

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”

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Background: The impact of pediatric atopic dermatitis (AD) on families is largely hidden from view, and AD is commonly misunderstood as a minor skin condition. Few studies have examined the full burden of AD from the family perspective.

Objective: The aim of the study was to assess the burden of AD on children and families using a caregiver-centered survey.

Methods: A 72-item anonymous online survey was posted on social media sites targeted to or composed of parents of children with AD. It explored the following 9 domains of impact: sleep, social isolation, time requirements, life decisions, family relationship dynamics, energy/fatigue, mental health impacts, and unmet treatment needs. Atopic dermatitis severity was reported by respondents using the Patient-Oriented Eczema Measure. Statistical analyses were conducted using R 3.6.0.

Results: Two hundred thirty-five individuals completed the survey during the 1-month period that it was promoted via social media. Caregivers reported frequent sleep disturbance, exhaustion, worry, and social isolation related to their child’s AD.

Conclusions: Results highlight the need for psychosocial support and respite care for caregivers of children with AD.

Eczema, or atopic dermatitis (AD), is a common, chronic inflammatory condition that typically appears in childhood and has a significant impact on quality of life for children and their families.^{1,2} Compared with other pediatric chronic diseases, AD is among the most damaging to quality of life, second only to cerebral palsy in one comparative study.³

Persistent itch, which leads to chronic sleep disruption, is a hallmark symptom of AD. A child’s lack of sleep in turn can lead to difficulty with daytime functioning, emotional and behavioral problems, and delayed physical and social development.⁴ Scratching associated with itch can cause harm to the skin and require caregivers to monitor children at all times, even throughout the night.⁵ Caregivers of children with AD report exhaustion, frustration, and mood disorders.^{6–8} Bathing regimens, daily application of topical treatments, frequent laundry and cleaning, coordinating medical appointments, buying treatments, and communicating with insurance all place time and financial demands on families. However, this far-ranging impact is largely hidden from view, and AD is commonly

misunderstood as a superficial cutaneous condition. Few studies have examined the full burden of AD from the parent and family perspective.

In this study, we conducted an online survey to examine the impact of childhood AD on both patients and their families using a caregiver-centered approach.

METHODS

Nine domains of impact (ie, sleep, social isolation, time requirements, life decisions, family relationship dynamics, energy/fatigue, mental health impacts, and unmet treatment needs) were selected by the investigators, 5 of whom are parents of children with AD. Items designed to measure these domains were selected based on relevance to the patient and family experience, and gaps in research were identified by the research team.

A 72-item anonymous online survey was 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 for a 1-month period (April 16, 2019–May 17, 2019).

An understudied facet of living with AD is the daily time investment required to maintain the home, prevent and treat flares, and coordinate with medical providers and insurance. To explore this aspect of impact, the survey queried parents and caregivers about time spent on specific activities and tasks related to their child’s AD, including bathing, applying topical therapies and wet wraps, comforting/distracting, communicating with doctors, insurers, and pharmacies, traveling to/from appointments, doing housework to reduce triggers/allergens, and shopping for medicines and supplies. Atopic dermatitis severity was reported by respondents using the Patient-Oriented Eczema Measure (POEM) embedded in the survey.⁹

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Statistical analyses were conducted using R 3.6.0. Survey responses were analyzed using normal and nonparametric descriptive statistics as appropriate for each item. Scale scores and severity categories (clear, mild, moderate, severe, very severe) were computed for AD severity (POEM), subjective burden, and energy. Interitem consistency was assessed using Cronbach α . Total hours per week spent by respondent in AD-related tasks were computed. Age-adjusted impact of AD on these constructs was examined using linear, logistic, or ordinal regression analyses with AD severity category and child age as predictors and impact, energy, and AD task hours per month as outcomes. Atopic dermatitis severity category was parameterized using Helmert contrasts, comparing each severity level with the mean of the less severe levels (eg, mild vs clear, moderate vs mild and clear combined, severe vs moderate, mild, and clear combined, very severe vs all other levels combined).

The study was approved by the institutional review board at the University of Illinois at Chicago.

RESULTS

Demographics

Two hundred thirty-five individuals completed the survey during the 1-month period that it was promoted via social media; an additional 59 individuals began but did not complete the survey and 3 individuals were ineligible because of not having a child younger than 18 years with AD; these 62 respondents were excluded from analyses.

Table 1 presents demographics of respondents and their children. The mean (SD) age of respondent's children was 5.1 (4.6) years and 58% were male children. Parents reported residency in 17 different countries across all continents, except South America and Antarctica, although most (60%) resided in the United States. The vast majority (84%) had a child with moderate to severe AD based on a 28-point POEM scale.

We modified the 45-item Childhood Atopic Dermatitis Impact Scale (CADIS) using 25 CADIS question items that explored parent emotion, sleep, and concerns about child esteem and social isolation.¹⁰ All items were intercorrelated; Cronbach α for a single averaged subjective burden score was 0.94.

Interestingly, 22% of parents reported that their physician had told them that their child's growth was delayed. Such growth delay warrants further research and may be related to sleep difficulties, poor nutrition, corticosteroid therapy, or other factors.¹¹

Overall Impact

An overall subjective burden score was calculated by averaging twenty-five 5-point CADIS items to create a score ranging from 1 to 5. Subjective burden (mean [SD], 3.3 [0.79], on a scale 1–5) was positively correlated with POEM score (Fig. 1A). Controlling for child age, burden was significantly higher for each successive severity level compared with the average of the less severe levels, with an

TABLE 1. Respondent Demographics

	Overall
N	235
Country, n (%)	
United States	153 (65.1)
United Kingdom	32 (13.6)
Canada	21 (8.9)
Australia	10 (4.3)
Ireland	3 (1.3)
Croatia	2 (0.9)
Netherlands	2 (0.9)
South Africa	2 (0.9)
Zambia	2 (0.9)
Bosnia and Herzegovina	1 (0.4)
Estonia	1 (0.4)
Hong Kong	1 (0.4)
India	1 (0.4)
Malaysia	1 (0.4)
New Zealand	1 (0.4)
Poland	1 (0.4)
Singapore	1 (0.4)
Marital status, n (%)	
Married	193 (82.1)
Never married	26 (11.1)
Divorced	11 (4.7)
Separated	3 (1.3)
Widowed	2 (0.9)
Adults in house, mean (SD)	2.07 (0.71)
Children in house, mean (SD)	2.18 (1.28)
Children with AD in house, mean (SD)	1.28 (0.57)
Child's age, mean (SD)	5.10 (4.59)
Sex of child, female	100 (42.6)
Been told child's growth is delayed, n (%)	
Yes	52 (22.1)
No	176 (74.9)
I'm not sure	7 (3.0)
POEM score, mean (SD)	16.21 (7.67)
POEM eczema severity category, n (%)	
Clear (0–2)	13 (5.6)
Mild (3–7)	23 (10.0)
Moderate (8–16)	76 (32.9)
Severe (17–24)	85 (36.8)
Very severe (25–28)	34 (14.7)

average increase of 0.42 (standard error [SE], 0.11) on the subjective burden scale from clear to mild, and increases ranging from 0.27 to 0.23 points (SE, 0.03–0.04) for each successive level compared with prior levels.

Caregiver/Child Sleep

Consistent with other studies, parents reported frequent sleep disruption, both in reference to their child with eczema and themselves. When asked how frequently AD affects their child's ability to sleep, most reported that it did so "all the time" (33%) or "often" (29%). Reflecting on their own sleep, 60% reported that they wake up 2 or more

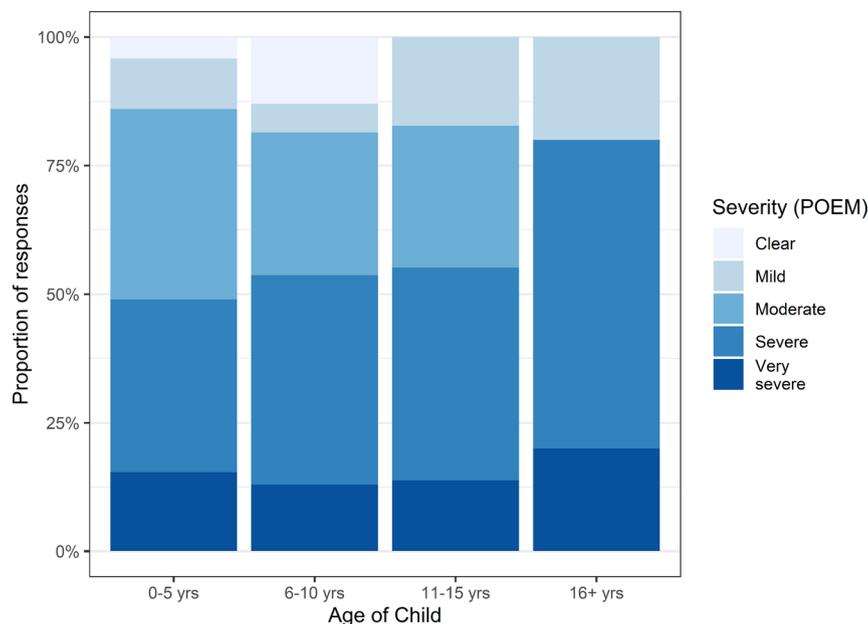


Figure 1. Distribution of AD severity by age of child.

times per night to care for their child with AD, whereas 32% reported waking up 3 or more times per night. Sleep interference was associated with AD severity, using a cumulative logit model and controlling for child age, with parents of children with each more severe category of AD reporting more frequent sleep disruption than parents of children in the less severe categories ($P < 0.008$ for each comparison).

Caregiver Energy/Fatigue

Low energy was associated with AD severity. In a linear regression controlling for child age, parents of children with each more severe category of AD had lower self-reported energy scores than parents of children in the less severe categories, with a difference of 1.8 (SE, 0.17) on the 5-point scale for clear versus mild, and roughly 0.4 points per level (SE, 0.07–0.13) for comparisons with increasing levels of severity.

Fatigue has an impact on working parents who must find a way to function at work despite sleep loss. In response to the statement “my child’s eczema affects my spouse’s or my work performance due to fatigue, missed time, and decreased productivity,” 67% of parents experienced this scenario sometimes, often, or all the time.

Time Burden

Respondents reported a mean (SD) of 22 (18) hours per week spent in AD-related tasks. Some activities required less than 1 hour per week but still required a monthly time commitment. The time burden was significantly associated with severity (Fig. 1B). Child age was not significantly associated with AD-related time burden. Parents with children who were clear or mild severity spent an average of 9.5 hours on AD care per week (SE, 4), with parents of children at

each increasing severity level spending an average of 5–10 additional hours compared with lower levels (SE, 2–3).

Commitment to AD care required tradeoffs with personal time, socializing, and hobbies. Reflecting this adjustment, 67% to 70% of parents said that their child’s AD made it hard to do what they enjoy, and it affected their social life sometimes, often, or all the time.

Caregiver Psychosocial Impact

The unpredictability of AD and its chronicity is a source of anxiety for parents. Figure 2 summarizes the responses to the psychosocial items.

On a question related to worry about AD coming back even when the child’s skin is asymptomatic, 82% of parents reported that they feel this way often or all the time. Parents also reported concern about whether their child would outgrow AD (79% worrying often or all the time) and adverse effects from treatments (76% worrying often or all the time). They indicated that they feel a sense of helplessness and guilt related to their child’s AD (74% often or all the time) and that their child’s AD makes them feel sad or depressed (52% often or all the time).

As one parent shared in the survey, “It is very painful, tiring, and hopeless feeling when taking care [of] a child with AD. It seems nonstop and never ending [sic] nightmare.” Another commented, “It’s terrible to watch your children suffer and not be able to help!”

Social Isolation

Parents reported worry related to their child’s ability to make friends with 44% reporting that they worried about this “often” or “all the time.” Likewise, 58% worry often or all the time that AD will affect their child’s self-esteem.

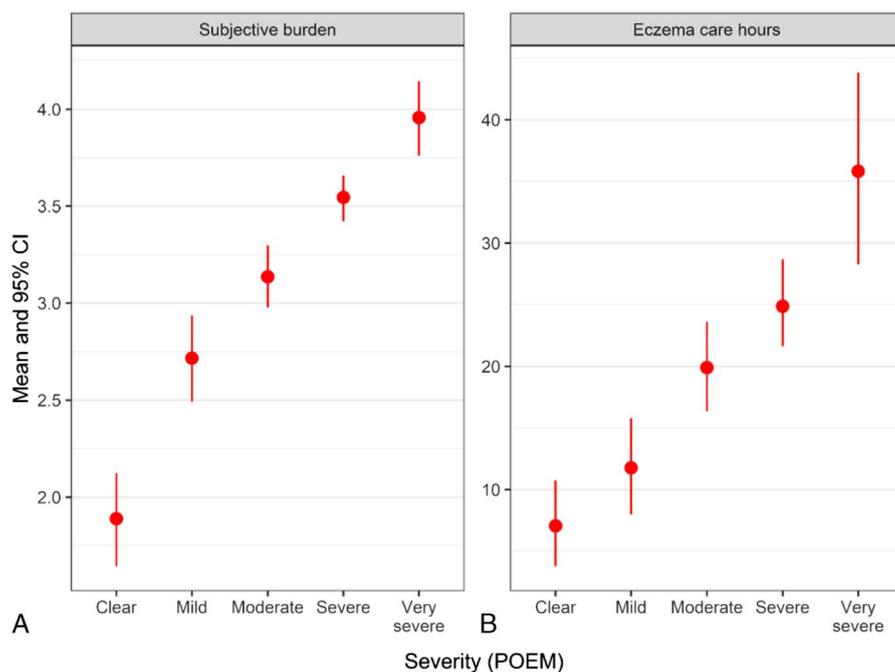


Figure 2. Distribution of responses by AD severity.

Parents face several challenges to maintaining a social life. The intensity of caregiving required to monitor and manage a child with AD makes it difficult to delegate care to others. Forty-eight percent of parents said that they sometimes worry about leaving their child with others (babysitters, relatives) because of AD often or all the time. The risk of exposing the child with AD to allergens or triggers is a second deterrent to socializing for parents/caregivers. Forty-six percent of parents reported that they often or all the time avoid social situations where their child with AD might be exposed to allergens or triggers. A third reason for avoiding social situations relates to how strangers react to the appearance of AD and the manifestations of its symptoms. Parents/caregivers said that it bothered them when strangers comment on the appearance of their child's skin and/or offer advice (51% often or all the time), and 47% said that they often or all the time feel blamed or judged that their child's AD still persists despite treatment. Taken together, these experiences and fears may lead to self-imposed social isolation.

Satisfaction With Treatments and Medical Professionals

Currently, few treatments exist for childhood AD and many parents report poor control with current medications.¹² Nearly half of respondents expressed dissatisfaction with available treatment options (47%) and the help they had received from doctors and other medical professionals (53%).

Life Decisions

Given the profound impact that moderate to severe AD has on families, it is not surprising that a significant proportion of parents reported that their child's condition influenced major life decisions.

One-third reported that caring for a child with AD influenced their decision to work outside the home (33%), and one-third reported that it influenced their decision to have more children (34%).

DISCUSSION

Caring for a child with moderate to severe AD is a time-intensive, emotionally demanding around the clock job that leads to high levels of parental worry, exhaustion, and family strain. Sleep disruption may contribute to difficulty coping with AD management and parenting demands. As one parent stated in the survey, "I'm so tired, overwhelmed and feel like I'm failing as a mother."

Indeed, childhood AD can have far-reaching and profound impacts that affect parents' decision to work or to have more children. Atopic dermatitis may thus impact household income in 2 ways: by requiring substantial ongoing spending on treatments and management approaches and by reducing the ability of parents to have 2 incomes.

Our results underscore the importance of recognizing the full impact of childhood AD on families and dispelling the myth that it is a superficial skin condition. Furthermore, our results highlight the need for psychosocial support and respite care for caregivers of children with AD.

Parent- and patient-centered research methods allow for unique inquiry into the true impact of a condition from the family perspective. Future research is needed to develop and validate a parent- and patient-centered quality-of-life instrument for AD.

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