

# Financial Burden of Atopic Dermatitis Out-of-Pocket Health Care Expenses in the United States

Wendy Smith Begolka, MBS,\* Raj Chovatiya, MD, PhD,† Isabelle J. Thibau, MPH,\* and Jonathan I. Silverberg, MD, PhD, MPH‡

**Background:** Atopic dermatitis (AD) is associated with considerable financial cost. However, the full burden of out-of-pocket (OOP) expenses is not well understood.

**Objective:** We sought to characterize the OOP health care expenses associated with AD management.

**Methods:** A 25-question voluntary online survey was administered to National Eczema Association members worldwide ( $n = 113,502$ ). Inclusion criteria (US residents age  $\geq 18$  years who either self-reported had AD or were primary caregivers of individuals with AD) were met by 77.3% (1118/1447) of respondents.

**Results:** Respondents reported OOP expenses in 3 categories: (1) health care providers and prescriptions, including health care provider visit deductibles (68.7% [686]), prescription co-pays (64.3% [635]), and prescriptions not covered by insurance (48.6% [468]); (2) nonprescription health care products, including moisturizers (94.3% [934]), hygiene products (85.0% [824]), allergy medications (75.1% [715]), itch relievers (68.25% [647]), dietary supplements (52.2% [491]), and sleep aids (37.0% [336]); and (3) complementary approaches, including cleaning products (74.7% [732]), clothing/bedding (44.8% [430]), alternative medications (19.0% [180]), and adjunctive therapies (15.9% [150]). The median annual AD OOP expense was US \$600 (range, US \$0–\$200,000), with 41.9% (364) reporting expenditures US \$1000 or greater.

**Conclusions:** Out-of-pocket expenses place a significant financial burden on individuals with AD. Additional studies are needed to better understand associations and impact of OOP costs.

Atopic dermatitis (AD) is a common chronic inflammatory skin disease that affects 13% of children and 7% of adults in the United States.<sup>1–3</sup> Atopic dermatitis is associated with significant morbidity, including profound itch, skin pain, sleep disruption, and mental health disturbances.<sup>3–7</sup> In addition, AD is associated with impaired health-related quality of life and a multidimensional burden consisting of physical, emotional, and psychosocial effects.<sup>7–13</sup>

Children and adults with AD have more outpatient office visits,<sup>9,14</sup> emergency department visits,<sup>9,15</sup> and hospital admissions with prolonged

hospitalizations<sup>9,16,17</sup> in the United States compared with those without AD. Increased health care resource utilization is associated with substantial direct costs and increasing costs over time even after adjusting for inflation.<sup>15,17</sup> The multidimensional burden of AD is also associated with considerable indirect costs to society, including sick days and lost work productivity. The combined direct and indirect inflation-adjusted annual costs of AD were estimated to be US \$5.3 billion in 2015; this amount may underestimate the actual disease-related financial burden.<sup>18</sup>

From the \*National Eczema Association, Novato, CA; †Department of Dermatology, Northwestern University Feinberg School of Medicine, Chicago, IL; and ‡Department of Dermatology, The George Washington University School of Medicine and Health Sciences, Washington, DC.

Address reprint requests to Wendy Smith Begolka, MBS, National Eczema Association, #B300, 505 San Marin Dr, Novato, CA 94945. E-mail: wendy@nationaleczema.org.

W.S.B. and R.C. contributed to this work equally.

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Out-of-pocket (OOP) expenses are particularly important in the day-to-day lives of AD patients and their families. Although US population-based surveys demonstrated multifactorial increases in overall OOP health expenses related to AD,<sup>12,19</sup> OOP costs are not well characterized from an individual perspective. Few studies investigated the broader complement of health care expenses and OOP economic burden of AD on patients and their caregivers. Furthermore, management of AD and its comorbidities can be challenging. Currently available treatment options have variable long-term effectiveness and safety, which may warrant switching between therapies, use of combination therapy, and use of complementary or adjunctive health care approaches to achieve satisfactory disease control. We hypothesized that individuals with AD have a wide array of unappreciated OOP costs beyond major categories of health care expenses, such as health care provider (HCP) visits and prescription medications. In this study, we sought to characterize and quantify the OOP health care expenses and financial burden associated with AD management.

## METHODS

### Study Design

A 25-question voluntary online survey was administered between November 14, 2019, and December 21, 2019, to all National Eczema Association members, including 113,502 unique individuals with AD and nonaffected family members worldwide. To enhance reach, the survey was also advertised on a variety of social media platforms. Electronic informed consent was obtained prior to survey initiation, and respondents who reached the end of the survey were offered an optional opportunity to enter in a drawing to win 1 of 10 US \$50 gift cards. Survey responses were not linked in any way to the gift cards. Study inclusion criteria included the following: US residents, adults (age  $\geq 18$  years) and either self-reportedly had AD or were primary caregivers of children with AD.

### Survey Questions

Diagnosis of AD was determined by an affirmative answer to the question: "Have [you/the person with atopic dermatitis] been diagnosed with atopic dermatitis by a health care provider?" Demographics were collected, including age, sex, race/ethnicity, region of residence, geographical setting, household income, and insurance coverage. Current AD severity (clear, mild, moderate, and severe) and control (very well, moderately well, somewhat, minimally, and not controlled) were determined by patient global assessment, and the number of flare days in the last month (0/1–3/4–7/8–10/ $\geq 11$ ) was also assessed. Comorbid diseases were assessed by asking about HCP-diagnosed asthma, allergic rhinitis, food allergy, frequent/persistent skin infections, and anxiety and/or depression.

Respondents were asked about specific topical/external (antimicrobials, corticosteroids, crisaborole, pimecrolimus, tacrolimus, phototherapy) and systemic (azathioprine, cyclosporine, methotrexate, tacrolimus, mycophenolate mofetil, dupilumab, oral corticosteroids,

injectable corticosteroids) prescription therapies, total number of prescriptions in the past year (0/1/2/3/4/5/ $\geq 6$ ), and number of HCP visits for AD in the past year (0/1/2/3/4/5/ $\geq 6$ ). The OOP expenses related to evaluation or treatment of AD in the past 30 days (US \$0/US \$1–50/US \$51–100/US \$101–150/US \$151–200/US \$201–250/US \$251–275/US \$275–300/ $>$ US \$300) were assessed for (1) current medical and therapeutic approaches (eg, HCP, individual prescription drugs, and care coordination expenses), (2) nonprescription over-the-counter (OTC) medications and other health-related personal products (eg, bandages and bathing/hygiene products), and (3) adjunctive approaches (eg, traditional Chinese medicine or similar, specialized clothing, bedding, or cleaning products). Respondents were also asked to compare OOP expenses in the past 30 days to average monthly OOP expenses (significantly more, somewhat more, same, somewhat less, significantly less) and estimate yearly OOP expenses for AD.

### Data Analysis

Statistical analysis was performed using SAS version 9.4 (SAS Institute, Cary, NC).  $\chi^2$  Tests were used for comparisons of categorical variables, including sociodemographic and AD severity and control measures. Corrected *P* values of 0.05 or less were considered significant.

## RESULTS

### Respondent Characteristics

The survey was started by 1447 persons, of which 954 (65.9%) fully completed; 1118 (77.3%) met the inclusion criteria. The cohort included adults with AD (% prevalence [frequency]: 77.5% [866]) and parents and/or primary caregivers of children/teens (<18 years: 20.0% [224]) or young adults (18–25 years: 2.5% [28]) with AD (Table 1). The majority of respondents identified as female (76.5% [855]), White (72.38% [697]), and non-Hispanic (90.5% [871]). More than half of respondents had employer-sponsored insurance coverage (57.7% [550]) and a household income of US \$50,000 or greater (61.7% [589]), with a median income of US \$50,000 to US \$74,999. Respondents were fairly evenly distributed across the United States, and most lived in a suburban location (56.6% [544]).

### Respondent Disease Burden and Comorbidities

Nearly three-quarters of respondents classified AD severity as either moderate (% prevalence [frequency]: 47.5% [531]) or severe (26.5% [296]) (Table 2). Most reported only minimally (23.2% [259]) or somewhat (40.1% [448]) controlled AD, and approximately half had 8 disease flare days or more (53.0% [588]) in the past month and 3 HCP visits or more (48.8% [523]) for evaluation or management of AD in the past year. Comorbidities among respondents included asthma (34.5% [382]), allergic rhinitis (50.4% [557]), food allergy (38.5% [426]), frequent/persistent skin infections (19.0% [210]), and anxiety and/or depression (36.5% [404]).

**TABLE 1. Respondent Characteristics**

Variable—Freq (%)	Overall	No. Treatments			P	Step-up Therapy		
		0	1–2	≥3		No	Yes	P
Age, y								
≤2	42 (3.8%)	5 (4.5%)	17 (4.9%)	18 (2.9%)	0.20	31 (4.9%)	9 (2.0%)	0.16
3–5	69 (6.2%)	8 (7.1%)	21 (6.1%)	39 (6.3%)		49 (7.7%)	18 (4.1%)	
6–11	68 (6.1%)	6 (5.4%)	18 (5.2%)	41 (6.7%)		41 (6.5%)	23 (5.2%)	
12–17	49 (4.4%)	4 (3.6%)	14 (4.1%)	28 (4.5%)		21 (3.3%)	25 (5.7%)	
18–25	139 (12.4%)	15 (13.4%)	31 (9.0%)	83 (13.5%)		70 (11.0%)	60 (13.6%)	
26–35	130 (11.6%)	16 (14.3%)	43 (12.5%)	67 (10.9%)		76 (12.0%)	51 (11.5%)	
36–50	173 (15.5%)	24 (21.4%)	51 (14.8%)	96 (15.6%)		103 (16.2%)	70 (15.8%)	
51–64	247 (22.1%)	18 (16.1%)	74 (21.5%)	148 (24.0%)		135 (21.3%)	103 (23.3%)	
≥65	201 (18.0%)	16 (14.3%)	75 (21.8%)	97 (15.7%)		109 (17.2%)	83 (18.8%)	
Sex								
Female	855 (76.5%)	97 (86.6%)	261 (75.9%)	473 (76.7%)	0.10	496 (78.1%)	335 (75.8%)	0.76
Male	251 (22.5%)	13 (11.6%)	78 (22.7%)	139 (22.5%)		129 (20.3%)	105 (23.8%)	
Nonbinary/other	4 (0.4%)	0 (0.0%)	2 (0.6%)	2 (0.3%)		3 (0.5%)	1 (0.2%)	
Prefer not to answer	8 (0.7%)	2 (1.8%)	3 (0.9%)	3 (0.5%)		7 (1.1%)	1 (0.2%)	
Race								
White	697 (72.4%)	65 (69.9%)	231 (74.3%)	401 (71.7%)	<0.0001	412 (73.8%)	281 (70.6%)	0.50
Black/African American	102 (10.6%)	10 (10.8%)	29 (9.3%)	63 (5.7%)		53 (9.5%)	48 (12.1%)	
Asian	58 (6.0%)	1 (1.1%)	25 (8.0%)	32 (5.7%)		37 (6.6%)	21 (5.3%)	
Native Hawaiian/Pacific Islander	7 (0.7%)	2 (2.2%)	1 (0.3%)	4 (0.7%)		2 (0.4%)	5 (1.3%)	
American Indian or Alaskan Native	8 (0.8%)	2 (2.2%)	0 (0.0%)	6 (1.1%)		5 (0.9%)	2 (0.5%)	
Multiracial	63 (6.5%)	9 (9.7%)	20 (6.4%)	34 (6.1%)		36 (6.5%)	26 (6.5%)	
Other	28 (2.9%)	4 (4.3%)	5 (1.6%)	19 (3.4%)		13 (2.3%)	15 (3.8%)	
Hispanic ethnicity								
No	871 (90.5%)	82 (88.2%)	283 (91.0%)	506 (90.5%)	0.65	510 (91.4%)	354 (88.9%)	0.53
Yes	92 (9.6%)	11 (11.8%)	28 (9.0%)	53 (9.5%)		48 (8.6%)	44 (11.1%)	
Household income, US \$								
≤24,999	175 (18.3%)	25 (27.5%)	63 (20.5%)	87 (15.7%)	0.04	101 (18.3%)	73 (18.5%)	0.80
25,000–49,999	190 (19.9%)	23 (25.3%)	57 (18.5%)	110 (19.8%)		115 (20.8%)	74 (18.7%)	
50,000–74,999	192 (20.1%)	20 (22.0%)	61 (19.8%)	111 (20.0%)		117 (21.2%)	73 (18.5%)	
75,000–99,999	122 (12.8%)	10 (11.0%)	45 (14.6%)	67 (12.1%)		69 (12.5%)	53 (13.4%)	
100,000–124,999	103 (10.8%)	4 (4.4%)	30 (9.7%)	69 (12.4%)		52 (9.4%)	50 (12.7%)	
125,000–149,999	61 (6.4%)	1 (1.1%)	23 (7.5%)	37 (6.7%)		36 (6.5%)	25 (6.3%)	
≥150,000	111 (11.6%)	8 (8.8%)	29 (9.4%)	74 (13.3%)		63 (11.4%)	47 (11.9%)	
Insurance								
None	41 (4.3%)	8 (8.8%)	15 (4.9%)	18 (3.2%)	0.08	27 (4.9%)	14 (3.5%)	0.56
Employer-sponsored coverage	550 (57.7%)	46 (50.6%)	168 (54.6%)	336 (60.5%)		310 (56.1%)	235 (59.5%)	
Medicaid or state assistance	93 (9.8%)	10 (11.0%)	32 (10.4%)	51 (9.2%)		53 (9.6%)	40 (10.1%)	
Medicare	160 (16.8%)	11 (12.1%)	58 (18.8%)	91 (16.4%)		93 (16.8%)	66 (16.7%)	
Policy purchased on state/federal health exchange	37 (3.9%)	4 (4.4%)	16 (5.2%)	17 (3.1%)		22 (4.0%)	15 (3.8%)	
Policy purchased on the commercial market	29 (3.0%)	3 (3.3%)	7 (2.3%)	19 (3.4%)		21 (3.8%)	8 (2.0%)	

(Continued on next page)

**TABLE 1.** (Continued)

Variable—Freq (%)	Overall	No. Treatments			P	Step-up Therapy		
		0	1–2	≥3		No	Yes	P
Tricare or VA benefit	22 (2.3%)	3 (3.3%)	7 (2.3%)	12 (2.2%)		10 (1.8%)	12 (3.0%)	
Unsure	22 (2.3%)	6 (6.6%)	5 (1.6%)	11 (2.0%)		17 (3.1%)	5 (1.3%)	
Geographical setting								
Urban	229 (23.8%)	20 (21.5%)	69 (22.3%)	140 (25.1%)	0.08	107 (19.2%)	80 (20.2%)	0.60
Suburban	544 (56.6%)	47 (50.5%)	191 (61.6%)	306 (54.8%)		310 (55.6%)	230 (58.1%)	
Rural	188 (19.6%)	26 (28.0%)	50 (16.1%)	112 (20.1%)		141 (25.3%)	86 (21.7%)	
Region								
New England	65 (6.8%)	2 (2.2%)	28 (9.0%)	35 (6.3%)	0.18	35 (6.3%)	30 (7.5%)	0.87
Mid-Atlantic	128 (13.3%)	17 (18.3%)	36 (11.6%)	75 (13.4%)		82 (14.7%)	45 (11.3%)	
East North Central	145 (15.1%)	14 (15.1%)	41 (13.2%)	90 (16.1%)		87 (15.6%)	57 (14.3%)	
West North Central	53 (5.5%)	9 (9.7%)	17 (5.5%)	27 (4.8%)		31 (5.6%)	22 (5.5%)	
South Atlantic	185 (19.2%)	17 (18.3%)	55 (17.7%)	113 (20.2%)		103 (18.5%)	81 (20.4%)	
East South Central	61 (6.3%)	4 (4.3%)	20 (6.4%)	37 (6.6%)		33 (5.9%)	28 (7.0%)	
West South Central	90 (9.4%)	5 (5.4%)	36 (11.6%)	49 (8.8%)		51 (9.1%)	37 (9.3%)	
Mountain	74 (7.7%)	11 (11.8%)	22 (7.1%)	41 (7.3%)		44 (7.9%)	29 (7.3%)	
Pacific	162 (16.8%)	14 (15.1%)	56 (18.0%)	92 (16.5%)		92 (16.5%)	69 (17.3%)	

## OOP Expenses

### Current Medical and Therapeutic Approaches

When asked about OOP expenses for HCPs and prescriptions in the past 30 days (incurred on top of insurance premiums), 68.7% (frequency: 686) of the respondents reported OOP expenses for co-pays and/or deductibles for doctor or other HCP office visits (excluding mental health providers), with 31.2% (311) spending more than US \$100 (Fig. 1A). The majority of respondents also reported OOP expenses for prescription medication co-pays covered by insurance (64.3% [635]), with 33.9% (335) spending greater than US \$50 and nearly half (48.6% [468]) spending money on prescription medications not covered by insurance. Most respondents did not report OOP expense for emergency room/urgent care visits (86.7% [804]), hospitalization (97.5% [896]), outpatient phototherapy (95.4% [875]), outpatient laboratory testing (76.8% [716]), and mental health services or other behavioral counseling (85.6% [790]).

### Nonprescription Health-Related Products

Nearly all respondents reported OOP expenses for nonprescription OTC moisturizers/emollients (94.3% [934]) in the past 30 days, with most spending up to US \$50 (52.8% [523]) (Fig. 1B). Similarly, the majority of respondents spent up to US \$50 on OTC hydrocortisone and other agents for itch relief (53.5% [507]), allergy medications (eg, antihistamines) (56.0% [533]), and hygiene/bathing products (eg, specific hair care products, soaps, and bath additives, such as bleach) (57.2% [555]). Similar numbers of respondents also reported OOP expenditures on pain relief (49.3% [449]), bandages or other dressings (48.4% [446]), dietary supplements (52.2% [491]), and sleep aids (excluding antihistamines) (37.0% [336]).

### Complementary Approaches and Care Coordination

Approximately 1 in 5 respondents (19.0% [180]) reported expenditures for alternative OTC medicines (eg, traditional Chinese

medicine, ayurvedic medicine, naturopathic medicine, and/or homeopathic medicine), and 15.9% (150) reported expenditures for adjunctive therapies (eg, acupuncture, yoga, or other relaxation approaches (Fig. 1C). Many respondents reported spending up to US \$100 on specialized cleaning products (ie, laundry, household cleaners) (63.3% [620]) and specialized clothing (eg, pajamas, bedding) (32.6% [313]). Although nearly half of all respondents spent money on transportation/parking to obtain medical care or prescription medicine (46.8% [444]), most had no expenditures for childcare services while obtaining medical care (94.8% [872]).

### Total Costs

A similar number of respondents reported that their OOP expenses over the past 30 days were either the same (42.5% [410]) or higher (40.7% [393]) than their average monthly OOP expenses (Fig. 2A). The median annual estimated OOP expense due to AD was US \$600 (range, US \$0–\$200,000). Forty-two percent (364) of the respondents reported expenditures in excess of US \$1000, and 8.5% (74) reported expenditures in excess of US \$5000 (Fig. 2B).

### Polypharmacy and Step-up Therapy

Most respondents reported currently using 3 or more prescription therapies (% prevalence [frequency], 57.5% [617]), with 32.1% (344) using 1 to 2 therapies and 10.4% (112) reporting no prescriptions. Those with more prescription therapies were more likely to be White or Asian and have increasing household income, increased disease severity, reduced control, increased number of flare days per month, allergic and infectious comorbidities, and increased number of HCP visits ( $P \leq 0.05$  for all) (Tables 1 and 2). Step-up therapy (ie, systemic therapy including injectable, oral, or phototherapy) was used in 41.0% (442) of the respondents. Those requiring step-up therapy were more likely to have increased disease

**TABLE 2. Respondent Disease Burden**

Variable—Freq (%)	Overall	No. Treatments			P	Step-up Therapy		
		0	1–2	≥3		No	Yes	P
Current atopic dermatitis severity								
Clear	29 (2.6%)	5 (4.5%)	10 (2.9%)	11 (1.8%)	<0.0001	18 (2.8%)	10 (2.3%)	<0.0001
Mild	238 (21.3%)	39 (34.8%)	103 (29.9%)	89 (14.4%)		159 (25.0%)	69 (15.6%)	
Moderate	531 (47.5%)	53 (47.3%)	150 (43.6%)	305 (49.4%)		318 (50.1%)	192 (43.4%)	
Severe	296 (26.5%)	12 (10.7%)	73 (21.2%)	200 (32.4%)		126 (19.8%)	163 (36.9%)	
Current atopic dermatitis control								
Minimally controlled	259 (23.2%)	21 (18.8%)	81 (23.6%)	146 (23.7%)	0.03	157 (24.7%)	93 (21.0%)	0.21
Somewhat controlled	448 (40.1%)	41 (36.6%)	126 (36.6%)	264 (42.8%)		256 (40.3%)	179 (40.5%)	
Moderately well controlled	300 (26.8%)	29 (25.9%)	99 (28.8%)	161 (26.1%)		166 (26.1%)	119 (26.9%)	
Very well controlled	102 (9.1%)	19 (17.0%)	34 (9.9%)	43 (7.0%)		49 (7.7%)	49 (11.1%)	
No. flare days in past 30 d								
0	44 (4.0%)	7 (6.3%)	17 (4.9%)	17 (2.8%)	0.05	22 (3.5%)	20 (4.5%)	0.62
1–3	271 (24.4%)	33 (29.5%)	93 (27.0%)	133 (21.6%)		155 (24.4%)	105 (23.8%)	
4–7	206 (18.6%)	19 (17.0%)	69 (20.1%)	114 (18.5%)		126 (19.8%)	74 (16.8%)	
8–10	151 (13.6%)	11 (9.8%)	47 (13.7%)	91 (14.8%)		84 (13.2%)	65 (14.7%)	
≥11	437 (39.4%)	42 (37.5%)	118 (34.3%)	261 (42.4%)		248 (39.1%)	177 (40.1%)	
Comorbidities								
Asthma	382 (34.5%)	32 (28.8%)	105 (30.6%)	234 (38.1%)	0.02	203 (32.0%)	171 (38.7%)	0.03
Allergic rhinitis	557 (50.4%)	48 (43.2%)	158 (46.1%)	335 (54.5%)	0.03	305 (48.0%)	242 (54.8%)	0.04
Food allergy	426 (38.5%)	30 (27.0%)	104 (30.3%)	278 (45.2%)	<0.0001	223 (35.1%)	192 (43.4%)	0.01
Frequent/persistent skin infections	210 (19.0%)	10 (9.0%)	31 (9.0%)	164 (25.7%)	<0.0001	79 (12.4%)	125 (28.3%)	<0.0001
Anxiety and/or depression	404 (36.5%)	33 (29.7%)	122 (35.6%)	240 (39.0%)	0.14	211 (33.2%)	185 (41.9%)	0.009
HCP visits in past year								
0	113 (10.6%)	56 (50.0%)	40 (11.7%)	17 (2.8%)	<0.0001	100 (15.9%)	12 (2.8%)	<0.0001
1–2	435 (40.6%)	44 (39.3%)	219 (63.9%)	172 (27.9%)		295 (46.9%)	135 (31.2%)	
3–4	284 (26.5%)	9 (8.0%)	61 (17.8%)	214 (34.7%)		141 (22.4%)	142 (32.8%)	
≥5	239 (22.4%)	3 (2.7%)	23 (6.7%)	213 (34.6%)		93 (14.8%)	144 (33.3%)	

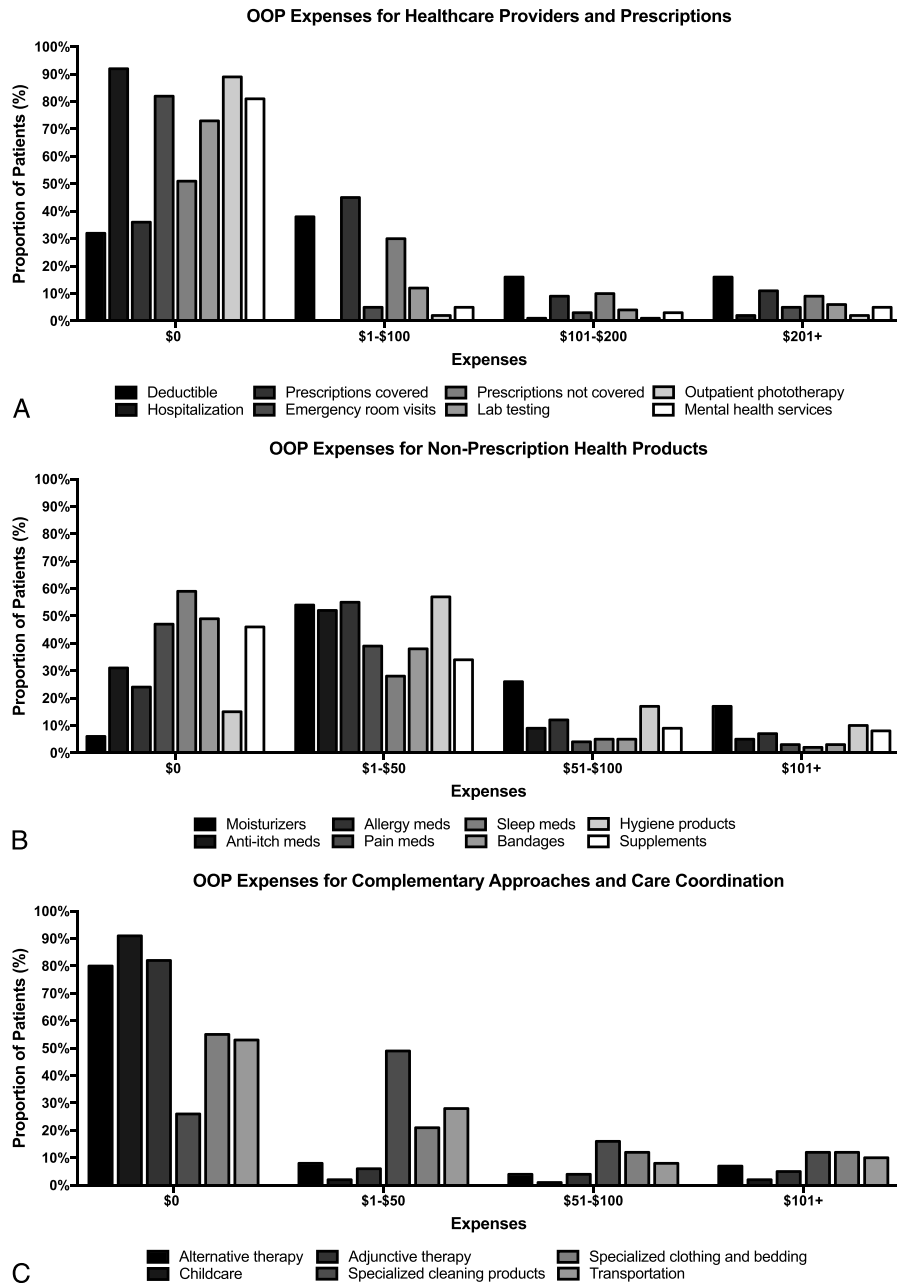
severity; allergic, infectious, and mental health comorbidities; and increased number of HCP visits ( $P < 0.04$  for all).

## DISCUSSION

Using a survey-based approach to highlight the perspective of AD patients and caregivers in the United States, we found a wide array of previously unreported OOP expenses in medical, non-medical, and supportive health care categories (Fig. 2C). Most respondents reported OOP expenses for co-pays and/or deductibles for office visits and prescription medication, moisturizers, OTC itch relievers, allergy medications, hygiene products, dietary supplements, and specialized cleaning supplies; nearly half reported OOP costs for prescription medications not covered by insurance, analgesics, dressings, and transportation/parking; many others reported OOP expenditures for sleep aids, alternative or adjunctive therapies, and specialized clothing. Most individuals had equivalent or higher OOP expenses in the past month when compared with average monthly OOP expenses for AD care, and many reported yearly OOP costs greater than US \$1000. A majority of individuals had recently used or were concurrently using at least 3 prescription therapies, with almost half requiring step-up therapy. Together, these results show a significant OOP

financial burden for AD, reflecting the real-life efforts of patients to better manage their disease.

The majority patients and caregivers reported an OOP expense for an HCP visit for AD in the past 30 days, and nearly all (89.4%) had at least 1 office visit in the last year. In contrast, OOP expenditures for emergency department visits and inpatient hospitalizations were relatively lower among respondents. This is in line with health care utilization findings from a recent US population-based study that showed that the median number of AD-related HCP visits for individuals with AD was approximately 1 per year, and the proportions of AD patients reporting at least 1 urgent care, emergency department visit, and inpatient hospitalization were 8.2%, 9.6%, and 6.7%, respectively.<sup>9</sup> The OOP costs for mental health services were quite low among respondents, which was surprising given the strong association between AD and mental health disorders, including depression, anxiety, and psychological distress.<sup>7,20,21</sup> The mental health burden of AD is underappreciated, and a substantial proportion of individuals with AD with mental health symptoms go undiagnosed.<sup>20</sup> Thus, only a subset of AD patients with mental health comorbidities may seek mental health care. In addition, AD patients with mental health comorbidities may only seek out psychological or psychiatric care if it is well covered by their insurance. Thus, it is important that HCPs, who manage AD regularly, screen for mental health symptoms. Other contributing



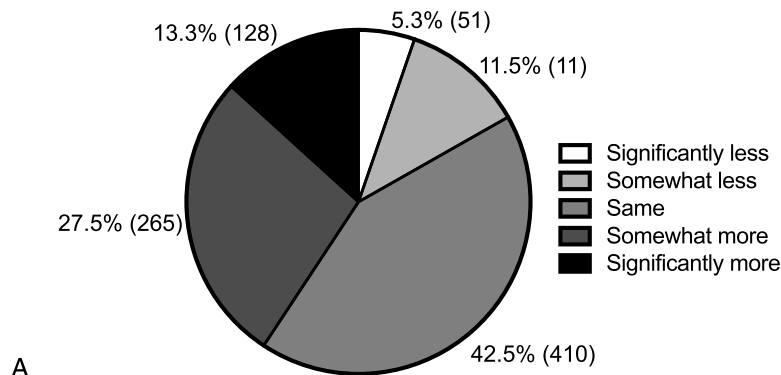
**Figure 1.** Breakdown of out-of-pocket (OOP) expenses. A, Out-of-pocket expenses for HCPs and prescriptions. B, Out-of-pocket expenses for non-prescription health products. C, Out-of-pocket expenses for complementary approaches and care coordination.

factors to assess in future studies might include stigma for seeking psychiatric care, impaired access because of lack of referral from the primary provider, and cost considerations (eg, unwilling to pay, too expensive).

The most common OOP expenses for OTC health products, and for any therapeutic approach in general, were emollients/moisturizers and hygiene/bathing products. This reflects the results of a similar survey-based study in France, which showed that these were the 2 most commonly used products associated with OOP cost among AD patients (74.4% and 65.2%, respectively).<sup>22</sup> Neither of these categories is routinely reimbursed by health insurance, because they are

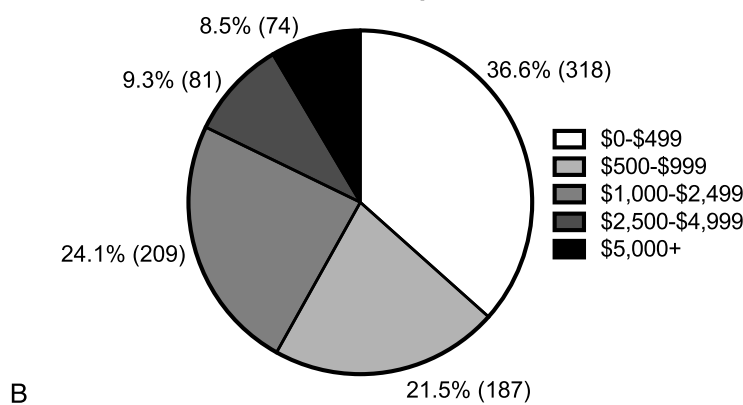
seen as patient comfort rather than direct medical treatment. However, optimization of moisturization and bathing are universally seen as first-line nonpharmacologic approaches for managing AD.<sup>23</sup> Emollients in particular are critical for increasing skin hydration and addressing the dysfunctional epidermal barrier underlying AD, thereby reducing pruritus, xerosis, erythema, lichenification, and fissuring. However, commonly used moisturizers vary significantly in cost, as well as potential allergenicity and irritancy, without a clear correlation to efficacy.<sup>24</sup> More than 60% of the respondents also reported OOP expenditures for specialized laundry/household cleaning

### Total OOP Expense in Past 30 Days vs. Monthly Average

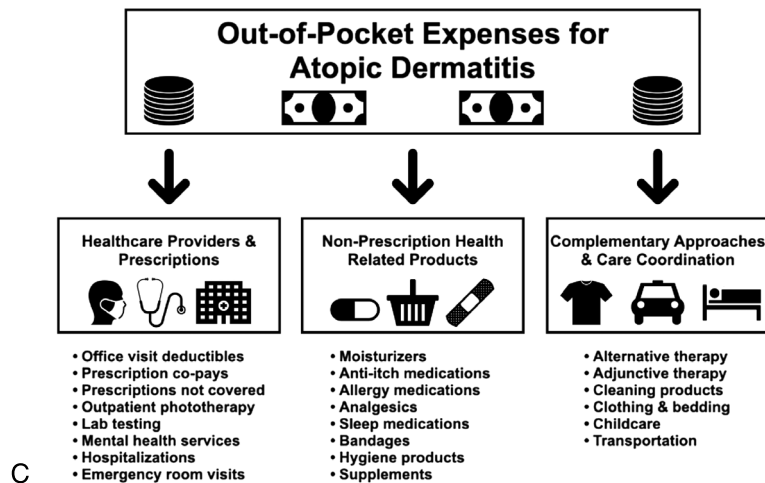


A

### Annual OOP Expense



B



C

**Figure 2.** Total OOP expenses. A, Total OOP expense in past 30 days versus monthly average. B, Annual OOP expense. C, Summary of OOP expenses for AD. AD, atopic dermatitis; OOP, out-of-pocket.

products and specialized clothing. Although some patients report better AD control when avoiding certain chemical and mechanical irritants, well-controlled studies to broadly support these types of costly environmental modification are lacking.<sup>25</sup> Ultimately, given that personal preferences dictate the use of many of these products, HCPs should prioritize patient education, willingness for use, and adherence in the context of affordability to help control OOP cost.

These data highlight significant OOP expenses for health-related categories that are not routinely recommended or discussed during standard AD care encounters. The majority of respondents reported expenditures for OTC dietary supplements and a sizeable proportion of money spent on alternative, nonwestern medical care or adjunctive approaches. Although there is some evidence to suggest a positive role for certain types of complementary and alternative

medicine (CAM) in improving the symptoms of AD, current data are largely insufficient to make widely applicable evidence-based recommendations.<sup>26,27</sup> Previous studies showed that CAM use in AD patients is not uncommon and is associated with a longer disease duration, increased severity, and history of multiple previous conventional treatments.<sup>28</sup> Our data highlight the real-life considerations of patients who struggle with controlling the symptoms of AD and use treatment approaches that may not be currently proven and/or recommended. Health care providers should make a renewed effort to understand the patient perspective (eg, motivations, expectations, benefits), review the most up-to-date evidence regarding CAM use, and assist in crafting a fiscally responsible care plan.

Reflecting the marked impairment in health-related quality of life, AD patients assume high OOP costs for disease management.<sup>29</sup> However, studies examining the total burden of OOP expenses for AD patients in the United States are scarce. A survey-based study of a large managed care organization in 1997 estimated the total OOP cost per patient year to be US \$314 (US \$500 in 2019), with medications and household products being the top categories of expenditure.<sup>30</sup> The total OOP cost for US AD patients was estimated to be US \$371–\$489 per person year in 2010 and 2012 (US \$435–\$573 in 2019) based on the results of the National Health Interview Survey, which did not include specific breakdown of OOP cost categories.<sup>12</sup> Although not directly comparable because of differences in insurance structure and health care costs, recent surveys of large European countries showed similar OOP expenses when converted to US dollars, with moisturizers and hygiene products occupying the top categories of expenditure.<sup>22,31</sup> Our data revealed a median annual cost of US \$600, with the most common areas of expenses for moisturizers, hygiene and household products, and deductibles for outpatient care and medications. This figure is likely more accurate than previous estimates given that our study was the first to directly survey AD patients and caregivers across the United States.

Atopic dermatitis is a highly heterogeneous disorder with variable severity, lesional distribution, symptoms, and disease course. Furthermore, AD patients also experience a chronic disease course punctuated by intermittent flares, which necessitate different treatment approaches. These features likely contribute to polypharmacy, complicated treatment regimens, and alternative treatments among patients with AD.<sup>32</sup> Our data demonstrate considerable prescription polypharmacy among AD patients, especially for those with increased severity, poorer control, increased HCP visits, and private or Medicare insurance. Many respondents reported OOP expenses for prescription medications regardless of insurance coverage. Atopic dermatitis patients are likely to benefit from simplification of the treatment regimen by deprescribing ineffective or redundant treatments<sup>33</sup> and transitioning to streamlined step-up therapy as warranted. Indeed, our data show much room for improvement in the use of step-up therapy among those with the highest disease burden (ie, increased severity, flares, and HCP visits). Additionally, most individuals also reported expenditures for OTC allergy, anti-itch, and pain medications. Although treatments

in these categories may have a legitimate role in managing symptoms and comorbidities associated with AD, the use of certain therapies (eg, oral antihistamines for chronic treatment of AD) may not be aligned with evidence-based guidelines and are likely to further increase polypharmacy and contribute to excessive OOP financial burden. Although combination treatment may be warranted in some cases, HCPs should be sensitive to treatment efficacy, patient safety, evidence-based recommendations, and OOP costs when considering the treatment plan.

Strengths of this study include a large cohort of AD patients and caregivers distributed across the United States assessing real-world, OOP expenses for necessary AD care. The inclusion of 22 unique categories of OOP expenses, including HCP office visits, prescription therapies, nonprescription products, complementary approaches, and care coordination, allowed for a detailed understanding and accurate estimate of the OOP financial burden. Limitations include the cross-sectional nature of this study and inability to assess longitudinal changes in costs, treatments, and health care utilization. Selection bias is possible, because this was an Internet-based survey administered to members of the National Eczema Association and not the US population at large, although the respondent demographics indicate a variety of individuals with different insurance status, household income, and disease severity spread fairly evenly throughout the country. Self-reporting of costs and utilization may not be as accurate as a claims-based approach; however, this is offset by the ability to gather data directly from patients and caregivers about disease severity and comprehensive OOP costs. Diagnosis of AD was confirmed by self-reporting, which was previously validated in other types of studies.<sup>34,35</sup> Future studies are necessary to confirm these findings and better understand associations of OOP costs and their impact on family finances. In addition, more studies incorporating patient-reported outcomes in cost analysis are needed to better understand predictors of OOP expenses.

In conclusion, OOP expenses for individuals with AD are broad and occupy a number of unique health care categories. Health care providers and patients should be cognizant of these costs and engage in shared decision making to create a treatment plan that minimizes financial burden.

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