

The Impact of an Educational Program on the Life Quality of Children and Adolescents with Atopic Dermatitis and on Their Families

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Abstract

Introduction: Atopic dermatitis (AD) is a chronic inflammatory disease, of varying severity, characterized by pruritus and eczema, which interferes the quality of life of patients and their families.

Objective: To evaluate the impact on the quality of life of children and adolescents with atopic dermatitis (AD) and on their families, pre and post therapeutic education.

Material and Methods: Cross-sectional study, which has evaluated the scores of the Children's Dermatology Life Quality Index (CDLQI) of children and adolescents with AD and the caregivers Dermatitis Family Impact Questionnaire (DFI) during the medical consultation from March to August 2018. Thirty-four caregivers and patients with AD age ranged 5 to 15 years old have participated in the research, but only the 20 ones who joined the Project, which consists of offering therapeutic education during consultations and monthly appointments with a multidisciplinary team. The severity of the disease has been assessed according to the Scoring Atopic Dermatitis (SCORAD). The questionnaires were applied at the first and the last meeting on therapeutic education. The Chi-square test was used to evaluate categorical variables and Kruskal-Wallis the numerical variables.

Results: The mean age of patients was 9.75 years old ($SD \pm 3.00$) and parents 39 years old ($SD \pm 4.50$). The SCORAD mean before therapeutic education was 36.99 ($SD \pm 18.85$) and patients were categorized as: 25% mild, 40% moderate and 35% severe. The CDLQI mean was 7.50 ($SD \pm 6.62$) and the DFI was 14.95 ($SD \pm 8.78$). After therapeutic education, the mean for SCORAD was 35.99 ($SD \pm 22.58$), for CDLQI, 6.10 ($SD \pm 5.65$) and for DFI, 12.05 ($SD \pm 8.07$). A significant difference was observed in the DFI ($p < 0.05$).

Conclusion: AD interferes negatively on the life quality of patients and on their families. An educational program can positively interfere with adherence, therapy and disease prognosis.

Keywords: atopic dermatitis, eczema, quality of life

INTRODUCTION

Atopic dermatitis (AD) is a chronic, recurrent, multifactorial, heterogeneous inflammatory disease, depending on the interaction of environmental and genetic factors, of varying severity characterized by intense itching and eczema (1-3). It may affect any age, but 10.7% is more prevalent in childhood, especially in the first year of life (4) and it has markedly increased over the past three decades (5). The treatment is carried out in the long term and in order to have a good response depends on the patient's and their family's adherence (6). AD has a profound social,

psychological well-being, economical, academic and occupational impact on the quality of life of patients and their families. (4).

Many European countries have established educational programs for patients with AD and their parents in the last ten years (5). Multidisciplinary educational programs help patients and their caregivers to better understand the disease, assist in patient compliance and proactivity in their own treatment, in addition to relieve symptoms and, consequently, enhancing the life quality of all involved (5).

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OBJECTIVE

To evaluate the impact on the life quality of children and adolescents with atopic dermatitis (AD) and their families, pre and post educational program.

METHODS

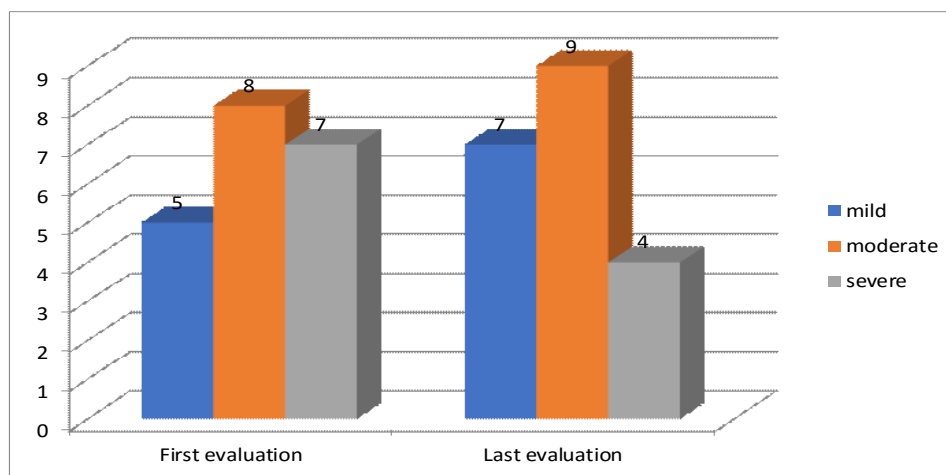
Cross-sectional study, which evaluated the scores of the Children's Dermatology Life Quality Index (CDLQI) questionnaire of children and adolescents (age ranged 5-16 years) with AD (7) according to Hanifin and Rajka criteria (8) and the Dermatitis Family Impact Questionnaire (DFI) of their caregivers (9) during medical consultation within the period from March to August 2018. Initially 34 caregivers and patients with AD age ranged 5 to 15 years old have participated in the research, but only the 20 patients who joined the project, which consist of offering therapeutic education during consultations and monthly appointments with a multidisciplinary team, constituted of allergists, dermatologists, pediatricians, a psychologist, a nutritionist and a social worker, for a period of four months follow-up. The lectures during the meetings were based on the Update Practical Guide on Atopic Dermatitis – Part I and II (Join position paper of the Brazilian Association of Allergy and Immunology and the Brazilian Society of Pediatrics) to teach patients and their relatives about etiopathogeny of atopic dermatitis, clinical, diagnosis, prevention, the importance of the treatment and skin care using practical demonstrations (10,11). During the meetings, the health professionals encouraged participants to share personal experiences. Patient received individual therapy.

The severity of the disease was assessed according to the Scoring Atopic Dermatitis (SCORAD) index and

classified as mild (scores < 25), moderate (between 25 and 50) or severe (> 50). The questionnaires were applied at the first and last meeting of therapeutic education. The Chi-square test was used to evaluate categorical variables and Kruskal-Wallis the numerical variables. The Project was approved by the Ethics Committee of the Municipal Health Secretariat of Rio de Janeiro number: 2.647.461

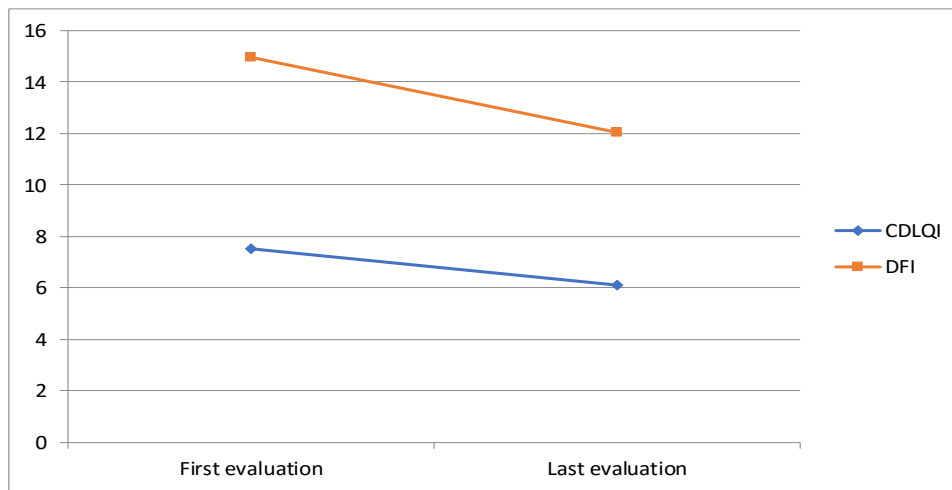
RESULTS

The mean age of patients was 9.75 years (SD ± 3.00) and parents 39 years (SD ± 4.50). The majority (85%) of the patients were residents of Rio de Janeiro, with an average of 4 people per family. Most female 12 (60%), 8 (40%) were brown skin, 7 (35%) white and 5 (25%) black. The most prevalent comorbidities were rhinitis in 14 (70%) patients, followed by asthma in 9 (45%) and obesity 5 (25%). The educational level of the parents was 8 (40%) primary, 10 (50%) high school and only 2 (10%) entered College. The SCORAD mean (0-103) before therapeutic education was 36.99 (SD ± 18.85) and patients were classified as: 5 (25%) mild, 8 (40%) moderate and 7 (35%) severe. The CDLQI mean (0-30) was 7.50 (SD ± 6.62) and the DFI (0-30) was 14.95 (SD ± 8.78). After the educational program, the SCORAD mean was 35.99 (SD ± 22.58), CDLQI, 6.10 (SD ± 5.65) and DFI, 12.05 (SD ± 8.07). A significant difference was observed in the DFI ($p < 0.05$). The patients were classified as 7 (35%) mild, 9 (45%) moderate and 4 (20%) severe (Graphic 1 and 2). When stratified by age (5-10 and 11-15 years), greater severity is observed, SCORAD (35.70 x 38.92), CDLQI (6.58 x 8.88) and DFI (14.08 x 16.25) in the older age group, but without statistical significance, probably because it is a small sample.



Graphic1. Severity AD classification pre and post educational measure

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Graphic 2. Impact assessment AD pre and post educational measures

DISCUSSION

Adherence to treatment in patients with chronic diseases is often difficult due to a number of factors, such as knowledge on the disease, financial and family availability to attend consultations, distance between the place of care and their residences, etc. Almost half of the patients who had started the program stopped the treatment. The main reason for the treatment failure is the low compliance of the patients and their caregivers, due to the lack of information on the disease (12). The adherence to treatment is important to avoid complications such as secondary infections and hospitalizations as a result of the aggravation of the disease.

The patients who have continued in treatment got amelioration by virtue the multidisciplinary program, that apart from increasing the bond with the health team, the patients and their families started to understand that despite being a chronic disease, there may be control and improvement on the quality of life of everyone involved, and the awareness they were not alone. The children and the adolescent took part on their own treatment. An improvement in caregiver's quality of life was observed after the educational program, which was statistically proven. Although it was not statistically significant, we observed an improvement in the quality of life of children and adolescents. Lyan Y *et al.* demonstrated in a multicenter study in China interventions that encourage self-management skills rather than focusing only on adherence to treatment reduces the

severity, and improves the quality of life knowledge and strategies to better face the disease (6).

In a study conducted by Staab D. *et al.*, it has been shown that an educational program for atopic dermatitis patients and their caregivers, helps in controlling the disease (13). In the studied population, we could observe that there was a decrease in SCORAD, with an increase in mild cases and a reduction in severe cases: before the educational program, we've had 25% mild and 35% severe and after it, we've observed 35% of mild cases and 20% of severe. Revealing better control of the disease once acknowledged about treatment.

This study had as limitation a sample from dermatology outpatient clinic in a pediatric municipal hospital in Rio de Janeiro/Brazil, with more moderate/severe cases and a small sample with low patient compliance to the program, probably because it was a population with a little financial resource.

In conclusion, AD interferes negatively in the quality of life of patients and their families, with the worst rates related to the higher severity of the disease. An educational program may positively interfere over adherence, therapy and the prognosis of the disease.

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