Italian Journal of Pediatric Allergy and Immunology number 02 | 2024 | 14-16

Mini Review

Psycho-social and economic burden of atopic dermatitis in children and transition changes

Giampaolo Ricci[1], Paolo Bottau[2]

[1] Professor Alma Mater, University of Bologna, Italy; [2] MD Pediatric and Neonatology Unit, Imola Hospital (BO), Italy

SUMMARY

Atopic dermatitis is the most frequent chronic skin pathology of childhood. In milder cases the condition tends to resolve, while in the moderate-to-severe forms the problems related to it go beyond the simple condition of illness and significantly affect the quality of life of the patient and their family. The burden of disease also has significant economic impact. These issues are amplified when the disease does not resolve and involves patients in adolescence and adulthood.

KEYWORDS: atopic dermatitis, quality of life, severity, pediatric, burden, transition

INTRODUCTION

Atopic dermatitis (AD) is the most frequent chronic pediatric skin disease and has a multidimensional impact on patients' lives. AD shows clinical pictures of very different severity: the moderate-to-severe forms represent a significant problem for the child and also for the family both from economic and psychosocial perspectives. However, even in mild forms the impact of the disease can be significant. Moreover, the burden of AD varies based on available treatments, which depends on accessibility, guideline recommendations, and differences in local healthcare budgets. Currently numerous data in literature show that the epidemiological curve of AD has two peaks: one in early childhood and the second in middle age and adulthood. This brief review will highlight the major problems that children and their families face in the management of AD.

INSTRUMENTS TO EVALUATE AD BURDEN

Clinical score

To define the burden of atopic dermatitis, we need validated tools that have reached consensus at an international level: only in this way can one compare data from different countries and have a global idea of the disease.

To date, there is a wide range of validated clinical scores to establish the severity of AD such as Eczema Area and Severity Index (EASI) mainly in north America, SCORing Atopic Dermatitis (SCORAD) mainly in Europe, and Validated Investigator Global Assessment for Atopic Dermatitis (vIGA-AD) and body surface area (BSA).

The results of all these tests demonstrate that there generally is a direct correlation between severity of symptoms and the burden of AD. However, in some cases even the mild forms can have a significant impact, especially if they begin in the first year of life when the parents they still have not understood how to properly manage the disease.

Received: March 15, 2024
Published: April 30, 2024

CORRESPONDENCE

Paolo Bottau
p.bottau@ausl.imola.bo.it

How to cite this article: Ricci R, Bottau P. Psycho-social and economic burden of atopic dermatitis in children and transition changes. Italian Journal of Pediatric Allergy and Immunology 2024;38(02):14-16. https://doi.org/10.53151/2531-3916/2024-480

The severity of AD is also measured by the intensity of itching, an aspect that in some clinical scores such as SCORAD is included in the overall evaluation. Alternatively it is possible to evaluate this parameter as its impact on quality of life (QoL)of children and their families.

Quality of Life score

Today there are many questionnaires that attempt to numerically define QoL in both children and parents. These are available in different versions aimed at the various ages of children or parents/caregivers. In all, sleep loss is considered one of the most important parameters in the overall assessment of the burden of AD.

The instruments to measure QoL in children with AD have been described in a review by the EADV (European Academy of Dermatology and Venereology) [1]. Below the most widely used questionnaires are reported.

Children's Dermatology Life Quality Index (CDQoL) (4-16 years) contains 10 items that include symptoms, feelings, leisure time, school, holidays, relationships, sleep, and impact of treatment. The responses are on a four-point scale: the higher the score, the more QoL is impaired.

Another specific validated questionnaire for infants and young children (proxy rating) is the Infants' Dermatitis Quality of Life Index (IDQoL).

An interesting and simple questionnaire for family members is the Family Dermatology Life Quality Index (FDLQI). The FDLQI is a 10-item questionnaire, with a recall period of one month. The questionnaire includes the domains of emotional and physical wellbeing, relationships, leisure activities, social life, burden of care, impact on job/study, housework, and expenditure.

Another widely utilized instrument to evaluate QoL is Dermatitis Family Index (DFI) that measures the impact of living with a child with AD on the QoL of their adult family members. This 10-item dermatitis-specific questionnaire measures the impact over the last week on QoL in the domains of housework, food preparation and feeding, sleep of others in the family, family leisure activities, time spent on shopping, expenditure, tiredness, emotional distress, relationships, and impact of the child's treatment.

Parents' Index Quality of Life-Atopic Dermatitis (PIQoL-AD) assesses the impact of the child's AD on the QoL of parents: it consists of 28 items with a dichotomous "yes/no" response format. The score ranges from 0 to 28: a higher score indicates poorer QoL.

Childhood Atopic Dermatitis Impact Scale (CADIS) is a QoL measure for parents of children with AD combined with a proxy measure for children under the age of 6 years. It measures the impact on QoL of the domains of symptoms, activity limitations and behavior, family and social function, parental sleep, and emotion.

Perception of psycho-social and humanistic burden

AD affects esthetic appearance and undermines self-esteem with important repercussions on the psycho-emotional development of children.

However, tools to estimate this impact are lacking.

One of the major difficulties encountered in the evaluation is to give a "weight" to the statements of the individual interviewees, because very often the perceptions of discomfort diverge significantly between the patient, family member/caregivers and the outside observer.

In the recent work, Paller et al. [2] on 1447 children/adolescents with moderate-to-severe AD (aged 6-11 years, n = 701; 12-17 years, n = 746), 1447 caregivers, and 1092 physicians tried to highlight this aspect. Patients and caregivers in both age groups ranked disturbed sleep as the most important QoL item, followed by feeling ashamed because of AD. Independent physicians ranked feeling ashamed because of AD as the most important QoL item for both. However, patients' and caregivers' perceptions were generally more closely aligned than the patients' and physicians' perceptions. These data confirm that the physicians' perception does not always correspond to that of patients and families; it follows that greater account must be taken of the existent difficulties highlighted by the patient/caregivers, regardless of the severity of the disease.

Disability adjusted life years

Another parameter to evaluate QoL is Disability Adjusted Life Years (DALYs) that quantizes the years of healthy life lost. Using DALYs, the global burden of skin disease survey shows that eczema causes the highest burden of all skin diseases worldwide and is one of the top 50 most common causes of disease [3].

A recent paper evaluating data obtained from the Global Burden of Disease Study 2019 on incidence, prevalence, and DALY showed that the groups with < 5 years and 5-9 years were the two important populations that needed targeted measures to reduce disease burden of AD in China.

Regarding sex disparity, more attention should be given to males in < 5 years and to females from 10-19 years [4].

Economic burden

Data on the economic and humanistic burden in patients with pediatric AD and their families are scarce. The evaluation of the economic impact is much more complex, because it includes direct and indirect costs and also depends on the health level of the country. In a recent Dutch retrospective study, total costs, including direct and indirect costs, increased with the severity of AD, while the highest humanistic burden was found in patients with moderate AD, indicating a possible undertreatment in this group [5]. The total direct costs per patient per year was € 1,512 for mild forms, € 1,984 for moderate forms, and € 5,377 for severe forms. The total indirect costs due to absenteeism were € 300 for mild forms, € 696 for moderate forms, and € 601 for severe forms [5].

Transition changes

The transitional care of a patient with AD is becoming increasingly important because there is now evidence that in adult age persistent or new onset AD is common.

AD generally improves with age, but can persist into adolescence or adulthood and several studies have been published showing that there

can be various patterns relating to the evolution of the disease, ranging from early transient to chronic recurrent pictures. Finally, some patients experience regression of disease followed by recurrence.

It has been reported that in high-income countries 10% of adults are affected by AD and 10-20% of these have a severe form of the disease [6]. In these patients, AD can persist from childhood, but can be also a new onset form [6]. In the former case, the progression of the disease is particularly worrying for the patient, because frequently children 6 to 12 years of age believe that AD is temporary and will go away as they grow up [7].

Adolescents and adults have different clinical manifestations compared to infants and children. In adolescence and adulthood, eczema is normally diffuse, but localized lesions may be present typically affecting flexures, eyelids, and hands. Chronic hand eczema, or head-neck dermatitis is typical of adult age and can be the only sign of AD. In the case of head-neck dermatitis, the scalp, shoulders, and upper trunk are involved [6]. Some years ago, Grant and colleagues described 29 signs and symptoms that have been reported by adults with AD [8]. More than 70% of adults experiment signs like rash, rough skin, redness, and dryness, while the most burdensome and common symptoms are itch and pain.

Recognition of the changes on biopsycho-social development in adolescents and adults and the need for patients of this age to become competent and confident to gain autonomy in care is fundamental in the transition process. The transition is a more complex and complete procedure than simple "transfer" of a patient from pediatric to adult care. Recently, the EAACI has published guidelines on the transition of allergic and asthmatic patients that can also be applied to children with AD [9]. Two years later, the same group published a 'toolbox' paper that provides a selection of practical resources to help the multiple actors involved in the transition [10]. The key moments of the transitional process are: to use a multidisciplinary approach, to promote knowledge, to promote skills for self-management, involve family and peers, discuss implications for education and work, and transfer across service to lead the patient from parent-centerd care (child patient) to self-centerd care (adult patient) [9]. The same authors suggest that there is not a precise age to start this process, but that it must be determined based on the stages of development achieved and the actual autonomy acquired by the patient [11]. However, since adolescents and adults have very different physical and psychological characteristics, the transition must be done in two phases: from childhood to adolescence and from adolescence to adulthood. In general, adolescents welcome an active role in their AD management, but this also raises anxiety and concern about choosing the best treatment option and ultimately the doubt of not feeling ready for the transition by the physician and adult facilities [7].

This group of patients needs support to take care of themselves, to identify flareups and triggers, and to evaluate the effect of treatment. They also need psychosocial support to find a balance between the acceptance of a chronic disease and the hope that it will spontaneously regress [7]. Thus, patients must be supported and driven until at least the age of 18 years, but also beyond up to 25 years of age [9].

Acknowledgements
None.

Conflicts of interest statement
The authors declare no conflict of interest.

Funding
None.

Ethical considerations
The contributions are unpublished.

Author's contribution
GR, PB: conceived, designed the study and drafting the manuscript. The final manuscript was approved by all Authors.

References
1 Chernyshov P, Tomas-Aragones L, Manolache L, et al. Quality of life measurement in atopic dermatitis. Position paper of the European Academy of Dermatology and Venereology (EADV) Task Force on quality of life. J Eur Acad Dermatol Venereol 2017;31:576-593. https://doi.org/10.1111/jdv.14058

2 Paller AS, Weidinger S, Capozza K, et al.Dermatol Ther (Heidelb) 2023;13:961-980. https://doi.org/10.1007/s13555-022-00850-7

3 Laughter MR, Maymone MBC, Mashayekhi S, et al. The global burden of atopic dermatitis: lessons from the Global Burden of Disease Study 1990-2017. Br J Dermatol 2021;184:304-309. https://doi.org/10.1111/bjd.19580

4 Guo Y, Zhang KY, Zou YF, et al. National situation, trends, and predictions of disease burden of atopic dermatitis in Chinese children and adolescents.Front Microbiol 2023;14:1161969. https://doi.org/10.3389/fmicb.2023.1161969

5 Achten R, Van der Rijst L, Piena M, et al. Economic and humanistic burden in paediatric patients with atopic dermatitis. Acta Derm Venereol 2023;103:adv00881. https://doi.org/10.2340/actadv.v103.484

6 Langan SM, Irvine AD, Weidinger S. Atopic Dermatitis. Lancet 2020;396:345-360. https://doi.org/10.1016/S0140-6736(20)31286-1

7 EFA - European Federation of Allergy and Airways Diseases Patients' Associations. The burden of atopic eczema. European Consensus Report September 2022.

8 Grant L, Seiding Larsen L, Trennery C, et al. Conceptual model to illustrate the symptom experience and humanistic burden associated with atopic dermatitis in adults and adolescents. Dermatitis 2019;30:247-254. https://doi.org/10.1097/DER.0000000000000486

9 Roberts G, Vazquez-Ortiz M, Knibb R, et al. EAACI Guideline on the effective transition of adolescents and young adults with allergy and asthma. Allergy. 2020;75:2734-2752. https://doi.org/10.1111/all.14459.

10 Vazquez-Ortiz M, Gore C, Alviani C, et al. A practical toolbox for the effective transition of adolescents and young adults with asthma and allergies: An EAACI position paper. Allergy 2023;78:20-46. https://doi.org/10.1111/all.15533.

11 Andrenacci B, Cipriani F, Comberiati P, et al. Dermatite atopica moderata-grave: quali novità per il pediatra. Rivista di Immunologia e Allergologia Pediatrica 2023;37(04):23-37. https://doi.org/10.53151/2531-3916/2023-399