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ORIGINAL ARTICLE

Evaluation of the quality of life of family members of patients with Atopic Dermatitis

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Quality of life,
Dermatitis, Atopic,
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Abstract

Objective: The overall objective of this study is to evaluate the impact on the quality of life of families of patients with AD and determine if there is a relationship with disease severity. **Methodology:** This is an individual, observational, cross-sectional study in which the study population includes 20 pediatric patients aged 1 to 12 years and their caregivers. There will be two evaluation moments, in which the patients SCORAD will be assessed and the DFI will be applied to the family member. **Results:** When compared A1 e A2, SCORAD demonstrated a z-score of 2.76 ($p=0.0058$), while DFI showed a z-score of 2.52 ($p=0.0119$). The Spearman correlation coefficient demonstrated a positive correlation with statistical significance ($r_s = 0.74$, $p=0.0002$). **Conclusions:** When patients experienced a decrease in SCORAD scores, the quality of life of their family members improved, as evidenced by a decrease in DFI scores. Additionally, in the analysis of each individual consultation, we also observed that higher SCORAD scores in patients were associated with higher DFI scores. The results of this study reinforce what has been previously shown in other studies: the negative impact of AD not only on patients but primarily on their caregivers. Additionally, we observed that the more severe the disease, the greater the impact on the family.

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INTRODUCTION

Atopic dermatitis (AD) is a chronic inflammatory skin disease whose exact etiology is still not fully understood. However, it is believed that there is an important interaction between alterations in the skin barrier, immune dysregulation, and environmental factors¹. AD affects both sexes and all races without preference, and it has a strong hereditary component. It is often the first step in the development of other atopic diseases such as food allergies, asthma, and allergic rhinitis. The sequential development of these diseases throughout life is referred to as the atopic march².

Clinically, AD presents with xerotic skin associated with pruritic, recurrent, and fluctuating eczematous lesions that disrupt sleep, development, interpersonal relationships, and the productivity of the affected individuals.² There are several diagnostic criteria for AD, with the Hanifin and Rajka criteria still being among the most widely used³.

Various pathophysiological mechanisms contribute to the etiology and clinical manifestations of AD. The defect in the epidermal barrier promotes inflammation through the dysregulation of immunomodulatory proteins and the release of molecules such as alarmins (IL-1 β , IL-25, IL-33), which are cytokines released in response to tissue damage^{4,5}.

As a chronic disease, AD has a significant impact on healthcare costs worldwide and is associated with high morbidity and mortality, compromising the quality of life of patients and their families. Its disease burden is comparable to that of other chronic conditions such as epilepsy, diabetes mellitus, and cystic fibrosis⁶. However, it is crucial to understand that AD is not just a skin disease but a systemic one. The importance of appropriate treatment extends beyond improving the patient's skin condition and encompasses their overall psychosocial well-being and that of their family⁷.

In this context, studying the quality of life of family members of AD patients becomes important, seeking to understand the factors that this complex, chronic disease with high morbidity rates imposes on everyone around it. Some studies have already been conducted in this regard, showing a strong relationship between the severity of the patient's condition and the impact on the quality of life of their family⁸⁻¹⁰.

The overall objective of this study is to evaluate the impact on the quality of life of families of patients with AD and determine if there is a relationship with disease severity. Additionally, we aim to assess the role of dermatologists in the treatment of patients with AD and, consequently, in the quality of life of their families.

METHODOLOGY

This is an individual, observational, cross-sectional study in which the study population includes 20 pediatric patients aged 1 to 12 years and their caregivers, who were treated at a specialized tertiary dermatology outpatient clinic for atopic

dermatitis in São Paulo, Brazil, from January to September 2022. Participants signed an informed consent form.

This study was approved by the Ethics Committee of the University of Santo Amaro, with approval number 5,597,965, and had consent from the institution and the responsible parties of the patients through the informed consent form.

The inclusion criteria were as follows: clinical diagnosis of atopic dermatitis according to the classic criteria of Hanifin and Rajka; age between 6 months and 12 years; no associated secondary dermatitis; in the initial evaluation (A1), the patient should either be treatment-naïve or modifying a previous treatment due to treatment failure.

The Dermatitis Family Impact (DFI) questionnaire, in its translated version, was administered to the parents at two time points: during the initial evaluation (A1) and the second evaluation (A2), which took place during a follow-up consultation after 1 to 4 months. In both moments, in addition to the questionnaire administered to the primary caregiver of the child, we assessed the degree of atopic dermatitis in patients using the Scoring Atopic Dermatitis (SCORAD) system. Both the DFI and SCORAD were utilized^{11,12}.

The DFI questionnaire helps measure how the life and family dynamics of a child with AD are affected. It is designed to be completed by the primary caregiver and consists of ten questions, all referring to the previous week before the consultation and related to household chores, food preparation and eating, sleep, family leisure activities, expenses, fatigue, emotional stress, and relationships. It has been translated and culturally adapted to Brazilian Portuguese. Each question is scored as follows: extremely = 3; very = 2; a little = 1; not at all = 0. The total score ranges from a maximum of 30 to a minimum of 0, with values of 0 and 1 indicating no impact on quality of life, 2 to 6 indicating a weak effect, 7 to 12 indicating a moderate effect, 13 to 18 indicating a strong effect, and 19 to 30 indicating a very strong effect. A higher score indicates a greater impact of AD on the family's well-being¹³.

The assessment of SCORAD is based on the affected body surface area, calculated using the rule of nines, which is the same method used for burns (for example, a child with half of one arm affected has 4.5% of the body surface area with lesions, as one arm corresponds to 9% of their total body surface area). It also considers the intensity of eczema based on the presentation of elementary lesions (erythema, edema/papules, exudate/crusts, excoriation, and lichenification), as well as the impact of subjective symptoms such as itching and loss of sleep. A value below 20 indicates mild AD, between 20 and 40 is classified as moderate AD, and above 40 indicates severe AD¹¹.

For the statistical analysis, the Bioestat5 program was used. The Wilcoxon test was applied to compare the values of SCORAD and DFI between the two evaluated periods. The Spearman correlation coefficient was also used to compare the percentage differences between the values of the related scales. The percentage differences were calculated using the formula: $\Delta\% = [(Pre\text{-}value - Post\text{-}value) / Pre\text{-}value] \times 100$.

Additionally, a literature review was conducted on the topic by searching scientific articles in the PubMed database, comparing our results with those present in the academic field.

RESULTS

The study included 20 children aged 1 to 12 years and their respective primary caregivers, who were all mothers in our cases. In the patient sample, 55% were girls and 45% were boys. The values of SCORAD for each child and DFI for their respective caregivers were measured at the first and second evaluations, and the Bioestat5 program was used for statistical analysis.

The mean and median values of SCORAD and DFI at the first and second evaluations are presented in Tables 1 and 2. These values were compared using the Wilcoxon test and both showed a significant decrease between the two periods. SCORAD demonstrated a z-score of 2.76 ($p=0.0058$), while DFI showed a z-score of 2.52 ($p=0.0119$).

In order to compare the two scales, we calculated the percentage delta ($\Delta\%$) for each scale and applied the Spearman correlation coefficient. For this calculation, we used the formula: $\Delta\% = [(Pre\text{-}value - Post\text{-}value) / Pre\text{-}value] \times 100$.

Table 1. SCORAD values measured in the first (A1) and second evaluation (A2); the percentage delta of these values; and their respective means and medians.

PACIENT	SCORAD		
	A1	A2	$\Delta\%$
P1	30,6	39,87	-30,29
P2	74	16,5	77,70
P3	44,75	33,3	25,58
P4	52,4	0	100,00
P5	14,64	10,7	26,91
P6	58,9	38,35	34,88
P7	18	11	38,88
P8	60,9	58,05	4,67
P9	59,85	42,95	28,23
P10	27,25	14,95	45,13
P11	21,25	11,45	46,11
P12	58,95	18,4	68,78
P13	15,1	3,95	73,84
P14	84,2	92,5	-9,85
P15	39,15	13,95	64,36
P16	36	18	50,00
P17	25	15	40,00
P18	39,25	25	36,30
P19	23,95	11,25	53,02
P20	37,25	28	24,83
MEAN	41,07	25,16	39,95
MEDIAN	38,20	17,25	39,44

The Spearman correlation coefficient demonstrated a positive correlation with statistical significance ($r_s = 0.74$, $p=0.0002$). This indicates that a decrease in SCORAD was associated with a decrease in DFI, suggesting that improvements in disease severity were related to improvements in quality of life for caregivers.

Table 3 displays the effect on quality of life as measured by the DFI scores at each evaluation. It was observed that 55% of mothers had a strong or very strong effect in A1, highlighting the significant negative impact that this disease can have on family members.

Furthermore, the education level of family members was assessed, revealing that: 40% had primary education, 45% had high school education and 15% had higher education.

DISCUSSION

Atopic dermatitis (AD) is a chronic inflammatory disease characterized by recurrent flares and intense pruritus. It often begins in childhood, while severe cases may persist into adulthood, with approximately one-third of adult cases developing during this age range¹⁴.

Table 2. DFI values measured in the first (F1) and second evaluation (F2); the percentage delta of these values; and their respective means and medians.

Family member	DFI		
	A1	A2	$\Delta\%$
F1	10,0	16,00	-60,00
F2	23	3,0	86,90
F3	9,00	8,0	11,11
F4	10,0	1	90,00
F5	20,00	14,0	30,00
F6	19,0	8,00	57,89
F7	6	2	66,66
F8	20,0	10,00	50,00
F9	16,00	13,00	18,75
F10	7,00	10,00	-42,85
F11	16,00	10,00	37,50
F12	22,00	4,0	81,81
F13	4,0	0,00	100,00
F14	29,0	30,0	-3,44
F15	11,00	7,00	36,36
F16	2	0	100,00
F17	13	6	53,84
F18	21,00	14	33,33
F19	11,00	5,00	54,54
F20	18,00	13	27,77
MEAN	14,35	8,70	41,51
MEDIAN	14,50	8,00	43,75

Table 3. DFI result in the first and second evaluation.

Family member	DFI	
	A1	A2
F1	Moderate	Strong
F2	Very Strong	Weak
F3	Moderate	Moderate
F4	Moderate	No effect
F5	Very Strong	Strong
F6	Very Strong	Moderate
F7	Weak	Weak
F8	Very Strong	Moderate
F9	Strong	Strong
F10	Moderate	Moderate
F11	Strong	Moderate
F12	Very Strong	Weak
F13	Weak	No effect
F14	Very Strong	Very Strong
F15	Moderate	Moderate
F16	Weak	No effect
F17	Strong	Weak
F18	Very Strong	Strong
F19	Moderate	Weak
F20	Strong	Strong

Common clinical findings in AD include vesiculation, erythema, edema, xerosis, erosion/excoriation, exudation, crusting, and lichenification, although they vary based on the patient's age, phenotype, and the chronicity of the lesions^{15,16}. Itching is the hallmark of the disease and a significant factor contributing to the impact on patients and their caregivers¹⁶.

AD has a complex pathogenesis involving genetic, immunological, and environmental factors that lead to dysfunction of the skin barrier and dysregulation of the immune system¹⁶. The most well-known cause of epidermal impairment is the inherited deficiency of filaggrin, which also results in the expression of pro-inflammatory cytokines¹⁷.

The alarmins activate epidermal dendritic cells, which in turn trigger the stimulation of the Th2 pathway, leading to the release of IL-4, IL-5, IL-13, and IL-31^{5,6}. Th2 cytokines induce phosphorylation of STAT proteins through the activation of specific JAK, resulting in a positive feedback loop that contributes to the dysfunction of the epidermal barrier, inflammation, and itching^{1,5,17}.

Although AD is primarily characterized by the activation of the Th2 response, it has been shown that Th1, Th17, and Th22 responses also play an important role in certain types of AD^{5,17}.

Other factors involved in AD include dysbiosis of the skin microbiome (with a reduction in the diversity of skin bacterial populations and a proportional increase of

Staphylococcus aureus), systemic immune responses, and cutaneous neuroinflammation^{1,18}.

It is important to note that the specific inflammatory changes of AD are observed not only in the affected skin but also in unaffected skin, suggesting a systemic aspect of the disease¹⁹.

In this context, studies have linked AD to various conditions, such as an increased risk of systemic infections²⁰, cardiovascular diseases, and neuropsychiatric disorders like depression, anxiety, attention deficit hyperactivity disorder (ADHD), and attention deficit disorder (ADD)²¹.

Guo et al. (2020)²² demonstrated that skin diseases are more likely to cause psychological problems compared to other illnesses. There are significant differences in the degree of anxiety and depression based on the type of skin disease and the severity of the patient's condition. The study evaluated patients with AD, psoriasis, acne, and unspecified dermatitis dependent on topical steroids, with AD having the highest incidence among the investigated patients. The recurrent episodes and low cure rate of these dermatoses make patients vulnerable to emotional problems.

This emotional impact is not only seen in patients but also in their family members. The stress of caring for children affected by AD can significantly contribute to increased levels of depression, anxiety, and distress in parents when compared to controls. In addition to providing special care, these children often exhibit more dependent behavior, requiring more time and patience from their parents²³. Furthermore, complications that can affect these patients, such as severe secondary infections, can lead to hospitalizations, further complicating and disrupting family dynamics.

On the other hand, it has been shown that stress is a common trigger for AD flares and can exacerbate itching²³. Thus, the physical and mental exhaustion experienced by caregivers, along with the consequent behavior of overprotection, can impact the child's physiological stress response system and contribute to the exacerbation of AD symptoms. This creates a vicious cycle, as the worsening of the disease reinforces the psychological exhaustion of the parents⁸.

Another important point to highlight is the social isolation experienced by patients due to the stigma associated with the disease from childhood to adolescence. In this context, parents report feelings of guilt and inadequacy when witnessing their children being rejected by society²³.

Within this context, it is increasingly important to understand the environment in which our patients are situated, as it has been shown that stress and the family environment are related to the severity of symptoms in children with AD²⁴. Therefore, our study aimed to assess the quality of life of family members of patients with AD using the DFI and correlate it with the severity of each patient's disease measured by SCORAD.

Previous studies have demonstrated that the impact of the disease is greater on mothers than on fathers. Although

the impact on social life, free time, and daily expenses was similar, the relationships of mothers with other people were more affected than those of fathers with other people²⁵.

In our study, we were unable to evaluate the difference between male and female caregivers because all the patients in our study were accompanied only by their mothers, who completed the questionnaires. We did not have the presence of any fathers during the consultations. However, this fact leads us to infer that mothers end up bearing the greatest responsibility for the daily care of these patients and consequently experience the greatest impact on their quality of life.

Our patients and their respective caregivers were assessed initially and then in a follow-up evaluation after 1 to 4 months. We observed that when patients experienced a decrease in SCORAD scores, indicating a reduction in disease severity, the quality of life of their family members improved, as evidenced by a decrease in DFI scores. This positive correlation between the change in SCORAD and DFI scores was statistically significant. Additionally, in the analysis of each individual consultation, we also observed that higher SCORAD scores in patients were associated with higher DFI scores.

Furthermore, our study found that 90% of patients showed improvement in SCORAD scores during the follow-up consultation. These findings highlight the importance of the dermatologist in this process. The patients included in the initial evaluation were either treatment-naïve or undergoing modifications to a previous therapeutic plan. Therefore, observing a decrease in SCORAD scores during the follow-up evaluation indicates an effective treatment approach, reducing disease severity and subsequently lowering the DFI scores, leading to an improvement in the family's quality of life. Hence, we emphasize the significance of a specialized team to coordinate this dynamic, generating a positive impact on the health of the patient and their family.

Similarly, other studies have been conducted with results similar to ours. It has been demonstrated that family quality of life is inversely correlated with the severity of AD in children, meaning that higher SCORAD scores are associated with lower family quality of life^{8,25,26}.

Kim et al. (2016)²⁷ also demonstrated a positive correlation between the quality of life of patients with AD and that of their parents, showing that the more severely affected the children, the greater the impairment in the parents' quality of life. The negative impact of AD on children's lives, particularly those with more severe disease, draws attention to the long-term effects caused by this condition on child behavior and development²⁶.

An analysis of AD within the family context observed that family quality of life was intrinsically related to the severity of AD, more so than the quality of life of the child themselves, further highlighting the significant impact of this comorbidity on the family, in line with our research²⁸.

Parents require information and education about the symptoms of the disease and how to manage it, as well as being included in the decision-making and treatment planning process. This strategy can reduce dysfunctional practices, as a greater understanding of the disease leads to positive effects on the quality of life of families⁸.

The dermatologist can play a crucial role in cooperating with parents to help them cope with the disease and refer them to mental health professionals when necessary⁸.

In chronic diseases such as AD, a multidisciplinary team is essential, including psychologists, nurses, occupational therapists, social workers, and other professionals who can, in their respective areas, work towards minimizing the suffering and finding solutions to the problems faced by families. Psychological counseling is, in fact, part of the therapeutic plan for AD, especially in cases of moderate to severe disease²⁹.

In this study, we observed that the majority of mothers had a low level of education, with only 15% having completed higher education. This fact should be taken into consideration by the healthcare professional caring for the child, as the caregiver's education and understanding are crucial in the management of AD. It is important to use simple, clear, and unambiguous language in order to ensure effective doctor-patient communication³⁰.

Additionally, it is essential to understand the financial reality of each household, a point that was not addressed in our study. This is important because treatment can be costly for parents, and sometimes adjustments may need to be made to accommodate their financial situation.

We acknowledge important limitations of this study, such as the restriction in data collection time (eight months) and the small sample size of only 20 participants, which may limit the generalizability of the findings to other locations, as these patients were from a single dermatology clinic in São Paulo. Additionally, in two cases, it was necessary to read the questionnaire to the participant as the child required attention from the caregiver, who was unable to complete the task without assistance. Therefore, the interviewer's mediation may have influenced the understanding of the questions. Furthermore, we did not assess each item of the questionnaire separately to understand which areas of the caregiver's life were most affected.

The results of this study reinforce what has been previously shown in other studies: the negative impact of AD not only on patients but primarily on their caregivers. Additionally, we observed that the more severe the disease, the greater the impact on the family.

An individual requires a patient-centered medical evaluation, considering their psychological, social, and family context. This allows for the development of an effective multidisciplinary treatment plan aimed at achieving effective disease control and improving the psychological well-being of both the patient and their family unit. It is essential to highlight the role of the dermatologist in this process, ensuring effective

treatment that promotes better health for the individual and their family.

However, large-scale studies and long-term follow-ups are necessary to gain a better understanding of the family dynamics and the impact of the disease on each household.

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