

Family Impact of Atopic Dermatitis in Infants/Preschoolers From EPI-CARE: An International Survey

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INTRODUCTION

- Atopic dermatitis (AD) is a chronic, systemic inflammatory disease, with substantial impact on patients.^{1,2}
- For children and adolescents with AD, their disease may also negatively impact parents/caregivers owing to effects on sleep, mental health, quality of life (QoL), the additional care required for daily treatment, and the need for meeting with healthcare providers.^{2,3}
- Much of the current knowledge of parent/caregiver AD-related burden is based on anecdotal reports or derived from pediatric clinics, which may represent more severe disease that is not reflective of the general AD population.⁴
- To date, few multinational studies have evaluated the impact of AD on parents/caregivers of pediatric patients.
- The Epidemiology of Children with Atopic Dermatitis Reporting on their Experience (EPI-CARE) study was conducted to provide current information on the epidemiology and burden of AD among children and adolescents aged 6 months to <18 years from countries in different geographic regions worldwide.⁵
- Here, we report the impact of AD on parents/caregivers of children aged 6 months to <6 years with AD in 18 countries from 5 regions (North America, Latin America, Europe, the Middle East/Eurasia, and East Asia) from the EPI-CARE study.

METHODS

- EPI-CARE is an international, cross-sectional, web-based survey conducted between September 2018 and December 2019, and was designed to be representative of general pediatric populations.
- In each country, parents/caregivers of children aged 6 months to <18 years were invited to participate without prior knowledge of the research topic.
- The survey comprised 2 sections: the first included questions to confirm subject eligibility, demographic information, and allowed selection of one child for families with multiple children. The second assessed disease severity, patient disease burden, and impact of AD on parents/caregivers.
- Eligible children were identified as having “diagnosed AD” based on meeting all items of the International Study of Asthma and Allergies in Childhood (ISAAC) criteria and self-report or parent/caregiver report of ever being told by a physician that they/their child had eczema.
 - As pediatric AD presents with age-dependent characteristics that include facial, scalp, and extensor involvement in infants and young children, children aged <6 years were also required to meet 2 additional criteria at any time: itchy rash affecting, at any time, the face (cheeks, forehead) and affecting, at any time, elbow to wrist or knee to ankle.
- AD severity was assessed using Patient Global Assessment (PtGA) in the past week where parents/caregivers described their child’s eczema severity over the last week as mild, moderate, or severe.
- Parents/caregivers reported the impact of their child’s AD on family QoL using the 10-item Dermatitis Family Impact (DFI) questionnaire (total DFI score range, 0–30; higher scores indicating greater impact), and 2 standalone questions related to the hours of AD-related care in the past week and missed work days in the past 4 weeks as a result of their child’s AD.
- As a mean DFI score >10 has been shown to represent a moderate to high alteration in QoL,⁶ the proportion of parents/caregivers reporting a mean DFI score of >10 was assessed.

RESULTS

Demographic Characteristics

- A total of 1489 parents/caregivers (mean [SD] age, 32.1 [7.4] years; 62.8% female; 84.7% employed or self-employed) and 1489 infants/preschoolers (mean [SD] age, 3.0 [1.6] years) with a diagnosis of AD participated in the survey (Table 1).

Table 1. Demographic Characteristics of the Parents/Caregivers of Children Aged 6 Months to <6 Years With Atopic Dermatitis

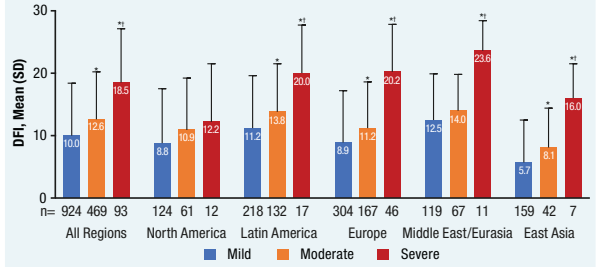
Variable	All Regions	North America	Latin America	Europe	Middle East/Eurasia	East Asia
n	1489	198	368	518	197	208
Child age, y, mean (SD)	3.0 (1.6)	3.0 (1.7)	3.1 (1.6)	3.1 (1.6)	2.8 (1.5)	3.1 (1.5)
Parents/caregivers						
Caregiver age, y, mean (SD)	32.1 (7.4)	31.5 (7.5)	31.4 (7.5)	32.4 (7.6)	32.2 (6.1)	35.7 (7.2)
Female sex, %	62.8	81.8	50.0	74.0	63.0	57.4
Employment status, %						
Employed or self-employed	84.7	70.5	93.5	82.2	87.4	76.1
Unemployed	7.2	12.2	2.7	8.8	6.3	14.6
Retired	0.8	2.5	—	0.6	0.8	1.4
Other ^a	7.3	14.8	3.8	8.3	5.4	7.9

y=years.
^aOther^{*} includes on sick leave, student, maternity/parental leave, other, prefer not to state.

Impact of AD on Parents/Caregivers

- Mean (SD) DFI scores significantly increased with AD severity and ranged from 5.7 (6.8) in East Asia to 12.5 (7.4) in the Middle East/Eurasia among children with mild AD, 8.1 (6.3) in East Asia to 14.0 (5.8) in the Middle East/Eurasia among children with moderate AD, and 12.2 (9.3) in North America to 23.6 (4.8) in the Middle East/Eurasia among children with severe AD (Figure 1).
- The proportion of parents/caregivers reporting a mean DFI score of >10 was 42.1% among those with children who had mild AD, 58.7% among those with children who had moderate AD, and 78.0% among those with children who had severe AD.

Figure 1. Impact of Atopic Dermatitis on Parent/Caregiver Quality of Life



AD=atopic dermatitis; DFI=Dermatitis Family Impact; PtGA=Patient Global Assessment.
^{*}P<0.05 versus mild; [†]P<0.05 versus moderate.
 Evaluated using the DFI questionnaire, by AD severity and assessed using PtGA.

- Among all regions and across all DFI domains, AD severity significantly impacted family QoL, with significantly more parents/caregivers of children with severe AD reporting “very much” or “a lot” of impact compared with parents/caregivers of children with mild or moderate AD (Table 2).

Table 2. Impact of Atopic Dermatitis on Domains of Quality of Life of Parents/Caregivers

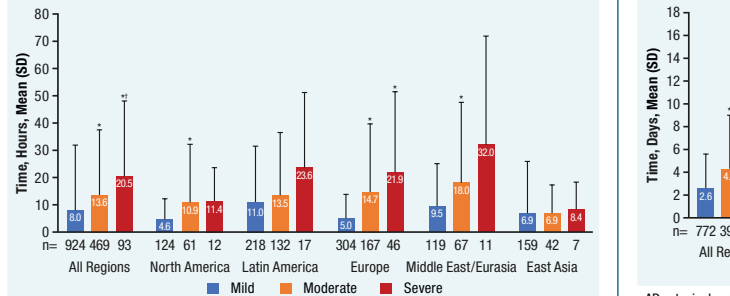
DFI item	Percent of Respondents Who Reported “Very Much” or “A Lot” of Impact Based on Mild/Moderate/Severe AD					
	All Regions	North America	Latin America	Europe	Middle East/Eurasia	East Asia
n, mild/moderate/severe AD	924/469/93	124/61/12	218/132/17	304/167/46	119/67/11	159/42/7
Housework	30.3/41.5*/68.7**†	26.5/32.7/31.2	34.8/49.6*/80.6**†	26.2/33.8/70.0**†	40.4/45.9/97.0**†	12.8/17.1/84.1**†
Food preparation/feeding	27.6/32.1/68.5**†	22.8/30.8/37.3	32.9/35.7/80.6**†	22.8/21.2/69.8**†	36.5/43.1/87.8**†	12.0/10.5/74.6**†
Sleep	29.5/43.4*/69.8**†	27.4/33.6/49.3	35.2/50.4*/65.3*	23.3/38.1**/78.8**†	34.6/49.6*/97.0**†	15.6/18.0/75.2**†
Leisure activities	25.3/37.8*/64.7**†	21.1/29.7/31.2	30.2/44.4*/66.0*	24.2/30.1/78.2**†	29.5/42.2/87.8**†	11.0/23.2**/74.6**†
Shopping	23.3/31.0*/57.5**†	23.3/21.4/37.3	25.5/36.0*/48.9*	19.8/24.5/70.5**†	31.5/41.4/87.8**†	8.1/12.8/58.1**†
Expenditures	29.9/43.1**/66.5**†	26.5/31.9/55.4*	37.3/51.0*/68.3*	24.3/33.6*/68.2**†	33.9/52.0**/87.8**†	12.2/20.9/41.5*
Tiredness	30.8/47.1**/67.7**†	24.0/40.3*/31.2	35.5/53.2**/75.0**†	26.2/42.8**/79.0**†	43.8/52.5/100.0**†	13.9/18.5/42.5*
Emotional distress	31.3/41.3**/59.8**†	26.8/28.0/34.8	34.6/45.9*/64.5*	29.6/42.1**/67.9**†	40.4/49.8/71.5*	16.0/20.9/67.4**†
Relationships	24.7/37.6**/62.6**†	20.9/28.5/37.3	27.6/46.4**/64.5*	23.6/28.3/66.3**†	31.8/40.5/100.0**†	12.4/16.8/49.1**†
Help with treatment	25.2/39.3**/64.4**†	20.1/23.7/36.1	33.0/51.3**/77.6**†	20.8/30.1**/69.5**†	28.0/42.0**/87.8**†	9.7/14.2/16.4

AD=atopic dermatitis; DFI=Dermatitis Family Impact; PtGA=Patient Global Assessment.
^{*}P<0.05 versus mild; [†]P<0.05 versus moderate.
 Evaluated using the DFI questionnaire, by AD severity and assessed using PtGA.

Temporal Components of Care

- In the last week, parents/caregivers reported spending more time on AD-related childcare as patient disease severity increased, with an average (SD) of 8.0 (16.3), 13.6 (23.9), and 20.5 (27.6) hours for mild, moderate, and severe AD, respectively (Figure 2).

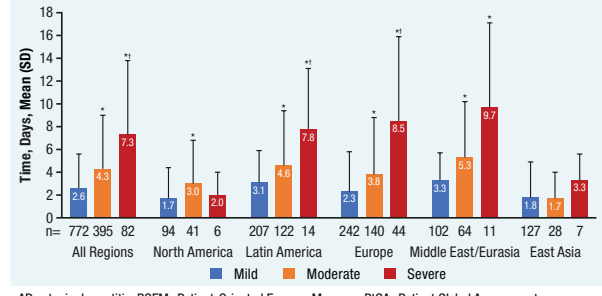
Figure 2. Time Spent Taking Care of the Child in the Past Week



AD=atopic dermatitis; PtGA=Patient Global Assessment.
^{*}P<0.05 versus mild; [†]P<0.05 versus moderate.
 Time spent taking care of the child in the past week owing to AD, by AD severity and assessed using PtGA.

- Parents/caregivers also reported the mean (SD) number of missed work days in the past 4 weeks as a result of their child’s AD, which increased with higher levels of AD severity, missing 2.6 (3.0) days (mild AD) versus 4.3 (4.7) days (moderate AD) versus 7.3 (6.5) days (severe AD) (Figure 3).

Figure 3. Days Missed From Work in the Past 4 Weeks



AD=atopic dermatitis; PtGA=Patient Global Assessment.
^{*}P<0.05 versus mild; [†]P<0.05 versus moderate.
 Days missed from work in the past 4 weeks owing to the child’s AD among parents currently working, by AD severity and assessed using PtGA.

CONCLUSIONS

- AD in infants/preschoolers has a substantial and multidimensional impact on their families’ lives.
- Although the burden increases with severity of AD in infants/preschoolers, there is a high burden on parents/caregivers regardless of disease severity.
- These results emphasize that the burden of childhood AD and its treatment extends beyond the individual patient and may impact parents/caregivers who are committed to meeting the caregiving needs of their children, especially at higher levels of disease severity.
- These results also highlight the importance of assessing the broader impact of AD on parents/caregivers in addition to the patient-reported burden.

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