whereas emotional stress aggravate the complain in up to 81% of atopic patients.⁴¹ Few systematic studies emphasize this aspect of the disease mainly by the difficulties in measuring itch. However, when we evaluated the pruritus frequency in the present study patients who took part in the support groups significantly changes the intervals between itch crisis from daily to one or two times in the week. At this point, educational groups are a good therapeutic intervention, as they teach how to handle the symptom and how to 'itch' without further damaging the skin.

Mood is an important aspect for all individuals, independent of age. Personal relationships, social interaction and school activities can suffer a negative influence by changes in humor.^{24,42} It was possible to show that the participation of atopic patients in support groups improve their sense of humor. It is also probable that, in a long-term, this improvement turns into a better disposition to face symptoms and personal relationships.

Rarely, patients complain about how symptoms interfere in their lives. Lack of information about the disease expressed by patients and their peers eases discrimination, with reflects on self-esteem.⁴³ The observation on how children deal with their disease, the fact that they consider themselves as out of normal, the innate difficulties during infancy and the disease influence on aesthetic patterns, emphasize the need to broaden the therapeutic approach for AD.^{44,45}

Small changes in the children's life quality can bring psychological harm, which would be hard to control. Social contacts can be discouraged; emotional changes can occur in the family, difficulties in school are frequent, and other physical problems aggravate the dermatitis. As AD is not a life-threatening disease, families frequently do not have appropriate educational and psychological support they need, resulting in greater stress and frustration. This can lead to a disbelief in the medication and, consequently, lack of adherence to the treatment, and more social expenditures.²⁴

The CDLQI questionnaire, similar in its structure to the DLQI, is used to evaluate the QoL of children and the burden that the disease brings in the patients' daily activities, mainly for those with serious diseases. Presently, it has been used for many dermatoses such psoriasis, AD, rosea pityriasis, epidermolysis bullosa and vitiligo.^{11,12}

In the evaluation of the final results of CDLQI answers, we have noticed improvement on the patients' general QoL, more significant in the leisure and personal relationships specific domains. Surely, the improvement on personal relationships and also the increase on children's leisure time, which includes social life, were beneficial.

Regarding the FDI questionnaire, some authors consider any score above zero as an indication of changes in the QoL.⁴⁶ The results of its application confirm the general observation that AD also has a marked influence on the QoL of atopic parents. The number of evaluated patients did not allow expressing this difference adequately, but there is a clear indication that this aspect could also be demonstrated objectively with a greater sample.

AD is a dermatose that directly influences the daily routine, functioning as its main organizer.⁴⁷ Educational and counseling programs are particularly important for atopic patients, as their disease requires much time for explanations and orientations. Besides learning about how to properly use medications and how to recognize aggravating factors, it must be demonstrated strategies to live a normal life, avoiding restrictive measures and excessive treatments.⁴⁸

Atopic patients and their caregivers generally have their own understanding about the disease and its aggravating factors, being able to identify clinical modification during the disease treatment. It is possible to achieve good results, treating these patients with the intervention

represented by support groups. This approach, besides being less expensive, can benefit a larger number of individuals for each doctor, becoming a good method in assistance health programs.

This study showed that participation on support groups clearly improves both clinical symptoms and the QoL of atopic patients. This methodology can be reproduced and even be a regular intervention for other skin diseases besides AD.

The therapeutic unit patient/physician/family working in synchrony leads to the ultimate goal that is the best and more effective for AD suffers, as observed by a participant mother:

'What I want from the group is not a cure for AD. I know that it does not exist. But, I want my son to share experiences with other kids that carry the same disease, growing up without serious traumas, knowing that he is normal and could enjoy his childhood'.

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