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*Correspondence to

Mariana Muzzolon

Graduate Program in Child and Adolescent Health at the Federal University of Paraná, 181 General Carneiro st, Curitiba, Paraná, Brasil.

Tel: +5541997878616

Email: muzzolon.mariana@gmail.com

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ORCID iDs

Mariana Muzzolon

<https://orcid.org/0000-0002-7289-1549>

Renata Robl Imoto

<https://orcid.org/0000-0003-3726-5240>

Mariana Canato

<https://orcid.org/0000-0003-4917-8312>

Kerstin Taniguchi Abagge

<https://orcid.org/0000-0002-9824-2459>

Vânia Oliveira de Carvalho

<https://orcid.org/0000-0002-4578-8781>

Conflict of Interest

The authors have no financial conflicts of interest.

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Educational intervention and atopic dermatitis: impact on quality of life and treatment

Mariana Muzzolon *, Renata Robl Imoto , Mariana Canato , Kerstin Taniguchi Abagge , and Vânia Oliveira de Carvalho

Federal University of Paraná, Curitiba, Brazil

ABSTRACT

Background: Educational intervention (EI) could improve understanding of atopic dermatitis (AD) and adherence to treatment, decreasing severity, and improving quality of life (QoL).

Objective: This study aims to evaluate the influence of an EI on the severity of the disease and on the QoL in children with AD.

Methods: A controlled clinical trial was performed, including children up to 14 years of age with AD. Patients were allocated into control group (CG), which received usual guidelines on AD during the outpatient visit, and a study group (SG) that, in addition to the usual guidelines, participated in the EI. The severity of AD was assessed by Scoring Atopic Dermatitis (SCORAD) and Eczema Area and Severity Index (EASI). QoL was assessed by the Children's Dermatology Life Quality Index and the Dermatitis Family Impact Questionnaire.

Results: Twenty-seven participants were included in the CG and 21 in the SG. There was a decrease in the median value for the QoL of children in the SG after the intervention ($p = 0.04$), as well as in the caregiver's ($p = 0.04$). In the CG, the median QoL of children and caregivers remained unaltered, for caregivers the median value for the QoL was equal throughout first and second evaluation ($p = 0.32$). In the SG, EASI values decreased after the intervention ($p = 0.04$), as well as SCORAD ($p = 0.04$). The CG did not show any decrease in the values of EASI ($p = 0.88$) scores nor of SCORAD scores ($p = 0.82$).

Conclusion: The EI rendered a decrease in severity of the disease and improvement in the QoL of patients and their caregivers.

Keywords: Atopic dermatitis; Eczema; Health education; Quality of life

INTRODUCTION

Atopic dermatitis (AD) is an inflammatory disease whose incidence has increased in the last 3 decades [1]. The diagnosis is clinical, defined by the Hanifin and Rajka criteria [2], and one of its main consequences is the decrease in the quality of life (QoL) of patients and their relatives. In children, this is due to the incessant pruritus, the changes that the treatment imposes on their routine, and the appearance of the lesions [3-5], not to mention the financial struggles caused by the necessary expenses for the treatment [6]. In preschoolers, pruritus causes sleep disturbance, which, in turn, leads to mood, attention, and behavior alterations [3, 7]. Regarding schoolchildren and adolescents, issues of self-image are the most affected aspect [7].

de Carvalho, Mariana Canato. Methodology: Vânia Oliveira de Carvalho, Renata Robl Imoto, Mariana Muzzolon. Project administration: Vânia Oliveira de Carvalho, Kerstin Taniguchi Abagge, Renata Robl. Writing - original draft: Vânia Oliveira de Carvalho, Mariana Muzzolon. Writing - review & editing: Vânia Oliveira de Carvalho, Mariana Muzzolon.

The decision to take the treatment allows adequate disease control, but for this, instruction of the patient and his caregivers is paramount [8]. However, the period of outpatient medical visits is insufficient for full instructions, which compromises the awareness about the disease and increases irregular use of therapy and search for unconventional treatments [3, 5, 8]. An alternative to this is the provision of support groups [9].

Educational interventions that include multidisciplinary practices for the care of AD are developed in different countries to favor comprehensive care for children and their families. These interventions can assist in coping with the disease and encouraging access to accurate information from reliable sources. In addition, they can promote teaching on the application of drugs, and discussions about the main concerns of the disease from patients and their parents. Psychological support is also essential to identify children's emotional triggers related to the disease, and to develop strategies which support these moments of crisis. Patients can also benefit from relaxation tactics to aid in sleep [4].

Psychologists can also help children understand the disease and encourage greater involvement in skin care. Other strategies, such as the use of theater performances and health games, can also assist in an effective communication with children on health-related topics. During these interventions, health professionals also have the opportunity to identify children who can benefit from additional support for mental health [9].

In Japan, for instance, Futamura et al. [10] coordinated a study that offered lectures on the epidemiology, pathophysiology, diagnosis and treatment of AD, as well as practical sessions on methods for children's skin care. A recent literature review demonstrated an improvement in disease severity from educational interventions and found that their scope varies between studies. Among the topics covered in educational interventions, skin care has been universally addressed by all programs in addition to psychological support and strategies to deal with AD. The literature is inconsistent regarding the correlation between disease severity and QoL. For example: the emotional factor was correlated with QoL in an evaluation carried out using the "Dermatology Life Quality Index", however, no correlation was found with eczema area and severity index (EASI) [11].

Therefore, this present study aimed to apply and evaluate the influence of an educational intervention on AD severity and the QoL of patients and their caregivers.

MATERIALS AND METHODS

This study was a controlled, nonrandomized clinical trial research aimed to evaluate the influence of an educational intervention on AD severity and QoL of patients and their caregivers through prospective data collection. A nonprobabilistic, convenience, and systematic sample was used to select the participants.

Participants and measures

Children up to 14 years old with a diagnosis of AD and their caregivers were included. Follow-up was carried out at the pediatric dermatology outpatient clinic of Complexo Hospital de Clínicas, Federal University of Paraná, located in Curitiba, Paraná Brazil. Patients with other chronic diseases (except asthma and rhinitis), those who had used systemic immunosuppressants in the previous 2 months, and those who did not attend the second evaluation were excluded.

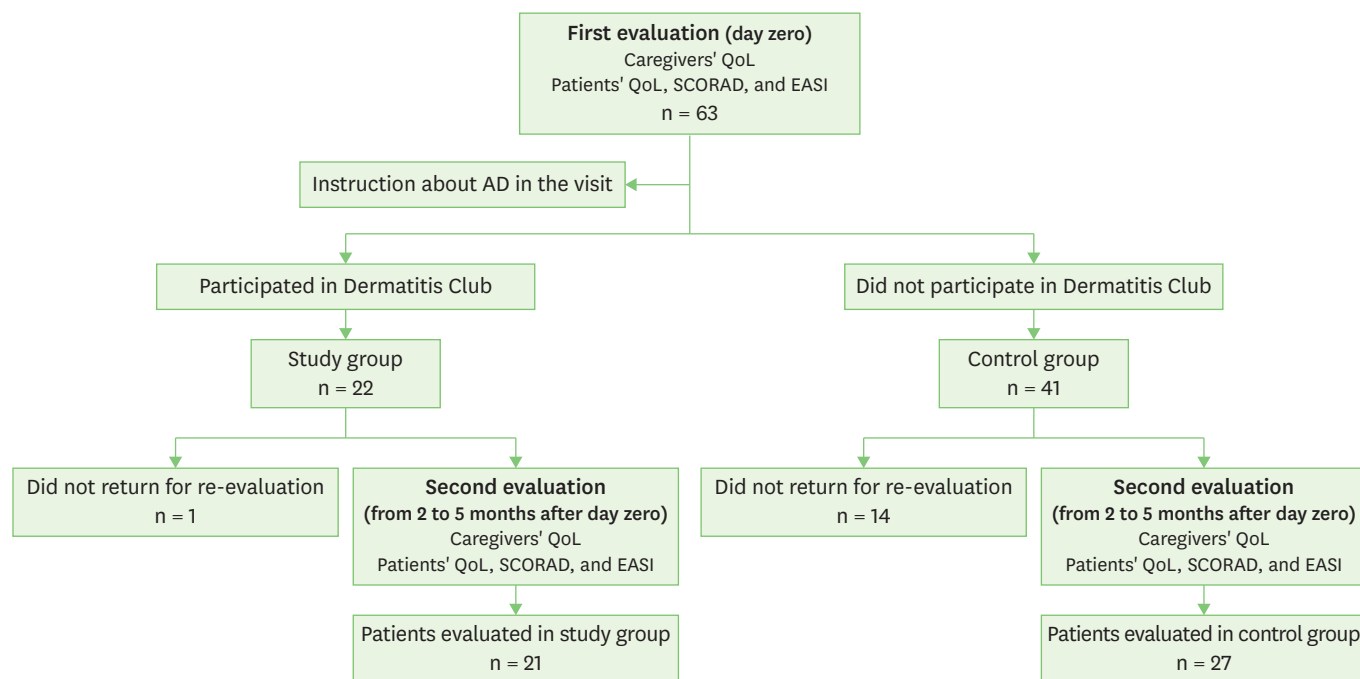


Fig. 1. Distribution of study participants. QoL, quality of life; SCORAD, Scoring Atopic Dermatitis; EASI, eczema area and severity index; AD, atopic dermatitis.

During the outpatient visit, patients received usual instruction about the disease and treatment. They were also invited to participate in an educational intervention called “Dermatitis Club.” Those who accepted the invitation were allocated in the study group (SG), while those who did not were allocated in the control group (CG). On the day of inclusion in the study, participants were submitted to an initial assessment on disease severity and their QoL. This was repeated in the second evaluation, which occurred 2 to 5 months later (**Fig. 1**).

Educational Intervention

The educational interventions lasted 90 minutes and were conducted in 2 stages: initially with parents and later with the children. At the parents meeting, participants attended a lecture that addressed general aspects of AD, such as pathophysiology, triggers, and treatment (**Fig. 2A**). Subsequently, they shared their personal experiences about the disease, enabling exchange of information and experiences regarding diagnosis and treatment. In the meeting, clear language was used, seeking maximum understanding of the participants. After the lectures, a conversation circle was opened, where the experiences learned were shared between parents and health professionals.

At the children meeting, participants participated in ludic activities such as drawings and paintings about their experiences with the disease. Following that, the children watched a puppet show that addressed the main care for disease control, such as the adequate bathing time and temperature, importance of skin hydration as well as worsening and improvement factors of AD (**Fig. 2B-D**). After these activities, the children were invited to reproduce the puppet show with drawings, and, to reinforce learning, they also participated in a hydration workshop, with instruction games about correct application of emollients (**Fig. 2C**). The presence of several children with AD in the same environment was proposed with intention of mutual support, integration, and representativeness. Personal experiences and the expression of feelings about the disease itself were shared between them.



Fig. 2. Activities carried out in the educational intervention (Dermatitis Club). (A) Presentation lecture for parents and questions and answers session. (B) Puppet show about atopic dermatitis for children. (C) Hydration workshop. (D) Drawing by one of the patients after the educational intervention.

Assessment Instruments

To determine efficacy of the educational intervention, both AD severity and the QoL of participants were assessed. The AD severity was assessed by 2 scores: EASI [12] and Scoring Atopic Dermatitis (SCORAD) [13]. Children's QoL was assessed using questionnaires validated for the Portuguese language. For children up to 4 years of age, Infant's Dermatitis Quality of Life Index (IDQOL) [14] was used, whereas Children's Dermatology Life Quality Index (CDLQI) [15] was applied to children older than 4. The caregivers' QoL was assessed through Dermatitis Family Impact Questionnaire (DFIQ) [16].

Eczema Area and Severity Index

For the assessment of EASI, each region of the child's body (head and neck; trunk; upper and lower extremities) is selected and the extent of AD is calculated. For this analysis, the score varies between 0 and 6 according to the percentage of injuries per area. As a final classification of AD severity according to the EASI score, there are no injuries (0.0), very mild (0.1-1.0), mild (1.1-7.0), moderate (7, 1-21.0), severe (21.1-50.1), and very severe (50.1-72.0) [12].

Scoring of Atopic Dermatitis

In the SCORAD analysis, the child's lesions are assessed, and the score is calculated according to the extent, the severity/intensity of the injuries and presence of subjective

symptoms. The disease is classified as mild (score less than 25), moderate (score between 25–50), or severe (score greater than 50) [13].

Infants' Dermatitis Quality of Life Index

The IDQOL contains 10 questions including: itching and scratching; mood of the child; sleep; leisure activities; problems during mealtimes; problems caused by treatment; level of comfort while dressing or undressing the child; and problems during bath times. There is an additional separate question regarding dermatitis severity, which is scored from none to extremely severe [14].

Children's Dermatology Life Quality

The CDLQI includes 10 questions regarding different aspects of the child's life affected by the disease in the last week. It consists of 6 domains: symptoms and feelings, leisure, school or vacation, personal relationships, sleep, and treatment [15].

Dermatitis Family Impact Questionnaire

The questionnaire contains 10 questions about household chores, food preparation, sleep, family leisure, shopping, spending, tiredness, emotional stress, relationships, and the impact of helping treatment in the primary caregiver's life [16].

All questionnaires (IDQOL, CDLQI, and DFIQ) refer to symptoms of the week prior to application of the questionnaire. The score in each question ranges from 0 to 3 points, totaling a maximum of 30 points. The higher the value obtained, the worse the QoL.

Ethical approval

The research was approved by the Human Research Ethics Committee of the Federal University of Paraná (approval number: 47181815.2.0000.0096). In all cases, it has received the consent and assent of the participants of the study. No incentives were used.

Analysis

Data were analyzed by the Statistica 10.0 software (Statsoft, Tulsa, OK, USA). The Wilcoxon and Mann-Whitney tests were applied for analysis, and the significance level was 5% for all tests.

RESULTS

The 2 evaluations were completed by 21 participants in the SG and 27 in the CG. Of the total, there were 29 girls (60.4%) and 19 boys (39.6%); the median age of children was 4 years and 9 months (14 months to 14 years); and 20 of them were in elementary or middle school (42%) (**Table 1**).

Regarding QoL, the average QoL of caregivers in the CG was 7 in both evaluations ($p = 0.32$). In the SG, a statistically significant improvement was observed between the first and second evaluations ($p = 0.04$). Likewise, the average QoL of the CG children was 6 in both evaluations ($p = 0.88$), while in the SG, it ranged from 8 (first evaluation) to 5 (second evaluation) ($p = 0.04$) (**Table 2**).

The mean time of outpatient follow-up was 14 ± 3.2 months with no difference between SG and CG (**Table 1**). In the first assessment, the severity by SCORAD was higher in SG compared to CG ($p = 0.03$) and also by EASI assessment $p = 0.02$ (**Table 2**).

Table 1. Distribution of participants according to gender, age, and schooling

Variable	Control group (n = 27)	Study group (n = 21)	Total
Sex, n (%)			
Male	9 (47.3)	10 (52.6)	19 (39.6)
Female	16 (55.2)	13 (44.8)	29 (60.4)
Age, median (range)	4 yr and 11 mo (13 mo–14 yr)	4 yr and 5 mo (14 mo–13 yr and 4 mo)	4 yr and 9 mo (14 mo–14 yr)
Follow-up (mo), mean ± SD	14 ± 2.1	13 ± 6.4	14 ± 3.2
Schooling, n (%)			
Not attending	10	9	19 (39.6)
Nursery	5	3	8 (16.7)
Elementary or middle school	9	11	20 (41.6)
High school	0	1	1 (2.1)

SD, standard deviation.

Table 2. Average values of children's and caregivers' QoL, and EASI and SCORAD scores of the control and study groups, in the first and second evaluation

Variable	Control group (n = 27)		p value	Study group (n = 21)		p value
	1st evaluation	2nd evaluation		1st evaluation	2nd evaluation	
QoL caregivers	7 (0–26)	7 (0–22)	0.32	8 (0–21)	6 (0–19)	0.04
QoL child	6 (3–20)	6 (1–27)	0.88	8 (0–16)	5 (0–13)	0.03
SCORAD	24.4 (10.2–60.5)	22.8 (0–49.5)	0.82	30.0 (6.2–54.8)	24.1 (0–49.5)	0.04
EASI	2.2 (0–24)	1.8 (0–38.8)	0.88	3.3 (0.4–20)	2.2 (0–16.4)	0.04

Values are presented as median (range).

QoL, quality of life; EASI, eczema area and severity index; SCORAD, Scoring Atopic Dermatitis.

Regarding disease severity, evaluated by the EASI and SCORAD indexes, we observed a reduction in the CG between the first and second evaluation, but it was not statistically significant ($p = 0.88$ and $p = 0.82$, respectively). In the SG, there was a significant reduction in disease severity, both for the EASI and SCORAD indexes ($p = 0.04$) (Table 2).

DISCUSSION

The impairment of QoL in AD patients and their relatives has been documented in the literature [6, 8, 17–19]. The exhaustive daily care routine and sleep deprivation of both children and their caregivers lead to tiredness, anxiety, and guilt [20, 21]. The results of this study are consistent with these data.

However, few studies evaluated the influence of Therapeutic Education on AD and the methods used in these few interventions differ, which makes it difficult to compare the data [22]. On the other hand, educational programs improved participants' QoL and/or AD severity in most studies involving SG and CG [9, 22, 23].

In 2006, in Germany, Staab et al. [23] randomized 992 children and adolescents to assess the impact of an intervention on disease severity and QoL in AD patients and their caregivers. This was a multicenter study in which the SG (n = 446) participated in 6 meetings, each lasting 2 hours, coordinated by a multidisciplinary team (pediatrician, psychologist, nutritionist, and dermatologist). At each meeting, the addressed topics aimed to raise caregivers' awareness about AD and techniques for drug-based and behavioral management of the disease. Participants were reevaluated after 6 and 12 months. There was improvement in both QoL and disease severity in the SG, and this improvement was maintained over a year, demonstrating long-term benefits of the educational program. However, it should be pointed out that the study evaluated only patients with SCORAD above 20 points, and it was not possible to evaluate whether the same results would be obtained for a less severe disease.

Grillo et al. [3] evaluated 61 patients (and their caregivers) before and after an educational intervention. Twenty-nine participants received information about the disease and its treatment during the routine consultation, while 32 participants attended a lecture on skin care, worsening factors of AD, and infections, as well as participating in a practice session on application of topical medications. Despite the QoL of children and their caregivers, measured with the same questionnaires used in the present study, not showing improvement after the educational intervention, the SCORAD disease severity index decreased in the group that participated in the intervention. Grillo et al. [3] argue that more time should be devoted to disease care in order to promote greater adherence to treatment, which can lead to an increased feeling of tiredness or exhaustion and, consequently, a decrease in QoL.

In 2008, Weber et al. [24] conducted a controlled study with 36 AD patients. Half of the patients were invited to join an AD support group while their children participated in recreational activities related to AD. The children's QoL, evaluated by the CDLQI, improved after the intervention, but this did not happen with the caregivers, although there was a tendency for QoL improvement in the second evaluation. The authors hypothesize that a larger sample would confirm the improvement in the QoL for the family.

The reduction in SCORAD and EASI values observed in the SG of the present study reiterates the positive effects of the educational intervention on AD patients. An Australian study evaluated sequential SCORAD of patients under the age of 16 diagnosed with AD [8]. The CG, comprising 50 patients, received general information about AD as a part of the consultation. The SG, with 49 patients, attended, in addition to consultation, a meeting where they practiced the application of emollients and topical medications. After 4 weeks, there was a significant reduction of SCORAD values in the patients who participated in the educational program.

Educational interventions also reduce AD severity measured by EASI [5]. One advantage of this score is that it does not include subjective items, which can raise the score. The results presented herein show a significant improvement in the EASI values, allowing to conclude that the educational intervention led to an objective decrease in the severity of AD.

There is no evidence showing from what age therapeutic education should be offered to patients [25]. However, it is known that patient engagement in treatment is important for proper control of AD [3, 25]. In the present study, educational intervention was directed not only to caregivers, but also to children of all ages, which may have been another factor contributing to the improvement of QoL and the reduction of disease severity.

One of the limitations of this study is that the answers provided by patients and caregivers during the application of QoL questionnaires refer only to a week prior to the consultation and do not necessarily reflect the disease course [26]. In addition, the standardization of educational intervention studies in AD cases is necessary for the analysis of results to be comparable, thus making it possible to conclude which modalities are most effective.

Another limitation was the small, nonrandomized sample and the single intervention, in addition, the patients included in the SG had greater severity of AD and perhaps for this reason they could be more motivated to adhere to the treatment, even so, both groups were evaluated afterwards of the same time interval and those who participated in the intervention showed improvement in the evaluated parameters. Randomized studies with larger samples could confirm the results found here.

The educational intervention was an effective method, which allowed the QoL improvement of participating AD patients and their caregivers, as well as some decrease of disease severity by SCORAD. Such programs, including activities for children, should be encouraged and incorporated into AD treatment plans, since, given the chronic nature of AD and the high psychosocial impairment associated with it, the management of the disease should not be restricted to symptoms treatment.

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