



Educational interventions for atopic dermatitis in children: what's new?

Intervenções educativas na dermatite atópica em crianças: o que há de novo?

Renata Robl Imoto¹, Thais Braga Cerqueira¹, Vânia Oliveira de Carvalho¹

ABSTRACT

Educating the caregivers of patients with atopic dermatitis may lead to improved quality of life and help minimize disease severity, since the pathology has an immeasurable emotional, social, and financial impact on the patient's families. However, there is no consensus on the ideal scope and frequency for providing educational information about atopic dermatitis and its treatment. The purpose of this integrative literature review was to evaluate studies on the effectiveness of educational interventions for parents and pediatric patients with atopic dermatitis regarding disease severity and quality of life. On August 8, 2022, we searched the PubMed and MEDLINE databases for studies published between 2000 and 2022 in Portuguese or English that included the terms: "atopic dermatitis", "education program", and/or "therapeutic education". A total of 15 articles were included in this review. The studies' methodologies and tools were heterogeneous, impeding comparison of the results. Of the covered topics, skin care and/or basic routines were always included. Although the literature showed that therapeutic education improved disease severity and quality of life for both caregivers and patients, there was no consensus among the authors. Therapeutic education may help increase treatment adherence and prevent complications. However, prospective studies with larger populations are essential for clarifying the ideal scope and frequency of education programs.

Keywords: Atopic dermatitis, child, education.

Introduction

Atopic dermatitis (AD) is a chronic relapsing disease with a prevalence greater than 20% in children.¹ This disease begins in childhood and continues into adulthood in up to 60% of patients.²

RESUMO

A educação dos cuidadores dos pacientes com dermatite atópica (DA) pode possibilitar a melhora da qualidade de vida e minimizar a gravidade da doença, já que esta tem um imensurável impacto emocional, social e financeiro nas famílias dos doentes. Entretanto, não há um consenso de qual o escopo ideal e frequência para a entrega das informações educativas sobre a patologia e terapêutica. Esta é uma revisão integrativa de literatura cujo objetivo foi avaliar estudos sobre a eficácia de intervenções educativas para pais e pacientes pediátricos com DA na gravidade da doença e na qualidade de vida. Foi realizada uma busca nas bases de dados do PubMed e MEDLINE, em acesso realizado em 08/08/2022, incluindo publicações de 2000 a 2022, nos idiomas português e inglês, incluindo os termos: "atopic dermatitis", "education program", "therapeutic education". Foram incluídos 15 artigos nesta revisão. As metodologias dos estudos são diversas e as ferramentas utilizadas pelos pesquisadores também são heterogêneas, o que dificulta a comparação dos resultados. Dos temas abordados, o cuidado da pele e/ou rotinas básicas foram temas sempre incluídos. E, apesar da literatura demonstrar melhora na gravidade da doença e na qualidade de vida dos cuidadores e pacientes com DA após as intervenções, isso não foi um consenso entre os autores. A educação terapêutica pode ser útil para aumentar a adesão ao tratamento e prevenção de complicações; porém, estudos prospectivos com casuística maior são primordiais para esclarecer qual o escopo ideal e frequência para a entrega destas informações.

Descritores: Dermatite atópica, criança, educação.

Therapeutic failure and difficulty in controlling AD result from inability to adhere to long-term therapeutic protocols, which usually involve many medications and need for changes in family routine. Lack of

1. Complexo Hospital de Clínicas da Universidade Federal do Paraná, Serviço de Dermatologia Pediátrica - Curitiba, PR, Brazil.

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information, excessive effort to control the disease, helplessness during periods of disease worsening, and lack of confidence in medical treatment lead to suboptimal management of AD and to increased use of health resources, including alternative therapies,^{3,4} often used without scientific evidence, hoping for a “miraculous cure.”

Education of parents of pediatric patients with AD makes it possible to reduce disease severity, improve quality of life, increase care perception, develop coping strategies, and reduce costs; therefore, it should be implemented in daily clinical practice.⁵ However, there is no consensus on the ideal scope and frequency for providing information about this topic.⁶

The purpose of this integrative literature review was to evaluate studies on the effectiveness of education interventions for parents and pediatric patients with AD regarding disease severity and quality of life.

Data sources

On August 8, 2022, we searched the PubMed and MEDLINE databases for studies published between 2000 and 2022 in Portuguese and English, for theoretical background and contextualization of the theme. Search descriptors were used both in Medical Subject Heading (MeSH) and *Descritores em Ciências da Saúde* (DeCS) databases, and the search was made in sources of published data.

The search strategy included the following terms: “atopic dermatitis,” “education program,” “therapeutic education.” We included empirical research articles that assessed therapeutic education with children and/or adolescents diagnosed with AD and/or their caregivers as interventional strategy. Furthermore, article reference lists were examined to identify relevant eligible papers that could supplement electronic search.

The scientific quality of studies was evaluated based on the following categories of analysis: (1) research objectives; (2) target population and participants' age; (3) study design and use of a control group; (4) follow-up to evaluate the maintenance of intervention results; (5) measuring instruments used; (6) topics covered in the program; and (7) main results found.

A total of 162 citations were initially identified. After reading of the titles, articles not related to the topic and repeated articles were excluded. Subsequently, article abstracts were read. Fifty-six articles were

selected for full reading, according to inclusion and exclusion criteria. After full reading of the articles, we included 2 more articles identified in the reference lists, which have not been found in the initial search. Therefore, a total of 15 articles were included in this review (Figure 1).

Results and discussion

Despite the use of evidence-based guidelines and several therapeutic options, symptoms of AD are not often controlled effectively. The disease has a significant emotional, social, and financial impact on children and their families.⁷ Patients with AD have impaired quality of life, greater chance of developing anxiety and depression, and increased need for health resources.⁷⁻¹⁰

The family of children with chronic diseases is overwhelmed with the care required to control the disease, which makes it difficult to provide appropriate care and comply with recommendations for long periods.¹¹ It has been described that children with AD demand approximately 2 to 3 hours of care daily.¹² Furthermore, skin care of children with AD requires that caregivers be able to perform additional tasks such as following care regimens to minimize flare-ups.^{13,14}

An observational study conducted in France between 2019 and 2020 evaluated the characteristics of parents, children, and adolescents who participated in therapeutic educational programs. A feeling of guilt was observed in parents of patients with AD, resulting either from the thought of having transmitted the disease to their children or exposed them to foods or environmental allergens that parents believe to cause AD, or from the feeling of abandoning their other children who do not have the disease.⁵

Evidence shows that patient's self-care has beneficial therapeutic effects. Problems such as anxiety, frustration, embarrassment, depression, and lifestyle changes can be minimized by means of support groups, family therapies, or individualized follow-up^{7,11,15}; therefore, one of the approaches to promote self-care skills is providing basic information on disease nature and treatment, through support and information services, in addition to providing learning material.¹⁶ A study conducted in Spain to evaluate satisfaction of parents of patients who participated in therapeutic educational groups on AD showed that these parents considered the provided information

useful to achieving efficient control of flare-ups and for improving quality of life.³

However, in clinical practice, it is difficult for health care professionals to properly educate their patients, since many physicians do not have sufficient time to successfully provide all relevant information during the short duration of a medical consultation.¹⁷ Education provided to parents and children during a consultation lasting for 20 to 30 minutes is insufficient,

because both physiopathology and treatment of AD are complex.¹⁸

Initiatives to incorporate digital tools, such as new forms of providing educational information, including videos and online resources, have shown promising results. With technological advances, there has been an increase in the use of mobile technologies and Internet access.⁶ It is possible to deliver alerts and reminders to patients for supporting behavioral

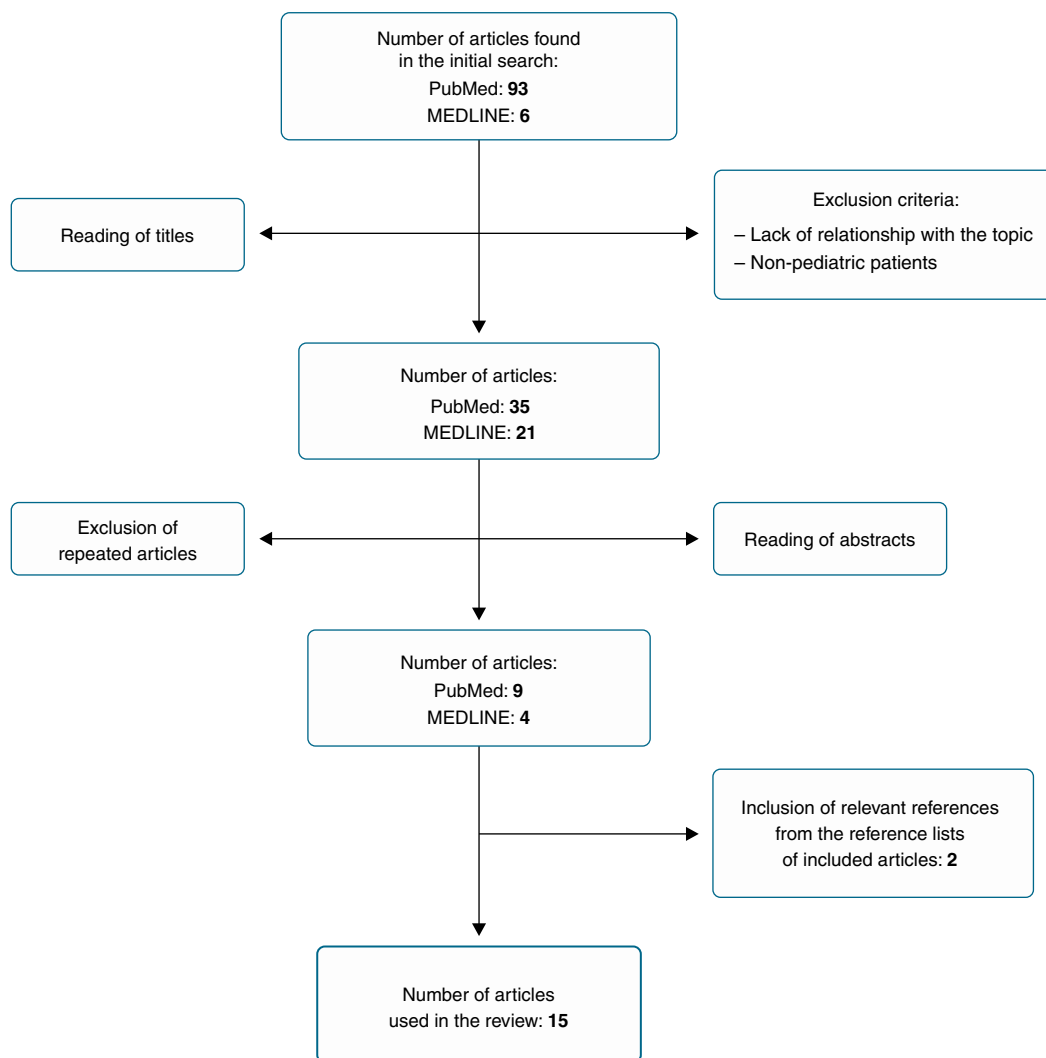


Figure 1
Study selection flowchart

changes via information technology tools, such as cell phone text messages and other wireless technologies.⁶

A systematic review published in 2020 included 13 randomized clinical trials and aimed to summarize evidence about the effectiveness of educational programs for parents of pediatric patients with AD.⁶ The present study added two new publications on the topic. Table 1 summarizes the results of the 15 retrieved articles on educational interventions in pediatric patients with AD.^{4,17-28,30}

The scope of educational interventions varies among the studies. Of the covered topics, skin care and/or basic routines were always included, highlighting the importance of using moisturizers to improve cutaneous barrier function, which is dysfunctional in patients with AD.

In addition to the importance of emollients, the topics “use of corticosteroids” and “corticosteroid phobia” were investigated by some authors.^{27,29} Topical corticosteroids are the mainstay of treatment of AD inflammatory lesions; however, fear of medication use is one of the main reasons for non-adherence and crises, affecting from 60 to 73% of patients.³¹

Therefore, despite lack of consensus on ideal scope and frequency for providing information on AD, it is essential that educational programs discuss topics such as skin care, psychological problems, and use of topical corticosteroids.⁶ Treatment adherence is usually low in patients with chronic diseases, especially in those with dermatosis whose treatment should be topically applied on a regular basis; moreover, family knowledge is crucial to adjust the therapy to each stage of the disease course.³

The methodologies of educational intervention studies in AD were heterogeneous, as well as the tools used by each researcher, impeding comparison of the results.

In six studies, participants attended one therapeutic educational session,^{17-20,22,23} and in two of which written material was provided with information about AD.^{18,22} Five studies included more than one session (with weekly or fortnightly intervals)^{4,21,24,26,29}; in two of which written material was provided to participants.^{24,26} One study used daily text messages²⁸; another one provided a handbook about routine care and AD³⁰; and two used videos on the disease.^{25,27}

The interventions conducted in the retrieved studies focus on secondary prevention of AD, which

would be patients' therapeutic education. However, these studies are limited in terms of educational interventions in primary prevention. A randomized trial with expecting mothers, and later their children, has been ongoing in China since 2020, aiming to evaluate the effect of prenatal educational intervention on the incidence of AD up to 2 years postpartum.³²

Therefore, there is the need for standardized methods to accurately evaluate improvements in self-management of AD.^{6,33,34}

Although the literature showed that therapeutic education improved disease severity and quality of life for both caregivers and patients with AD,^{4,17,18,21-24,26,27,29} there was no consensus among the authors.

Some authors did not find a difference in disease severity or quality of life between intervention and control groups and concluded that the educational intervention may have not been sufficient to change parents' behavior and improve eczema control in children.^{19,20,25,28,30} Furthermore, the relationship between educational interventions and clinical results, including eczema severity, quality of life, and family impact, is not often accurately analyzed in clinical investigations.¹⁷

It is known that designing an educational intervention is a complex activity, because it may have a variety of effects and specific interactions.⁴ Psychological and nutritional factors, as well as a combination of topical and systemic therapies, should also be considered as a strategy to control a disease with an underlying multifactorial physiopathology, such as AD.³⁵

Conclusion

It is common sense that the best approach for treating patients is considering their physical and emotional aspects, in addition to the impact of disease on their personal life and on the family context. Therapeutic education may help increase treatment adherence, and thus its efficacy, as well as prevent complications. Health teams should encourage initiatives based on educational tools and programs, in order to ensure the active engagement of patients in decision-making related to their care. Prospective studies with larger populations are essential for clarifying the ideal scope and frequency of education programs.

Table 1
Summary of articles about educational interventions for parents and pediatric patients with AD regarding disease severity and quality of life

Year/ Ref	Age (years)	Follow-up	Treatment/ control (n)	Treatment	Control	Content	Assessment methods	Result
2002 ¹⁹	0.5-4.0 4.0-16.0	12 weeks	55/42 50/50	Single session	Not specified	Skin care, treatment, basic medical information	CDLQI, IDQOL, DFI	There was no statistically significant improvement in quality of life or eczema
2006 ¹⁷	0.0-16.0	12 weeks	32/29	Single workshop	Standard routine care and written material	Skin care, basic medical information, triggering factors	SCORAD, DFI, CDLQI, IDQOL	Improvement in SCORAD in the intervention group. There was no difference in quality of life between the groups
2006 ⁴	0.25-7.0 8.0-12.0 13.0-18.0	12 months	274/244 102/83 70/50	Group sessions (once a week for 6 weeks)	Standard routine care	Skin care, basic medical information, psychological factors, food allergy, nutrition	SCORAD, POSCORAD, Quality of life questionnaire for parents, JUCKKI/JUCKJU	Improvement in disease severity in all intervention groups compared with control groups
2008 ²⁰	0.0-18.0	1 to 3 months (according to disease severity)	51/55	Single individual session	Not specified	Skin care, treatment, triggering factors, relief of pruritus, lifestyle	SCORAD, CDLQI, IDQOL	There was no difference in disease severity or quality of life between the groups
2008 ²¹	2.0-16.0	24 months	16/16	Fortnightly group sessions for 6 months	Not specified	General overview of the disease, treatment followed by discussion	CDLQI, DFI, McGill pain questionnaire (pruritus)	Improvement in pruritus and quality of life in the intervention group

EASI = Eczema Area and Severity Index, SCORAD = Scoring of Atopic Dermatitis, CDLQI = Children's Dermatology Life Quality Index, IDQOL = Infants' Dermatology Quality of Life Index, DLQI = Dermatology Life Quality Index, PO-SCORAD = Patient Oriented SCORAD, FDLQI = Family Dermatitis Life Quality Index, STAI = State Trait Anxiety Inventory, PPS = Perceived Stress Scale, DLQI = Dermatitis Life Quality Index, QoLIAD = Quality of Life Index for Atopic Dermatitis, BDI = Beck Depression Inventory, EQ-5D = EuroQol 5-Dimension, POEM = Patient-Oriented Eczema Measure, HADS-D = Hospital Anxiety and Depression Score, DFI = Dermatitis Family Impact, RC = randomized control trial, JUCKKI/JUCKJU = Itching cognitions questionnaires, AD = atopic dermatitis.

Table 1 (continuation)
Summary of articles about educational interventions for parents and pediatric patients with AD regarding disease severity and quality of life

Year/ Ref	Age (years)	Follow-up	Treatment/ control (n)	Treatment	Control	Content	Assessment methods	Result
2009 ²²	< 16	4 weeks	49/50	Single individual session with written material	Standard routine care	Basic medical information, triggering factors, treatment	SCORAD	Improvement in SCORAD and greater adherence in the intervention group
2010 ²³	< 4 4-16	12 months	37/34 35/35	Single group or individual session in nursing consultations	Standard routine medical care	Skin care, basic medical information, allergies, practical and theoretical sessions	SCORAD, CDLQI, IDOOL, DFI, Satisfaction program	Improvement in SCORAD and quality of life in both groups
2013 ²⁴	0.5-6.0	6 months	29/30	Two-day program with lectures and written material	Standard routine care and written material	Skin care, basic medical information, treatment, adverse effects, triggering factors	SCORAD, POSCORAD, questionnaire on pruritus, insomnia, amount of corticosteroid used, DFI	Improvement in disease severity and amount of corticosteroid used in the intervention group
2016 ¹⁸	0.5-12.0	2 months	64/64	Single lecture with written material	Routine standard care	Skin care, diagnosis, treatment, triggering factors, diet, quality of life	SCORAD, FDLOI, STAI, PPS	Improvement in disease severity, anxiety, pruritus, insomnia, and stress in the intervention group
2017 ²⁵	0.3-4.3	1 week	10/11	Video with tailored leaflet	Same video without leaflet	Skin care, ideal amount of moisturizers	Use of moisturizers, EASI	There was no difference in AD severity between the groups

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Table 1 (continuation)
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Year/ Ref	Age (years)	Follow-up	Treatment/ control (n)	Treatment	Control	Content	Assessment methods	Result
2018 ²⁶	4.0-14.0	6 months	293/249	Four sessions (once a week), videos and printed material to be used at home	Not specified	Skin care, long-term management, food allergy, psychological factors	SCORAD, IDQOL, CDLQI, Questionnaire to assess knowledge	Improvement in disease severity, quality of life, and use of emollient in the intervention group
2018 ²⁷	0-16	6 weeks	5/5	Video - AD	Video – placebo topic	Corticosteroid phobia, treatment adherence	EASI	Improvement in disease severity in the intervention group. No difference in corticosteroid phobia and adherence
2018 ²⁸	0.3-3.8	42 days or up to follow-up visit	14/16	Daily educational text messages	Standard routine care	Skin care, triggering factors	EASI	There was no difference in AD severity between the groups
	6-16	12 to 18 months	14/0	Six individual sessions + seven group sessions	Not specified	Understanding on AD, corticosteroids, emollients, allergies, treatment, pruritus, social isolation	SCORAD, school absenteeism	Improvement in SCORAD and school absenteeism for all patients
2021 ³⁰	0.0-16	3 months	91/84	Handbook	Standard routine care	Understanding on AD, treatment, psychological factors	EASI, IDQOL, CDLQI, DFI, POEM, Questionnaire on parenting self-efficacy and management of tasks related to AD improvement	No difference in symptom between the groups. The handbook improved family's confidence in their management skills

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Corresponding author:
Renata Robl Imoto
E-mail: natarobl@hotmail.com