

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/149579/>

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

Citation for final published version:

Capozza, K., Schwartz, A., Lang, J. E., Chalmers, J., Camilo, J., Abuabara, K., Kelley, K., Harrison, J., Vastrup, A., Stancavich, L., Tai, A., Kimball, A. B. and Finlay, A. Y. 2022. Impact of childhood atopic dermatitis on life decisions for caregivers and families. *Journal of the European Academy of Dermatology and Venereology* 36 (6) , e451-e454. 10.1111/jdv.17943

Publishers page: <http://dx.doi.org/10.1111/jdv.17943>

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.



“Our Life Has Revolved Around Eczema”: The Impact of Childhood Atopic Dermatitis on Life Decisions for Caregivers and Families

Authors:

Capozza, K., MPH^{1*}; Schwartz, A., PhD²; Lang, JE¹; Chalmers, J, PhD³; Camilo, J⁴; Abuabara, K, MD⁵; Kelley, K.,¹; Harrison, J.¹; Vastrup, A.⁶; Stancavich, L.¹; Tai, A.¹; Kimball, AB⁷; Finlay, AY, MD⁸

1. Global Parents for Eczema Research, Santa Barbara, USA
korey@parentsforeczemaresearch.com (corresponding author)
2. Departments of Medical Education and Pediatrics, University of Illinois, Chicago, USA
3. Centre of Evidence Based Dermatology, University of Nottingham, Nottingham, UK
4. ADERMAP - Associação Dermatite Atópica Portugal, Lisboa, Portugal
5. Department of Dermatology, University of California, San Francisco, USA
6. Atopisk Eksem Forening, Copenhagen, Denmark
7. Harvard Medical School, Cambridge, MA, USA
8. Division of Infection and Immunity, School of Medicine, Cardiff University, Cardiff, UK

Manuscript word count: 2940, 1 table and 3 figures.

Funding source: This work was supported by an unrestricted grant from Sanofi Genzyme and Regeneron

Conflict of interest disclosure: AY Finlay is joint copyright owner of the MLCDP. Global Parents for Eczema Research and AY Finlay, ZU Bhatti and MS Salek, are joint copyright owners of the revised questionnaire used in this study.

What’s already known about this topic?

- Prior studies have described the impact of childhood AD on caregivers at a point in time. Such research has shown significant psychosocial and quality of life impacts for caregivers of children with AD.
- Two studies have examined the impact of chronic conditions on life decisions for adult patients.

What does this study add?

- This is the first study to examine the impact of a child’s AD on life decisions for caregivers, and by extension, families. It finds that AD influences many life decisions for caregivers. These decisions may play out over the life course and lead to significant diversions from an intended life path.

What are the clinical implications of this work?

- The findings point to the need for better treatments for children with AD and support for their caregivers, who in the absence of other options, may choose to make drastic life changes in order to accommodate the burdens of managing childhood AD.

“Our Life Has Revolved Around Eczema”: The Impact of Childhood Atopic Dermatitis on Life Decisions for Caregivers and Families

Abstract

Background

Atopic Dermatitis (AD) is a chronic, inflammatory skin condition that influences important life choices for children, caregivers and families.

Objectives

Our objective was to assess the impact of a child’s AD on caregivers’ life decisions, including which decisions were likely to be affected, the degree of impact, and the relationship between AD severity and decision impact.

Methods

[A 32-item anonymous online survey was posted on social media sites targeted to or composed of parents of children with AD. It explored the following 7 domains of impact: Jobs/Career, Family/Relationships, Socializing/Lifestyle, Physical Activity, Education and Finances. Atopic dermatitis severity was reported by respondents using the Patient-Oriented Eczema Measure. Statistical analyses were conducted using R 3.6.0. The 32-item Major Life-Changing Decisions Profile was adapted for a caregiver audience and for the context of pediatric AD. The Patient Oriented Eczema Measure was used to assess severity. The revised survey was posted to social media sites targeted to caregivers of children with AD, worldwide.](#)

Results

366 caregivers responded to the survey and most had children with moderate to severe AD (67%). Ninety percent indicated at least some impact of AD on at least one of the life decisions. All life decisions included in the survey were reported by at least some respondents as having been influenced by the experience of having a child with AD. Impacts on home life, finances, career, and social life domains were most common. For the vast majority of decisions (81%), the influence of eczema was strongly associated with the severity of the child’s AD.

Conclusions

The results underscore the importance of recognizing the full impact of childhood AD on caregivers and families, not just at a point in time, but over the life course.

Background

Atopic dermatitis (AD) is a chronic, relapsing inflammatory skin condition that is increasing in prevalence in developed countries worldwide. AD impacts approximately 15% to 20% of children and 1% to 3% of adults globally.¹ Persistent itch, lack of sleep, difficulty avoiding triggers, stigma and embarrassment, as well as anxiety and mood changes related to the unpredictability of the condition exact a heavy toll on patients, their caregivers, and often, the entire family.²⁻⁵ The time demands of managing AD, the ubiquity of potential triggers, and the challenges with engaging in usual activities including social situations can lead to lifestyle,

career, relationship, and financial adjustments, that over time may alter the life course of caregivers and families.

Although the chronic, cyclical and unpredictable nature of AD results in a cumulative impact of the condition on families over time, almost no research has examined the influence of AD on major life decisions of caregivers raising children with AD. One prior study on caregiver burden found that one third of caregivers reported their child's AD influenced their decision to work outside the home and the same proportion reported that it influenced their decision to have more children.² Two studies examined the impact of chronic skin conditions on adult patients' major life changing decisions.^{6,7} Adult patients with chronic skin conditions reported significant impact on life decisions related to education, social, physical and professional domains.⁷

Our objective was to better understand the impact of children's AD on major life decisions of their caregivers, including which decisions were more or less likely to be affected, the degree of AD impact, and the relationship between AD severity and decision impact. Such data are needed to better understand the type of level of support that families impacted by pediatric eczema need.

Methods

The investigators, eight of whom are parents of children with AD, developed a questionnaire ~~adapted from the Major Life Changing Decisions Profile (MLCDP), integrating prior research on life decision impacts for chronic conditions and feedback from caregivers.~~⁸ ~~The original 32 item MLCDP measures impact of illness on major life changing decisions for adult patients and is organized in five domains: education, job/career, family, social, and physical. For this study, we reworded the MLCDP so that it was pertinent to caregivers of children with AD. Ten new questions and one new domain (financial decisions) were added in response to feedback from caregivers of children with AD (n=62) who provided feedback via a facilitated discussion and open ended survey. Fifteen questions were dropped due to their lack of relevance to AD and/or to a caregiver/pediatric patient population, leaving a total of 27 decision items. For each decision, the respondent was asked whether it was applicable (e.g. decisions about divorce are only applicable to partnered respondents) and, if so, to rate the impact of their child's AD on the decision using the MLCDP's 5 point Likert category rating scale (none, slight, moderate, strong, very strong). If they had multiple children with AD, they were instructed to report on the impact of the child with the most severe AD.~~ The survey also incorporated the Patient Oriented Eczema Measure (POEM), which provides a validated continuous and categorical measure of eczema severity, and a small number of demographic questions about the respondent's child.⁹ One open-ended question invited respondents to express views or inform the researchers with additional comments.

The online survey link was housed on the survey platform Survey Monkey and posted to social media sites targeted to or composed of parents of children with AD, worldwide, including the Facebook group of Global Parents for Eczema Research, an international coalition of parents of children with AD. Responses were collected anonymously for an 8-week period (Feb 27, 2021–

April 20, 2021). If the respondent did not agree with initial consent items, was not an adult, or did not report having a child with eczema, responses were discarded a priori. On examination of the data, we also excluded five “straight-lining” respondents who reported that AD had the same level of influence for every decision item.

We conducted statistical analyses using R 3.6 (R Core Team, Vienna, Austria). We computed POEM scale scores and severity categories (clear, mild, moderate, severe, very severe), and life decision domain subscores for each of the six domains by averaging the responses to items associated with the domain. Inter-item consistency among the life decision items in each domain was assessed using Cronbach’s α . We summarized decision impacts on each item and examined age-adjusted impact of AD severity on the items and domain subscores using linear regression analyses. AD severity category was parameterized contrasting each severity level with the next most severe level (i.e., mild vs clear, moderate vs mild, severe vs moderate, very severe vs severe).

Ethics approval was obtained from the Cardiff University School of Medicine’s Ethics Review Board on 25th February 2021. Consent to use the POEM was obtained from the University of Nottingham and consent to use and adapt the MLCDP was obtained from Cardiff University.

Results

Demographics

[Table 1](#) presents demographics of the 366 respondents and their children. Most respondents’ children (79%) were 13 years old or younger. POEM scores ranged from 0 (clear) to 28 (the maximum severity), and most children (67%) had moderate to severe AD (Figure 2). Parents reported residency in 22 different countries across all continents, except South America and Antarctica, although 84% resided in the United States, United Kingdom, Australia, India, or Canada.

Table 1. Demographics and descriptive severity data of respondents and children

	Overall (N=366)
Mean age of child, years (SD)	8.3 (6.2)
Age of child, years	
0-2	81 (22%)
3-7	99 (27%)
8-13	110 (30%)
14-17	46 (13%)
18+	29 (8%)
No response	1 (0%)
POEM score mean (SD)	13.5 (7.6)
POEM severity category	

Clear	26 (8%)
Mild	64 (19%)
Moderate	117 (35%)
Severe	107 (32%)
Very Severe	23 (7%)
No response	29 (8%)
Respondent's country	
USA	102 (28%)
UK	73 (20%)
Australia	53 (15%)
India	42 (12%)
Canada	37 (10%)
Portugal	19 (5%)
New Zealand	6 (2%)
Ireland	5 (1%)
Kenya	5 (1%)
South Africa	5 (1%)
Philippines	3 (1%)
Bahrain	2 (1%)
Hong Kong	2 (1%)
Malaysia	2 (1%)
Singapore	2 (1%)
Angola	1 (0%)
Cyprus	1 (0%)
Germany	1 (0%)
Israel	1 (0%)
Mexico	1 (0%)
Sweden	1 (0%)
Thailand	1 (0%)
No response	1 (0%)

Impact of AD on Life Decisions

Ninety percent of respondents (328/366) reported at least some impact of AD on at least one of the life decisions. All life decisions included in the survey were reported by at least some respondents as having been influenced by having a child with AD (Figure 1). The influence was strongest for those decisions that related to home life, and weakest for decisions relating to romantic relationships and family configuration. Influences of AD within each decision domain were positively intercorrelated; Cronbach's α for the six domain subscores ranged from 0.79 (financial domain) to 0.93 (job/career).

The questionnaire used is © Global Parents for Eczema Research and Bhatti ZU, Salek MS, Finlay AY, 2021

Financial impact

The domain of “financial impact” was added to the online survey based on caregiver feedback, and overall, respondents reported a strong impact of AD on key financial decisions: 76% of caregivers for whom the decision was applicable said AD influenced their decision to spend more on their home (55% reported a moderate to very strong influence). Such spending may be related to controlling triggers that have the potential to flare a child’s eczema. One caregiver stated: “We have spent more money cleaning vents, carpets, HEPA filters etc. to ensure dust particles are limited in the home.”

Sixty-four percent said AD influenced their decision to change their financial plans overall (45% moderate to very strong influence). “We have spent in the few months that my son has been diagnosed over [US]\$800 between creams and doctors’ appointments. It’s so very overwhelming financially on top of everything else,” shared one respondent.

Another stated: “The financial costs are also enormous but as a parent you feel you would do anything in your power to see them cured or feel better.”

Job / Career

Respondents reported a strong influence of their child’s AD on life decisions related to work. Seventy-one percent reported that it influenced their decision to work flexible hours (56% reporting a moderate to very strong influence on that decision) and 66% reported that it influenced their decision to work shorter hours (48% moderate to very strong). Sixty-four percent said that it influenced their decisions to work from home (53% moderate to very strong) and 62% reported that it influenced their decision not to work at all (50% moderate to very strong). A similar proportion (61%) said that it influenced their decision to take a temporary leave from work, and 52% said AD had an impact on the decision to change their job/career entirely.

One described the decision in this way: “Managing my child’s eczema has significantly affected my ability to return to work due to lack of support and inability to access day care services as these facilities would not be able to manage my child’s needs.”

Social and Physical Activities

Respondents reported striking and multi-dimensional impact on their personal and social lives, with a strong influence of AD on the decision to socialize, travel, engage in physical and community activities, hobbies and activities of enjoyment.

Seventy percent of respondents said eczema influenced their decision not to travel (53% moderate to very strong impact). One caregiver elaborated: “For traveling, we choose to mostly RV [use a recreational vehicle or motor home] so we have control over our environment and food can be made ourselves.” Seventy percent of respondents said that AD influenced their

decision to “not be involved in community activities” (49% moderate to very strong), 65% not to socialize (43% moderate to very strong), 68% to give up hobbies or activities of enjoyment (49% moderate to very strong), and 66% to change to a different physical activity (47% moderate to very strong).

The sheer time requirements of managing AD, the fear of triggering a flare, and the impact on caregivers’ mood and energy level may be factors that influence decisions that lead to narrowing of activities and sphere of engagement.^{2,4,10}

Home Life

Decisions related to home life, including clothing/household product choices, eating habits, and keeping a family pet were among the top decisions most influenced by AD with 96%, 93%, and 79% respectively of respondents identifying an influence of eczema on the decision (89%, 76%, 63% moderate to very strong influence). As one respondent explained, “We have spent tons of money on various moisturizers, detergents, organic clothes, allergen air purifiers, filters, and more. It definitely had an influence on our lifestyle in general.”

Fifty-one percent of respondents said that their child’s AD influenced their decision to move (40% moderate to very strong influence), while 39% said that it influenced their decision not to move. Many factors may influence this life decision including the desire to find a favorable climate for AD, and proximity to preferred health care providers and extended family who can help with babysitting and management.

Education

A child’s AD had less influence on decisions related to education. However, a still substantial number of respondents reported that AD was a factor in decisions related to homeschooling their children (49%), changing schools (45%) or a parent’s decision to leave their own education early (40%).

Relationships

Major decisions related to relationships and family configuration were also less commonly influenced by AD. For example, only 32% reported that AD influenced their decision to get a divorce or separation, and 36% said that it influenced their decision not to have children. A similar proportion said that it influenced their decision to refrain from having a romantic relationship

Association between AD Severity and Life Decisions

For most decisions, the influence of eczema was strongly associated with the severity of the child’s AD as indicated by their self-reported POEM score. Decisions related to romantic

relationships, divorce, when and if to have children, and education were the least influenced by the severity of the child's AD. Regression analyses of domain subscores found no differences by child age category, but significant increases in AD influence associated with each additional level of AD severity, with two exceptions. For the family domain, there was no difference in influence for severe vs. very severe AD; for the education domain, there was no difference in influence for clear, mild, and moderate AD.

Figure 2 summarizes the distribution of the impact of AD on each decision domain by AD severity. Figure 3 shows the joint distributions of pairs of domain subscores.

Discussion

In our sample of caregivers of children with mostly moderate to severe AD, the condition had a significant impact on life decisions for caregivers and families. Some of these decisions lead to deviations from a planned life path that have long-term consequences for the entire family: the decision to reduce work hours, change careers or leave the workforce entirely changes caregivers' career prospects and likely impacts families' finances. Women especially face barriers to re-entering the workforce after a career diversion related to child care or caregiving to a child with medical needs.^{11,12} Loss of income likely accumulates over time to erode the financial stability or financial course of the family. This change is compounded by the increases in expenses associated with managing AD and maintaining a lifestyle that protects the child from exposure to triggers and flares.¹³

Caregivers in this study report a range of social, lifestyle, and home life changes that together suggest adjustments that narrow horizons and increase isolation: the decision to give up hobbies and activities of enjoyment, to retreat from community and social activities, to change physical activities, and to refrain from traveling. For less common life decision impacts, such as the decision to get a divorce or to not have another child, AD still played a role, with 32-36 percent of caregivers reporting that AD influences these major life decisions related to family configuration.

While research findings on the influence of health conditions on major life changing decisions are still limited, the exploration of the secondary impact of health conditions on caregivers, partners and other family members is at an even earlier stage. However, there is an obvious interrelationship between chronic diseases of childhood and caregiver life decisions. For example, if having a child with severe AD influences a caregiver's decision to move to a different city, this in turn will influence the life course of the child and wider family. The current study therefore raises issues of potential relevance to understanding life course impairment beyond the specific example of pediatric AD.

This study did not seek to rank the importance of individual life decisions: such judgements would be highly subjective. Some of the decisions asked about in the survey (such as to get divorced) might be of more profound importance than others (such as to use different

clothing/bedding). A high prevalence of a particular decision being affected is therefore not necessarily related to the 'importance' or personal or societal consequences of that decision.

This study's primary limitation is its use of a convenience internet sample. Although respondents participated from many different countries, they likely represent caregivers who are more active in internet AD fora, who in turn are more likely to be experiencing a greater than average impact from the AD. This is reflected in the preponderance of children with moderate to severe AD. Such caregivers may also be from higher income households.

A further major strength of this study is the identification and measurement of the major impact that having a child with AD has on a wide range of major life changing decisions. This demonstrates for the first time that Life Course Impairment is an important aspect of secondary disease burden, as well as being relevant to those affected by disease. Finally, this study is unique in that it was designed and executed by investigators that included six parents and six researchers from five countries.

~~Strengths of this study include the rigorous method to ensure that the MLCDP was modified appropriately to address the requirement of measuring impact on caregivers rather than on patients, and that the study was initiated and organized by the patient support group directly impacted by these issues. A further major strength of this study is the identification and measurement of the major impact that having a child with AD has on a wide range of major life changing decisions. This demonstrates for the first time that Life Course Impairment is an important aspect of secondary disease burden, as well as being relevant to those affected by disease.~~

The results underscore the importance of recognizing the full impact of childhood AD on families, not just at a point in time, but over the life course. Our results highlight the need for better treatments for children with AD to reduce the sizeable burden on patients, caregivers and families. Support for caregivers of children with more severe AD is needed to lessen the strain and provide a path forward for families during difficult times – one that does not rely upon significant life alterations and sacrifices to accommodate the demands and burdens of AD.

~~Finally, this study is unique in that it was designed and executed by investigators that included six parents and six researchers from five countries. The survey instrument reflects extensive qualitative feedback from caregivers of children with AD. Of the top 10 life decisions most frequently selected as impacted by AD, six were added per caregiver feedback in the study design phase. This finding underscores the importance of patient-centered research methods in identifying the dimensions of impact that truly align with the experience of study populations. Future research is needed to develop and validate the instrument used in this study, the Eczema Caregiver Life Decisions Survey.~~

Acknowledgements

We wish to thank the caregivers, and their children with AD, who completed the survey. The study was funded by an unrestricted grant to Global Parents for Eczema Research from Sanofi Genzyme and Regeneron.

Conflicts of interest

AY Finlay is joint copyright owner of the MLCDP. The Global Parents for Eczema Research and AY Finlay, ZU Bhatti and MS Salek, are joint copyright owners of the revised questionnaire used in this study.

References

1. Nutten S. Atopic dermatitis: global epidemiology and risk factors. *Ann Nutr Metab.* 2015;66 Suppl 1:8-16. doi:10.1159/000370220
2. Capozza K, Gadd H, Kelley K, Russell S, Shi V, Schwartz A. Insights From Caregivers on the Impact of Pediatric Atopic Dermatitis on Families: "I'm Tired, Overwhelmed, and Feel Like I'm Failing as a Mother." *Dermatitis.* 2020;31(3):223-227. doi:10.1097/DER.0000000000000582
3. Kiebert G, Sorensen SV, Revicki D, et al. Atopic dermatitis is associated with a decrement in health-related quality of life. *Int J Dermatol.* 2002;41(3):151-158. doi:10.1046/j.1365-4362.2002.01436.x
4. Lewis-Jones S. Quality of life and childhood atopic dermatitis: the misery of living with childhood eczema. *Int J Clin Pract.* 2006;60(8):984-992. doi:10.1111/j.1742-1241.2006.01047.x
5. Beattie PE, Lewis-Jones MS. A comparative study of impairment of quality of life in children with skin disease and children with other chronic childhood diseases. *Br J Dermatol.* 2006;155(1):145-151. doi:10.1111/j.1365-2133.2006.07185.x
6. Bhatti ZU, Salek S, Finlay AY. Concept of Major Life-Changing Decisions in Life Course Research. *Dermatological Diseases and Cumulative Life Course Impairment.* 2013;44:52-66. doi:10.1159/000350389
7. Bhatti ZU, Finlay AY, Bolton CE, et al. Chronic disease influences over 40 major life-changing decisions (MLCDs): a qualitative study in dermatology and general medicine. *J Eur Acad Dermatol Venereol.* 2014;28(10):1344-1355. doi:10.1111/jdv.12289
8. Bhatti ZU, Salek SS, Bolton CE, et al. The development and validation of the major life changing decision profile (MLCDP). *Health and Quality of Life Outcomes.* 2013;11(1):78. doi:10.1186/1477-7525-11-78

9. Charman CR, Venn AJ, Williams HC. The patient-oriented eczema measure: development and initial validation of a new tool for measuring atopic eczema severity from the patients' perspective. *Arch Dermatol*. 2004;140(12):1513-1519. doi:10.1001/archderm.140.12.1513
10. Yang EJ, Beck KM, Sekhon S, Bhutani T, Koo J. The impact of pediatric atopic dermatitis on families: A review. *Pediatric Dermatology*. 2019;36(1):66-71. doi:10.1111/pde.13727
11. Hauge LJ, Kornstad T, Nes RB, et al. The Impact of a Child's Special Health Care Needs on Maternal Work Participation during Early Motherhood. *Paediatric and Perinatal Epidemiology*. 2013;27(4):353-360. doi:https://doi.org/10.1111/ppe.12063
12. Hewlett SA, Luce CB. Off-ramps and on-ramps: keeping talented women on the road to success. *Harv Bus Rev*. 2005;83(3):43-46, 48, 50-54 passim.
13. Smith Begolka W, Chovatiya R, Thibau IJ, Silverberg JI. Financial Burden of Atopic Dermatitis Out-of-Pocket Health Care Expenses in the United States. *Dermatitis*. 2020;Publish Ahead of Print. doi:10.1097/DER.0000000000000715