

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/181928/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Silverberg, Jonathan I., Skayem, Charbel, Le Floc'h, Caroline, Begolka, Wendy Smith, Taieb, Charles, Demessant-Flavigny, Ann'Laure, Kerob, Delphine and Finlay, Andrew Y. 2025. Nearly half of American children with atopic dermatitis experience significant quality of life impairment, often underestimated by parents. *British Journal of Dermatology* , ljaf411. 10.1093/bjd/ljaf411

Publishers page: <https://doi.org/10.1093/bjd/ljaf411>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



Nearly Half of American Children with Atopic Dermatitis Experience Significant Quality of Life Impairment, Often Underestimated by Parents

Jonathan I Silverberg,¹ Charbel Skayem,^{2,3} Caroline Le Floch,⁴ Wendy Smith Begolka,⁵ Charles Taieb,⁶ Ann'Laure Demessant-Flavigny,⁴ Delphine Kerob,^{4,7} and Andrew Y Finlay⁸

¹ Department of Dermatology, The George Washington University School of Medicine and Health Sciences, Washington, District of Columbia, USA

² Sorbonne University, Faculty of Medicine, Paris, France

³ Hôpitaux de Paris (AP-HP), Hôpital Ambroise Paré, Boulogne-Billancourt, France

⁴ La Roche-Posay International, Levallois-Perret, France

⁵ National Eczema Association, Novato, CA, USA

⁶ Patients Priority, European Market Maintenance Assessment, Paris, France

⁷ Hôpitaux de Paris (AP-HP), Hôpital Saint Louis, Paris, France.

⁸ Institute of Infection and Immunity, School of Medicine, Cardiff University, Cardiff, UK

Correspondence: Charles Taieb,

Email: charles.taieb@emma.clinic

Funding sources: This study was granted by the Scars of Life Unit by La Roche Posay

Conflicts of interest: Wendy Smith Begolka, Charbel Skayem, Jonathan I. Silverberg and Charles Taieb are no conflicts of interest to declare in this study. Andrew Y Finlay is joint copyright owner of the CDLQI. Cardiff University receives royalties for CDLQI use, AYF receives a share of these under standard university policy. Ann'Laure Demessant-Flavigny, Caroline Le Floch, and Delphine Kerob, are employed by the La Roche Posay Laboratory

Data availability: The datasets generated during and/or analyzed during this study are available from the authors upon reasonable request.

Ethics statement: The project was reviewed by a French ethics committee and was found to be in accordance with the ethical standards set forth by that committee. IDRCB 2023-A02722-43 [Committee for the Protection of Individuals South-East I dated 11 March 2024].

Patient consent: All individuals gave their consent with the understanding that their information may be publicly available.

Dear Editor, Atopic dermatitis (AD) is a common chronic skin condition in children that can substantially affect their quality of life.¹⁻⁴ However, the extent of this impact and how accurately parents perceive it has been rarely evaluated on a nationwide level.⁵ This study aims to evaluate the impact of AD on American children aged 6 to 12 years using the Children's Dermatology Life Quality Index (CDLQI)⁶ and evaluate associating factors.

A representative sample of the general population of the United States aged 18 years or more was recruited using stratified, proportional sampling with a quota sampling design with replacement. In this design, dyads who did not complete the entire questionnaire were replaced by dyads matched for key characteristics (age, sex, etc.).⁹ Families with children aged 6 to 12 years suffering from AD were identified within this panel. The study was conducted as an online self-administered survey. The overall response rate was 93%.

The study was conducted through an online self-administered survey. The overall response rate was 93%. Data were collected on sociodemographic characteristics, AD severity (Patient-Oriented Eczema Measure, POEM), parental stress (Perceived Stress Scale, PSS)⁷, parental burden (Atopic Burden Scale – ABS-A)⁸, subjective parental assessment of AD impact, and the Children's Dermatology Life Quality Index (CDLQI). Additional variables included projection into the future (optimism/pessimism), attention disorders, sleep disorders, family history of AD, asthma, and urticaria. These variables were incorporated into the multivariate regression models.

Underestimation was defined as a parental subjective assessment of impact being lower than the child's CDLQI score. Three groups were established based on the severity of CDLQI (mild:0-6, moderate: 7-12, severe >12). The Statistical analysis was performed to assess associations between these variables using multivariate regression models.

In total, there were 500 children with AD: 6–9 years (n=285) and 10–12 years (n=215). According to CDLQI, AD had little effect on the child's life in 20.4% of cases, a moderate effect in 31%, and a significant to very significant effect in 48.6%. Forty two percent (n=210) of parents

1 underestimated the impact of their child's AD, while 13.4% (n=67) overestimated it, when
2 comparing their subjective assessment to CDLQI.

3 Multivariate analysis revealed several factors significantly associated with higher CDLQI scores,
4 indicating a greater impact on the child's quality of life. Table 1 These included higher parental
5 income, being in the 10–12 years age group, pessimism about the future, stressed parents, attention
6 disorders, and sleep disorders. Furthermore, moderate and severe AD were linked to higher
7 CDLQI values compared to mild AD. Family history of atopic eczema and asthma were not
8 associated with higher CDLQI scores. Given that almost half of parents underestimate the impact
9 of AD, parental-reported outcomes or assumptions should not be solely relied upon in clinical
10 decision-making, particularly in moderate to severe cases, where the misalignment may lead to
11 under-treatment or insufficient psychosocial support.⁹⁻¹⁰

12 Several reasons may explain parental underestimation of the impact of AD, including reluctance
13 to use corticosteroids, a tendency to normalize symptoms over time, and the difference in
14 timeframe between child-reported questionnaires (which usually cover one week) and parental
15 evaluation, which may be based on a longer period. This finding reinforces the importance of
16 systematically using child-reported outcome measures, as parental perception alone may not
17 always accurately reflect this burden. Parental assessment can nevertheless provide
18 complementary information during consultations, but it should not replace the child's own
19 evaluation of quality of life. Increasing parents' awareness of the burden of AD is also crucial to
20 avoid the risk of undertreatment.

21 Multivariate analysis suggests that psychosocial and socioeconomic dynamics may modulate the
22 perceived burden of disease, with older children likely more aware of or impacted by stigma,
23 school demands, or social limitations.

24 Moreover, interestingly, children from higher-income families reported higher CDLQI scores.”.
25 This may reflect heightened expectations regarding appearance, peer acceptance, or participation
26 in activities where visible skin disease becomes more disruptive.

27 The strongest independent predictors of a high CDLQI score were moderate and severe AD
28 severity, as assessed by POEM, reinforcing the direct link between clinical severity and perceived
29 quality-of-life impairment. In contrast, family history of AD or asthma had no impact on CDLQI
30 scores, suggesting that the lived experience of AD in children is not significantly shaped by
31 familial atopic background.

This nationally representative study demonstrates that AD substantially impairs the quality of life in nearly half of U.S. children aged 6–12 years. Parental assessments often fail to capture the true extent of this burden. Reliance on parental reporting for the diagnosis of AD, the nature of the design, and potential recall bias should be considered as limitations to the interpretation of the results.

These findings advocate for routine use of child-reported outcome measures like the CDLQI in clinical practice to guide management decisions. Furthermore, targeted interventions should address not only the dermatologic symptoms but also associated neurobehavioral conditions and parental stress, which significantly contribute to the child's lived burden of disease.

References

1. Skayem C, Richard MA, Saint Aroman M, Merhand S, Ben Hayoun Y, Baissac C, Halioua B, Taieb C, Staumont-Sallé D. Epidemiology of atopic dermatitis: a global worldwide study. *Clin Exp Dermatol*. 2025 May 31:llaf233. doi: 10.1093/ced/llaf233. Epub ahead of print. PMID: 40448692.
2. Halioua B, Skayem C, Merhand S, Hayoun YB, Taieb C. Long-term consequences on stigmatization and disease burden during adulthood among patients with childhood or adolescence-onset atopic dermatitis. *Br J Dermatol*. 2024 Aug 14;191(3):454-456. doi: 10.1093/bjd/ljae176. PMID: 38679576.
3. Silverberg JI, Dodiuk-Gad R, Takaoka R, Tan J, Gu C, Luger T, Halioua B, Aslanian F, Prakoeswa CRS, Demessant Flavigny A, Le Floc'h C, Kerrouche N, Methand S, Begolka WS, Smith ALT, Burstein S, Kerob D, Taieb C, Skayem C, Tempark T, Kelbore AG, Stratigos A, Steinhoff M, Seneschal J, Misery L. Atopic dermatitis starting in childhood has a stronger impact on adults: results from the "Scars of Life" international project in 27 countries. *Br J Dermatol*. 2025 Apr 26:ljaf158. doi: 10.1093/bjd/ljaf158. Epub ahead of print. PMID: 40286325.
4. Na CH, Chung J, Simpson EL. Quality of Life and Disease Impact of Atopic Dermatitis and Psoriasis on Children and Their Families. *Children (Basel)*. 2019 Dec 2;6(12):133. doi: 10.3390/children6120133. PMID: 31810362; PMCID: PMC6955769.

- 1 **5.** Lewis-Jones M., Finlay A. The Children's Dermatology Life Quality Index (CDLQI):
2 Initial validation and practical use. *Br. J. Dermatol.* 1995;132:942–949. doi:
3 10.1111/j.1365-2133.1995.tb16953.x.
- 4 **6.** Méni C, Bodemer C, Toulon A, Merhand S, Perez-Cullell N, Branchoux S, Taieb C. Atopic
5 dermatitis burden scale: creation of a specific burden questionnaire for families. *J Eur Acad*
6 *Dermatol Venereol.* 2013 Nov;27(11):1426-32. doi: 10.1111/jdv.12180. Epub 2013 May
7 16. PMID: 23675975.
- 8 **7.** Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *J Health Soc*
9 *Behav.* 1983 Dec;24(4):385-96. PMID: 6668417.
- 10 **8.** Kisieliene I, Mainelis A, Rudzeviciene O, Bylaite-Bucinskiene M, Wollenberg A. The
11 Burden of Pediatric Atopic Dermatitis: Quality of Life of Patients and Their Families. *J*
12 *Clin Med.* 2024 Mar 15;13(6):1700. doi: 10.3390/jcm13061700. PMID: 38541925;
13 PMCID: PMC10970967.

Table 1: Children's Quality of Life in Atopic Dermatitis: CDLQI Findings and Multivariate Analysis of Associated Factors

Effect of AD based on CDLQI	NO or Mild [0-6]	Moderate [7-12]	Severe / Very severe [>12]	P-value
Sex Of Child	N = 102	N = 155	N = 243	
Male	61 (59.8%)	74 (48.05%)	154 (63.64%)	0.008
Female	41 (40.2%)	80 (51.95%)	88 (36.36%)	
ABS-A [Parent burden score]	6.4 (± 8.63)	15.4 (±10.64)	26.43 (± 9.17)	<0.001
[PSS] Parent stress score	11.86 (±7.06)	14.24 (±6.76)	17.27 (± 5.26)	<0.001
Severity According To POEM	8.36 (± 5.07)	10.7 (± 4.97)	13.22 (± 5.46)	<0.001
Mild [3-7]	48 (47.06%)	46 (29.68%)	33 (13.58%)	<0.001
Moderate [8-16]	48 (47.06%)	88 (56.77%)	150 (61.73%)	
Severe / Very severe [17-28]	6 (5.88%)	21 (13.55%)	60 (24.69%)	
Time since disease onset (years)	4.98 (± 2.94)	4.02 (± 2.77)	3.05 (± 2.4)	<0.001
Comorbidities				
Asthma	21 (20.59%)	50 (32.26%)	91 (37.45%)	0.009
Urticaria	23 (22.55%)	41 (26.45%)	80 (32.92%)	0.112
Impact according to the parent				
Mild	53 (51.96%)	27 (17.42%)	19 (7.82%)	
Moderate	39 (38.24%)	110 (70.97%)	164 (67.49%)	
High	10 (9.8%)	18 (11.61%)	60 (24.69%)	
Parents underestimate the impact		27 (17.4%)	183 (75.3%)	
Parents overestimate the impact	49 (48%)	18 (11.6%)		
Variable included in regression model	Modality	Coefficients	P-value	
Age group	6-9 years (reference)			
	10-12 years	1.96 [0.896;3.02]	0.0003	
Parental income	Medium (reference)			
	High	1.91 [0.347 ;3.48]	0.0167	
AD severity (POEM)	Mild (reference)			
	Moderate	3.57 [2.33;4.8]	<0.0001	
	Severe	7.11 [5.46;8.76]	<0.001	
Projection into the future	Optimism about the future (reference)			
	Pessimism about the future	2.18 [1.14;3.22]	<0.001	
Parental stress (PSS)	Score >21	2.2 [0.76;3.64]	0.0028	
Family history of AD	Yes vs No	0.082 [-1.01;1.17]	0.883	
Attention disorders	Yes vs No	2.23 [0.717;3.73]	0.0039	
Sleep disorders	Yes vs No	2.31 [1.01;3.6]	0.0005	
Asthma	Yes vs No	0.77 [-0.387;1.92]	0.192	
Urticaria	Yes vs No	1.46 [0.315;2.61]	0.0126	

AD: Atopic Dermatitis . POEM : Patient-Oriented Eczema : PSS : Perceived Stress Scale; ABS-A : Atopic Burden Scale – Adult; CDLQI : Children's Dermatology Life Quality Index