

# THE SKIN I'M IN

## A NATIONAL REPORT OF THE PATIENT AND CAREGIVER EXPERIENCE WITH ATOPIC DERMATITIS



February 2018

## CONTENTS

---

<b>BACKGROUND</b> .....	1
<b>METHODS</b> .....	2
<b>RESULTS</b> .....	2
<b>Section I: Results from Individuals with Atopic Dermatitis</b> .....	3
i. Demographics .....	3
ii. Healthcare utilization en route to diagnosis.....	4
iii. Atopic Dermatitis diagnosis .....	5
iv. Misdiagnosis.....	6
v. Current healthcare team for management of Atopic Dermatitis .....	6
vi. Severity of Atopic Dermatitis .....	7
vii. Satisfaction with the healthcare system .....	9
viii. Complications and comorbidities.....	9
ix. Searching for an effective treatment .....	10
x. Treatment effectiveness .....	10
xi. Treatment side effects/adverse events .....	13
xii. Cost of treatments .....	16
xiii. Impact of cost.....	16
xiv. Lifestyle behaviours to prevent and control symptoms .....	17
xv. Impact of Atopic Dermatitis .....	17
xvi. Knowledge and patient needs.....	19
<b>Section II: Results from Caregivers of Individuals with Atopic Dermatitis</b> .....	22
i. Demographics .....	22
ii. Healthcare utilization en route to diagnosis.....	23
iii. Atopic Dermatitis diagnosis .....	24
iv. Misdiagnosis.....	25
v. Current healthcare team for management of Atopic Dermatitis .....	25
vi. Severity of Atopic Dermatitis .....	26
vii. Satisfaction with the healthcare system .....	27
viii. Complications and comorbidities .....	27
ix. Searching for an effective treatment .....	28
x. Treatment effectiveness .....	28
xi. Treatment side effects/adverse events .....	30
xii. Cost of treatments .....	32
xiii. Impact of cost.....	32
xiv. Lifestyle behaviours to prevent and control symptoms .....	33
xv. Impact of Atopic Dermatitis .....	34

xvi. Knowledge and patient needs.....	34
<b>DISCUSSION AND RECOMMENDATIONS .....</b>	<b>38</b>
<b>ACKNOWLEDGEMENTS .....</b>	<b>41</b>
<b>REFERENCES.....</b>	<b>41</b>

## EXECUTIVE SUMMARY

Atopic dermatitis is a chronic, inflammatory skin condition, affecting up to 17% of individuals in Canada. Mild atopic dermatitis is characterized by dry, red and itchy skin while those with moderate to severe atopic dermatitis experience thickened skin, and lesions that ooze and bleed during flare-ups.

To better understand how individuals with atopic dermatitis and those who act as their caregivers are affected by this condition, the Canadian Skin Patient Alliance, a national non-profit organization dedicated to advocate, educate and support Canadians living with skin diseases, conditions and traumas, developed the Atopic Dermatitis Patient Experience (ADPE) Survey. In November 2017, the survey was disseminated through social media strategies designed to target those in Canada with atopic dermatitis, and their caregivers. A small sample of responses from US and international patients and caregivers were included as many experiences and needs are likely to be universal.

### SURVEY HIGHLIGHTS

- 194 surveys in total - 132 from individuals with atopic dermatitis and 62 from caregivers

Of individuals with atopic dermatitis:

- 92% from Canada, 6% from United States and 2% from elsewhere
- 78% female
- Average age: 42 years
- Average age at diagnosis: 24 years
- 45% had mild atopic dermatitis and 55% had moderate/severe atopic dermatitis

Of caregivers:

- 87% from Canada, 13% from United States
- 79% female
- Average age: 36 years
- Average age at diagnosis of individuals receiving care: 5 months
- 32% had mild atopic dermatitis and 68% had moderate/severe atopic dermatitis

Most individuals were diagnosed within 30 days from their first symptom, indicating strong disease awareness among healthcare providers. Atopic dermatitis was most commonly diagnosed by family physicians/pediatricians, followed by dermatologists.

Respondents are currently using various non-prescription methods of controlling and preventing symptoms including skin care maintenance such as specific bathing routines and

moisturizer application, natural and herbal remedies, and acupuncture. Those with atopic dermatitis engage in numerous behaviours and lifestyle changes such as avoiding certain foods, refraining from hot baths and wearing long sleeves to prevent the symptoms or reduce exacerbations.

Among prescription treatments, topical steroids are most commonly used by both those with mild and moderate/severe atopic dermatitis. They were described as the most effective treatment, but many patients and parents of children with atopic dermatitis commented on their concerns regarding the risks of long-term use, including skin thinning and spider veins.

The impact of atopic dermatitis varies considerably depending on severity. Those with mild atopic dermatitis reported minor impact overall, and 28% are not currently using medicated treatment. However, those with moderate/severe atopic dermatitis reported an average of 2.3 nights of interrupted sleep monthly; 48% reported a poor effect on their work/school life and 68% reported a negative impact on their personal life. Caregivers are also impacted; 68% indicated that this condition negatively affects their lives.

Atopic dermatitis appears to be closely associated with other comorbidities, with over half of respondents suffering from seasonal allergies, and one-third from food allergies. This condition also renders individuals more susceptible to certain complications: 38% reported a past episode of oozing lesions, possibly due to a *Staphylococcus aureus* infection.

The majority of patients received information about atopic dermatitis from physicians or atopic dermatitis -related websites. They are generally satisfied with their knowledge of the condition but a sizable proportion would like more information, especially on non-medical means of controlling and preventing symptoms. Those with atopic dermatitis struggle with hiding symptoms and managing their depression and anxiety.

While our results corroborate many of the findings of the Eczema Society of Canada (ESC)'s 2017 survey on the quality of life of patients with atopic dermatitis, our respondents reported that their condition had a less severe impact for certain domains. This may be attributed to the ESC survey being completed by a larger proportion of patients with severe atopic dermatitis, compared to our survey.

Based on our findings, we have the following recommendations to improve the quality of life for patients living with atopic dermatitis:

- Develop educational materials to ensure that those newly diagnosed with atopic dermatitis have valuable information on prevention and control through both prescription and non-prescription means
- Provide funding for new treatments that show promise in managing symptoms
- Increase understanding of the impact of skin diseases, such as atopic dermatitis, on mental health, and create services to address related patient and caregiver needs

- Empower patients and caregivers with the tools and mechanisms to support their journey and navigate the healthcare system once diagnosed
- Provide sufficient training for family physicians and pharmacists on available medications for atopic dermatitis, including dosing and side effects

This report adds to the body of knowledge on the patient journey of individuals with atopic dermatitis and those who act as their caregivers. We hope that it will help to further promote progress around the awareness and management of this condition, and the care of those who suffer from it.

## BACKGROUND

**Atopic Dermatitis** is a chronic and highly prevalent dermatological condition, with symptoms ranging from dry, itchy red skin to repeated flares of oozing, crusted rashes.<sup>1-3</sup> As the most common type of eczema, it is estimated that up to 17% of Canadians suffer from atopic dermatitis at some point in their lives.<sup>4</sup> Initial symptoms include inflamed skin behind the knees, on the inside of elbows and on the face, neck and hands.<sup>5</sup> Atopic dermatitis is classified into mild, moderate and severe forms representing 45%, 45% and 10% of all cases respectively, and defined by frequency of itching, amount of skin affected, and presence of skin thickening and cracking.<sup>5,6</sup>

*“People often underestimate this disease but it is all consuming and so hard to manage. Sometimes I can’t even think straight because I’m so itchy. I have to work, be a mom, and function all while feeling so irritable due to lack of sleep and itchy skin.”*

Atopic dermatitis has the potential to negatively impact a patient’s life, impeding their ability to conduct daily activities with comfort and ease, and leading to concern over the next flare-up during periods of remission.<sup>1-3</sup> Additionally, those afflicted are at increased risk of developing asthma and allergies.<sup>2</sup>

A recent Eczema Society of Canada (ESC) survey of 1,035 Canadians with moderate to severe atopic dermatitis and caregivers to children with atopic dermatitis found that the healthcare journey often involves long waits for specialist appointments, with 69% of respondents having waited more than 3 months to see a dermatologist for treatment.<sup>7</sup> Survey results also demonstrated that patients visit multiple doctors for care, as 28% of respondents have seen more than three different doctors in the past two years to manage atopic dermatitis.<sup>7</sup>

In order to further explore the patient experience for those with mild, moderate and severe atopic dermatitis, including out-of-pocket costs, and patient needs with respect to their disease, the Canadian Skin Patient Alliance (CSPA) conducted a survey of those with atopic dermatitis, as well as individuals who act as caregivers for those with this condition. The focus of this research was on the patient experience from diagnosis and beyond, including path to diagnosis, symptom control, experience with treatments, healthcare utilization, patient needs, and impact on quality of life.

The findings of this study provide new knowledge on atopic dermatitis care in Canada, and will inform future research and policy to improve the patient experience for those suffering from this condition.

## METHODS

The CSPA developed the Atopic Dermatitis Patient Experience (ADPE) Survey, which was then reviewed for clarity and comprehensiveness by a Canadian dermatologist and members of the public.

### Survey eligibility criteria

- Residing in Canada
- Diagnosed with atopic dermatitis by a healthcare provider or acting as a caregiver to an individual with this condition

The survey was created in Survey Monkey (<https://www.surveymonkey.net/>) and designed to be completed within 20 minutes.

### ADPE Survey dissemination

We disseminated the electronic ADPE Survey link through various means to access a large cross-section of eligible potential respondents:

- CSPA's website/Twitter/Facebook
- Patient Commando's Twitter/Facebook
- Facebook pages of Atopic Dermatitis patient groups
- Facebook pages of Motherhood groups
- Canadian patient panel

The ADPE Survey was open from November 3<sup>rd</sup> to November 24<sup>th</sup>, 2017.

## RESULTS

In total, surveys were received from 194 eligible respondents, comprising 132 individuals with atopic dermatitis and 62 caregivers. Results from each group are presented separately in the following sections.

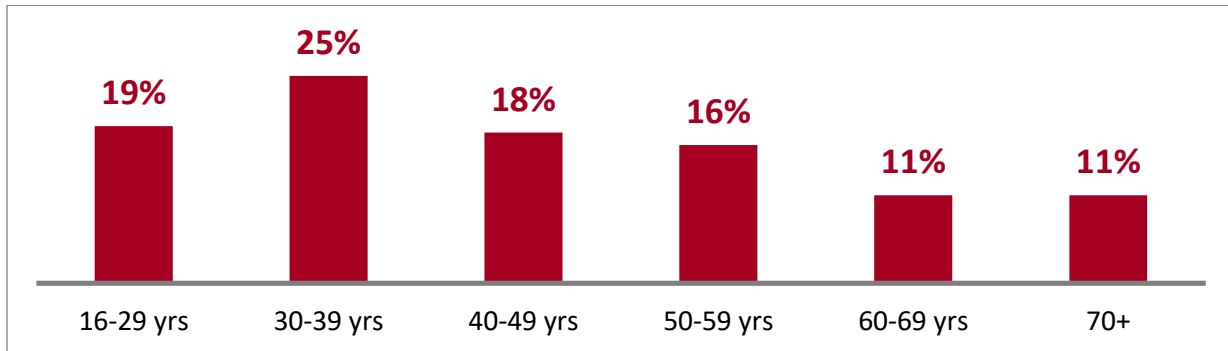
*“Having this condition has had a tremendous impact on my life. I don't sleep and I have trouble completing my daily activities without feeling debilitated by the itch and burning of my skin.”*



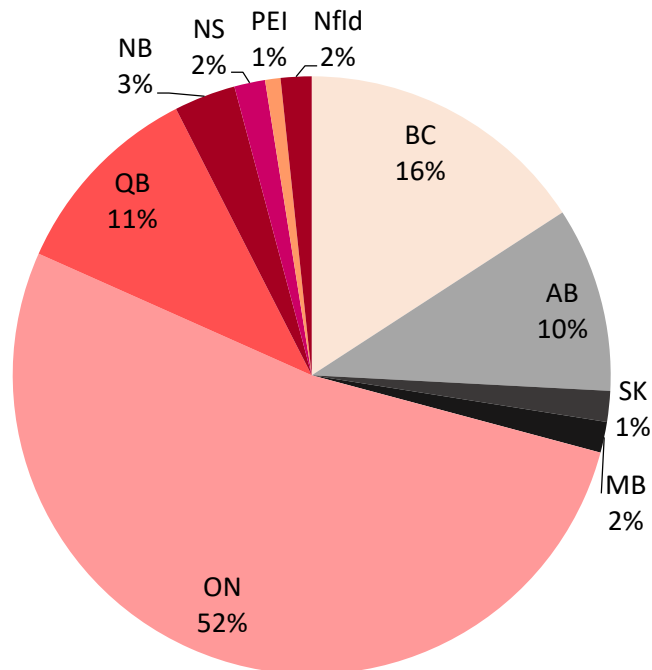
## Section I: Results from Adults with Atopic Dermatitis

### i. DEMOGRAPHICS

Of the 132 eligible respondents, 78% were female, and the average age was 42 years with a range of 18 to 92 years.



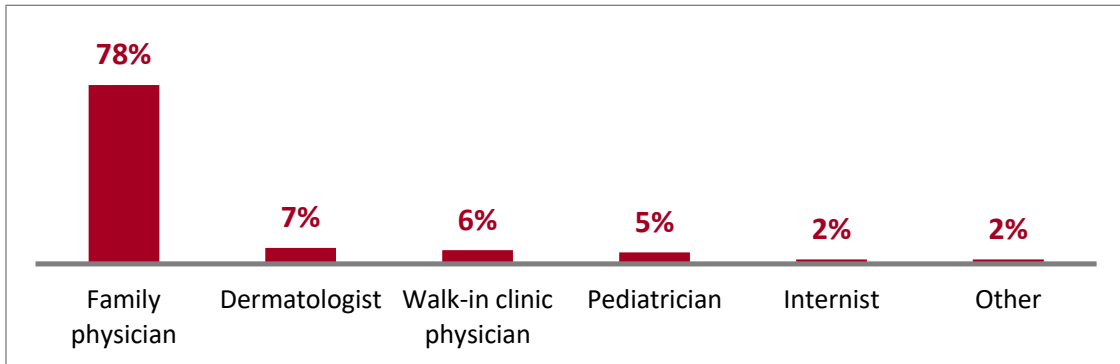
Of all respondents, 120 were from Canada (92%), with more than half residing in Ontario. We also had eight respondents from the U.S., and four from other countries; we included these in our results.



ii. HEALTHCARE UTILIZATION EN ROUTE TO DIAGNOSIS

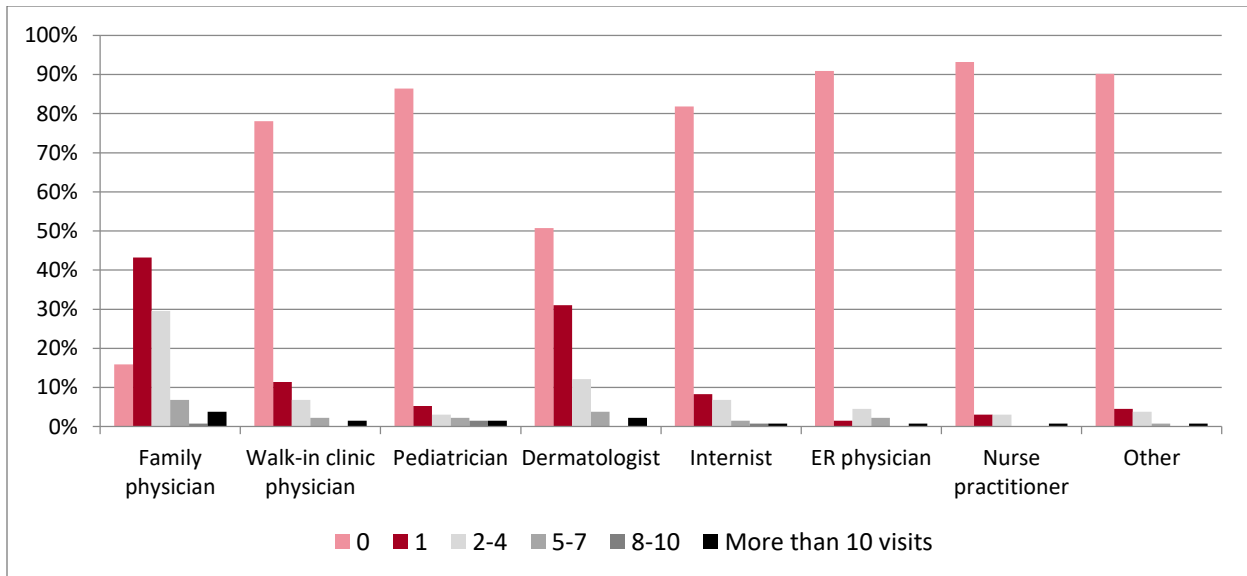
For 83% of respondents, the first HCP they saw for symptoms of atopic dermatitis was their family physician or pediatrician.

- 9% visited a specialist
- 2% of respondents consulted with “other” HCPs, including acupuncturists, and friends and family with medical backgrounds



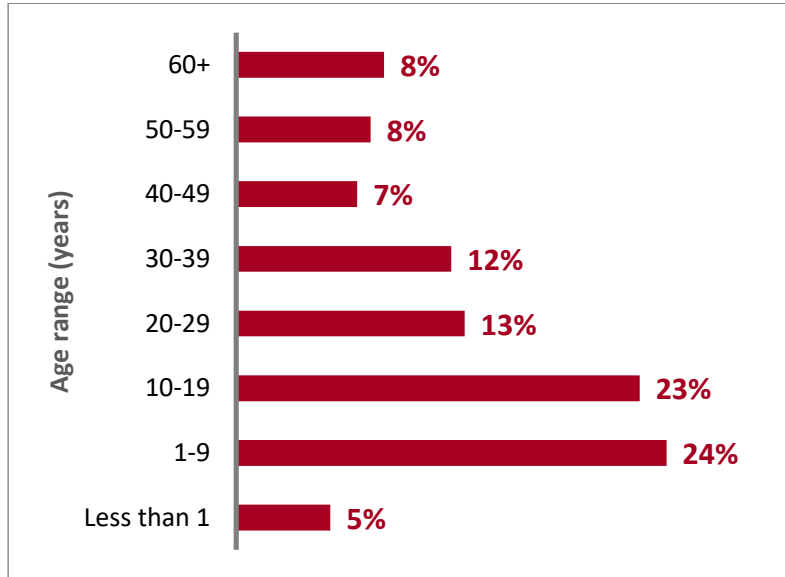
In seeking a diagnosis, 41% saw a family physician at least twice, and 4% did so at least 10 times.

- 18% visited an internist at least once
- 8% made two or more visits to the ER
- Nearly 10% sought care from other specialists, including endocrinologists, ophthalmologists and naturopathic doctors

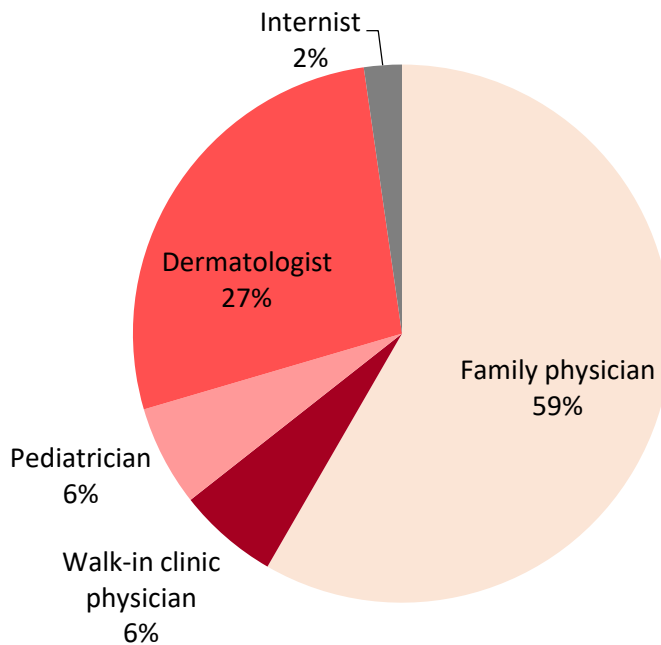


iii. **ATOPIC DERMATITIS DIAGNOSIS**

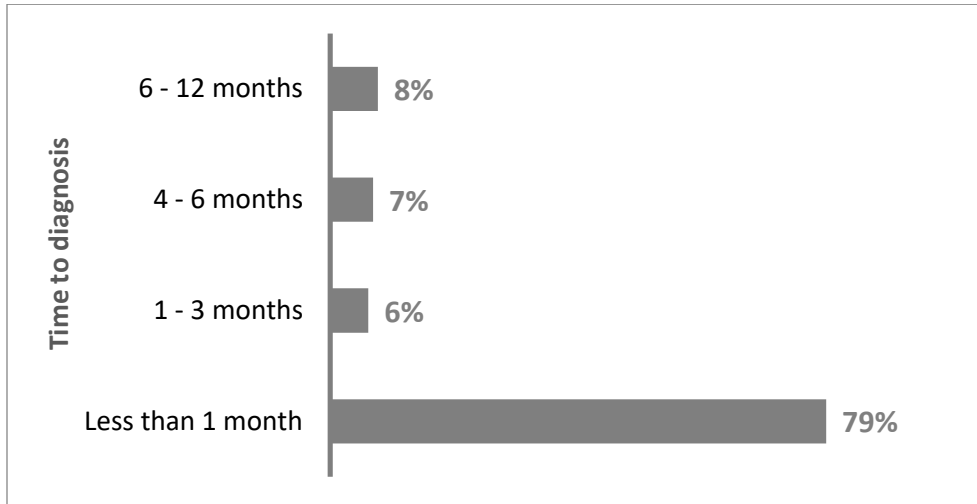
The average age of diagnosis was 24 years, varying from less than 1 year old to 75 years old. More than half of the respondents were diagnosed when they were less than 20 years old.



The majority of respondents (59%) were diagnosed by their family physician, while more than one-quarter received a diagnosis from their dermatologist.

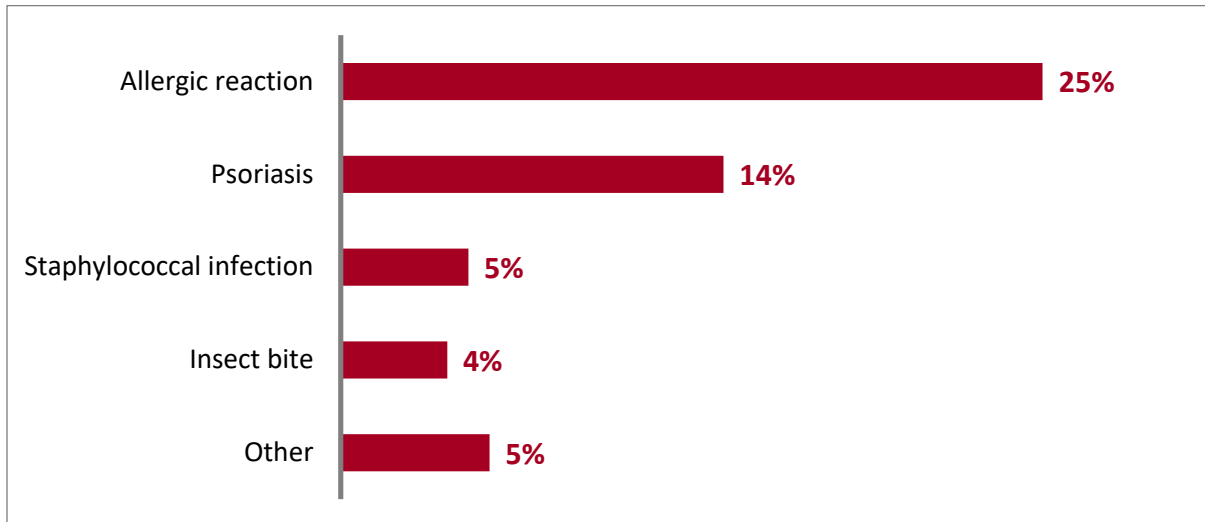


Individuals were diagnosed fairly quickly with 79% waiting less than 30 days between experiencing their first symptom and being told they have atopic dermatitis.



#### iv. MISDIAGNOSES

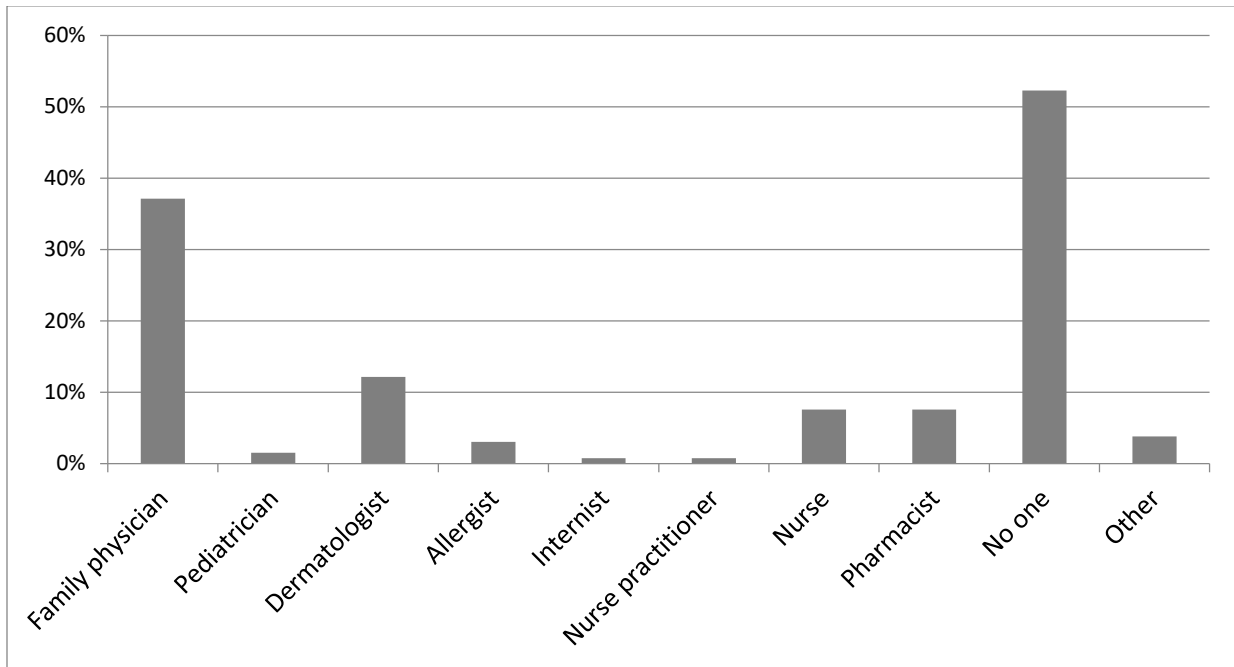
Prior to being diagnosed with atopic dermatitis, 36% of respondents received at least one misdiagnosis, most commonly “allergic reaction”. Five percent indicated that they were given a diagnosis that was not listed: *melanoma*, *herpes*, *acne*, *fungal infection* and *pilaris vulgaris*.



#### v. CURRENT HEALTHCARE TEAM FOR MANAGEMENT OF ATOPIC DERMATITIS

- 52% report that they care for their condition themselves
- Those who feel that they have HCP support for their symptoms commonly list their family physician as a member of their healthcare team, followed by their dermatologist

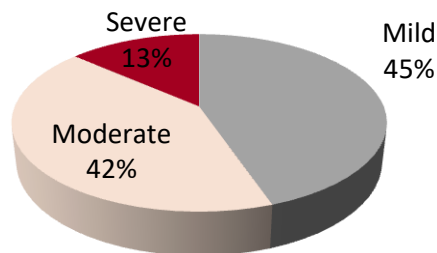
- A small percentage include other HCPs including naturopaths and providers at their local walk-in clinic, as part of their care team



#### vi. SEVERITY OF ATOPIC DERMATITIS

Nearly half of the respondents reported that they had mild AD, while the remaining indicated that they suffered from moderate/severe atopic dermatitis. This characterization may have been based on their physician’s diagnosis or self-evaluation.

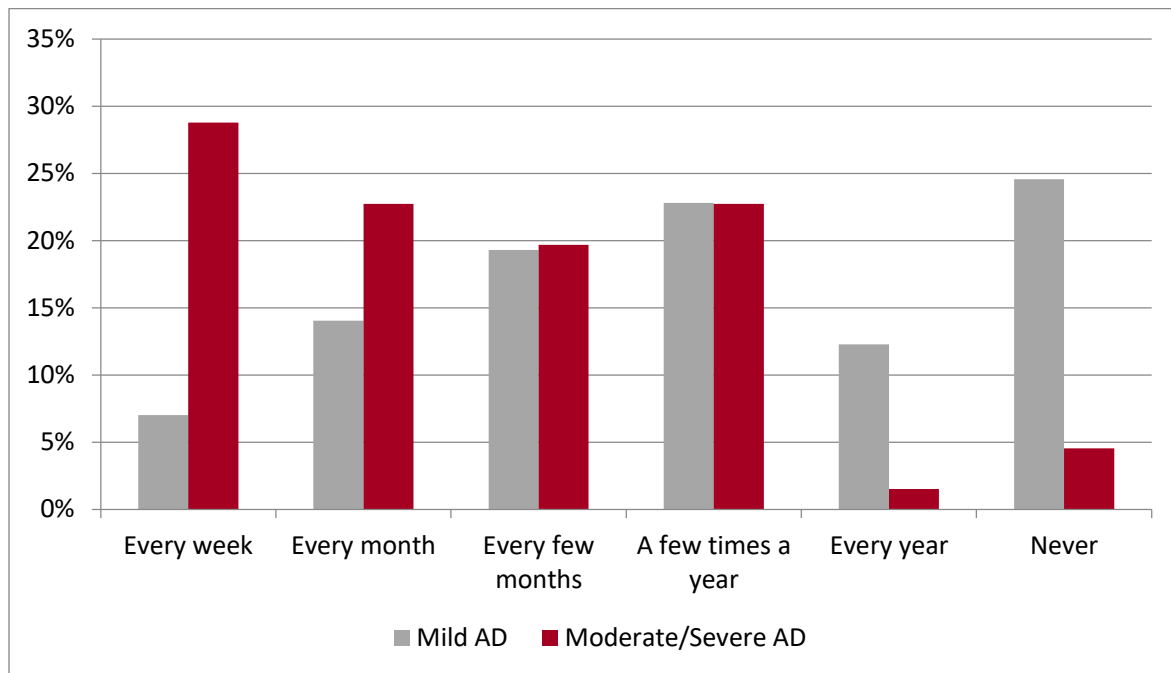
*“Having chronic moderate to severe AD is like having chicken pox 24 hours a day, 7 days a week.”*



Compared to those with a mild form of the condition, respondents with moderate/severe atopic dermatitis are more likely to describe their condition as chronic rather than as flare-ups between symptom-free periods.

	MILD ATOPIC DERMATITIS	MODERATE/SEVERE ATOPIC DERMATITIS
<b>Chronic</b>	12%	52%
<b>Flare-ups</b>	88%	48%

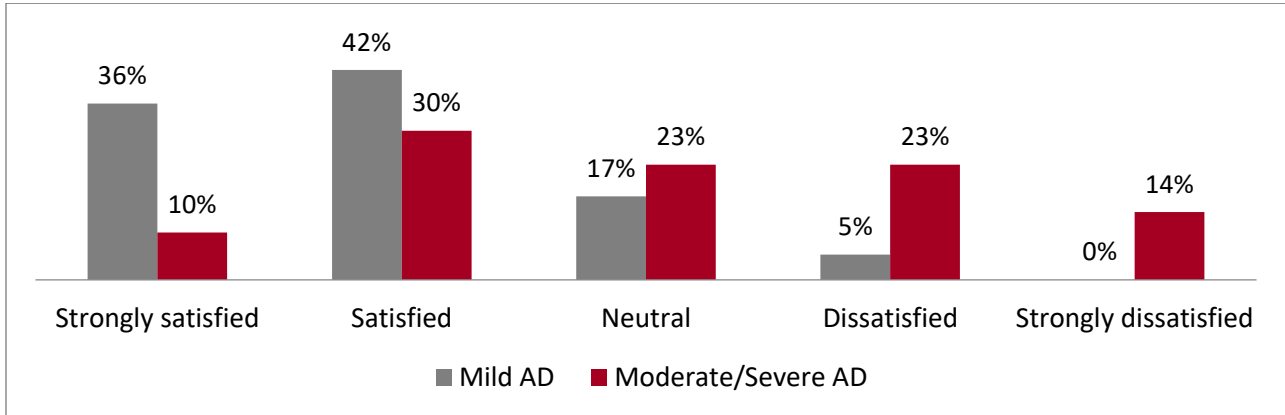
Nearly half of those with moderate/severe atopic dermatitis experience flares at least monthly. Those with mild atopic dermatitis are less likely to experience flares but 19% of those who do suffer them on a weekly or monthly basis.



*When my flare-ups are bad, my skin oozes and itches and blisters, preventing me from working.*

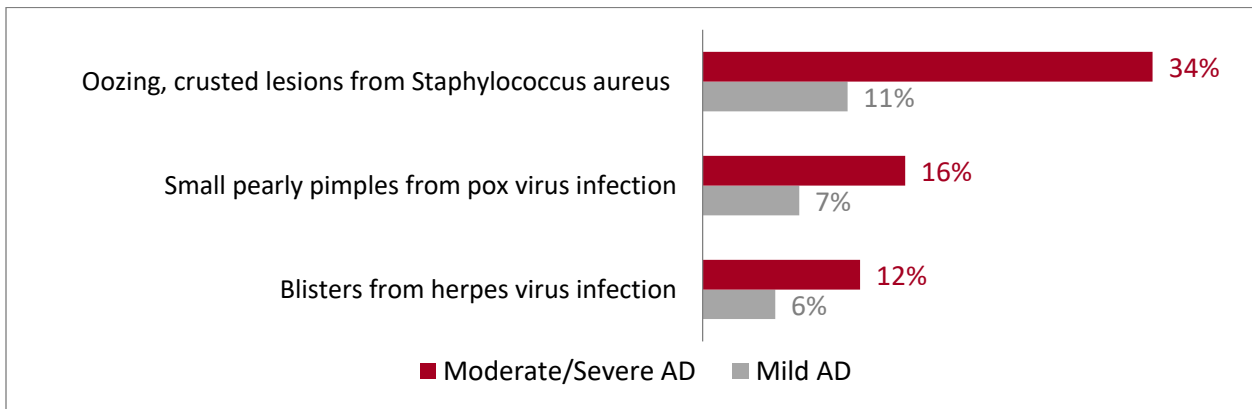
**vii. SATISFACTION WITH THE HEALTHCARE SYSTEM**

Overall, respondents are fairly satisfied with their healthcare system experiences for atopic dermatitis to date, perhaps partly due to their quick diagnosis. However, 37% of those with moderate/ severe atopic dermatitis are dissatisfied or severely dissatisfied, compared to 5% of those with a mild form of the condition.



**viii. COMPLICATIONS AND COMORBIDITIES**

Respondents have experienced complications of atopic dermatitis, most commonly lesions due to *Staphylococcus aureus* bacterial infection, affecting more than 1/3<sup>rd</sup> of those with moderate/severe atopic dermatitis and 11% of those with mild atopic dermatitis.



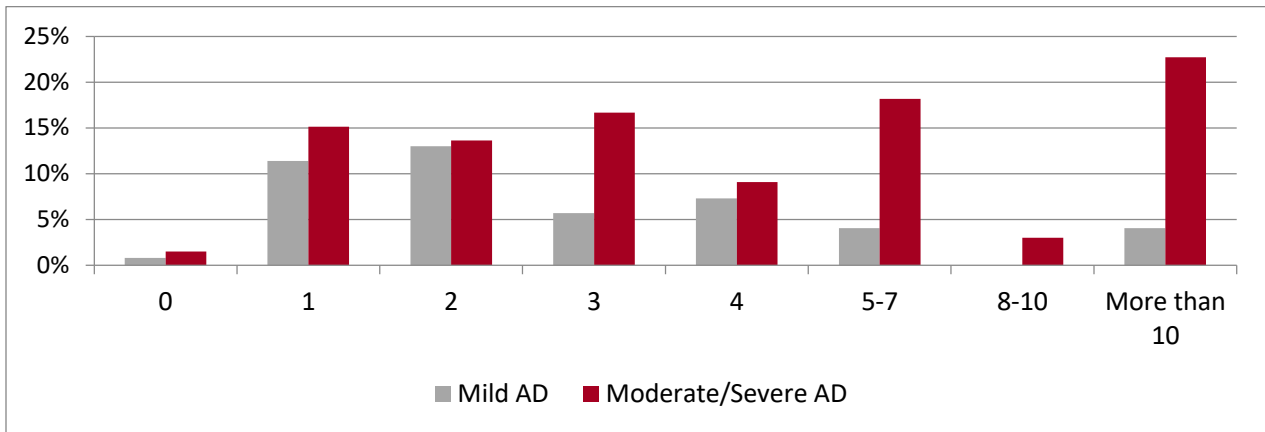
Those with atopic dermatitis often suffer from allergies as well: **54.5%** have seasonal allergies while **33.3%** have food allergies.

ix. **SEARCHING FOR AN EFFECTIVE TREATMENT**

*“I’ve yet to find a treatment that works and is worth the side effects.”*

The majority of respondents (78%) tried multiple treatments before finding relief.

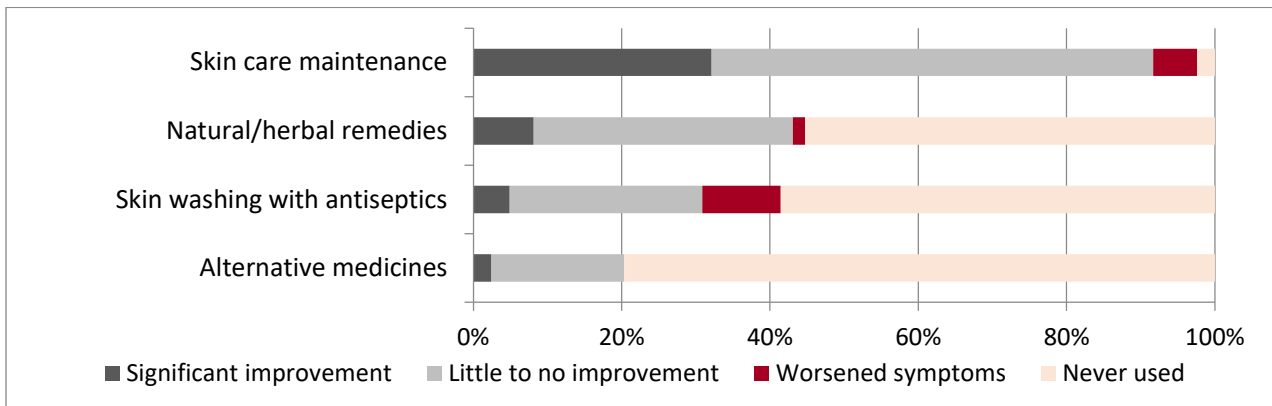
- For those with mild atopic dermatitis, the most common number of treatments tried was 2
- 23% of those with moderate/severe illness have tried more than 10 treatments
- 44% of those with moderate/severe illness have tried 5 or more treatments



x. **TREATMENT EFFECTIVENESS**

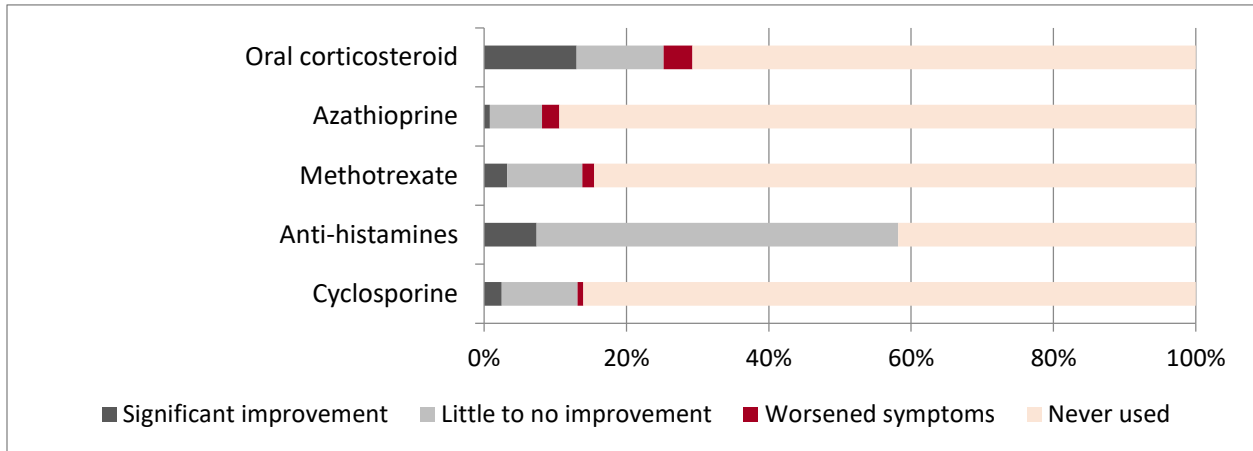
*“My creams are just a band-aid solution.”*

Patients have tried various at-home treatments, natural and alternative treatments to prevent and control symptoms of atopic dermatitis, with limited effect. Skin care maintenance, including bathing routines and moisturizing was most commonly used, although most respondents had little to no improvement in their condition.

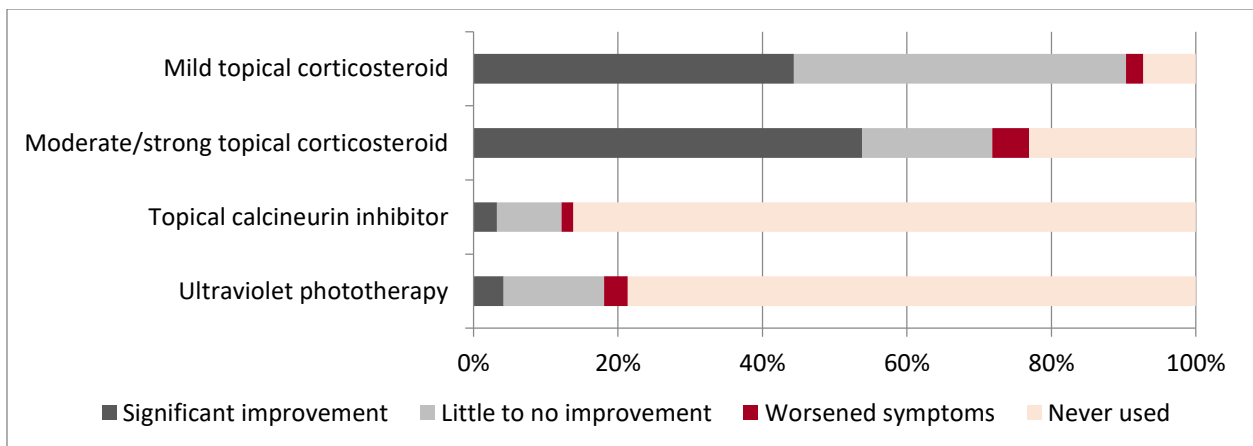




Of oral medications, anti-histamines have been used by the largest proportion of respondents, though they offer significant relief to only a minority of patients.

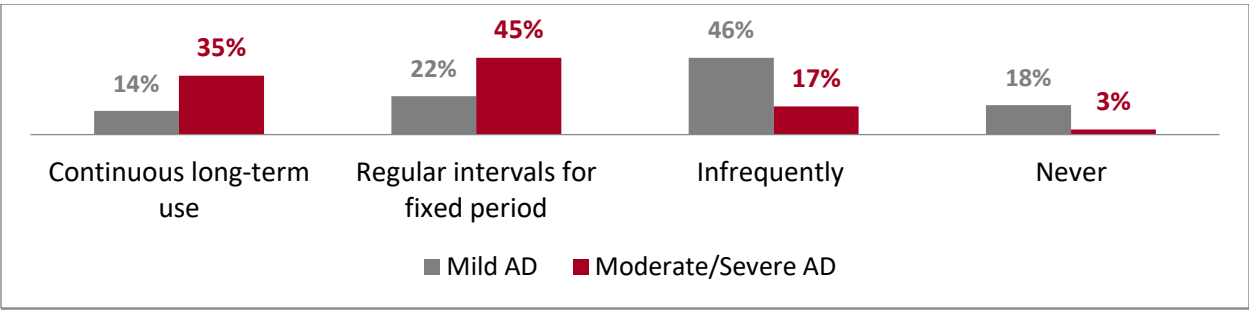


Topical corticosteroids are very commonly prescribed, and have offered the greatest effectiveness with more than 40% of respondents reporting significant improvement in symptoms.



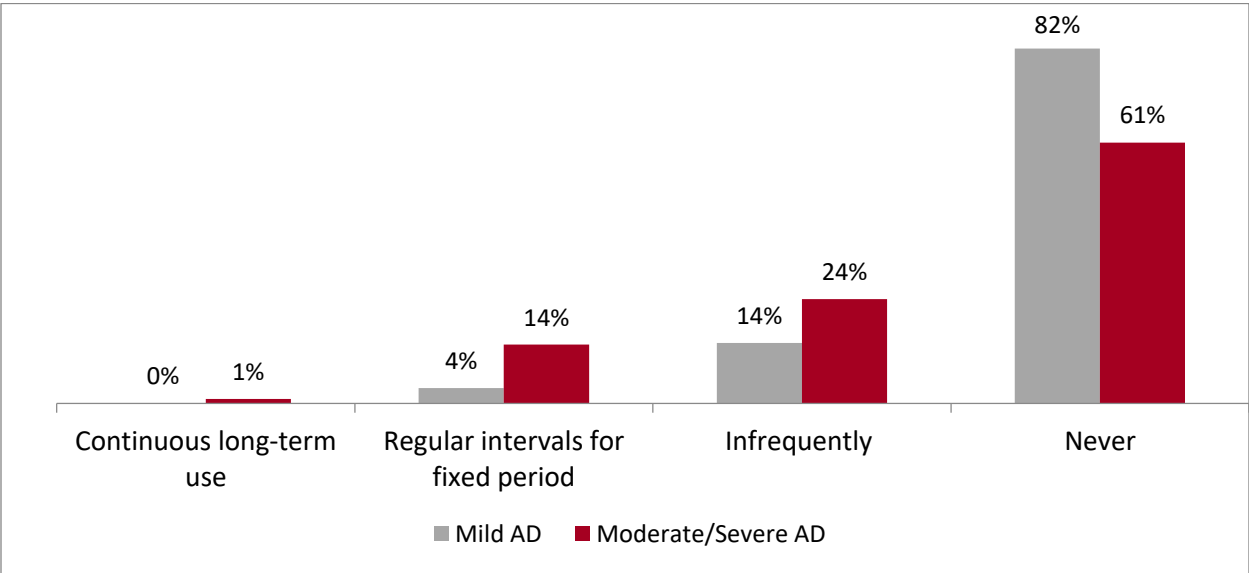
*“I haven’t found a cure or perfect routine. One thing works for months and then suddenly it doesn’t anymore and you have to start over.”*

**Topical corticosteroid use:** A higher proportion of those with moderate/severe atopic dermatitis have used topical corticosteroids compared to those with mild illness (97% vs. 82%). The majority (46%) of those with mild atopic dermatitis who have used them did so infrequently, while those with moderate/severe atopic dermatitis typically used them at regular intervals for fixed periods.

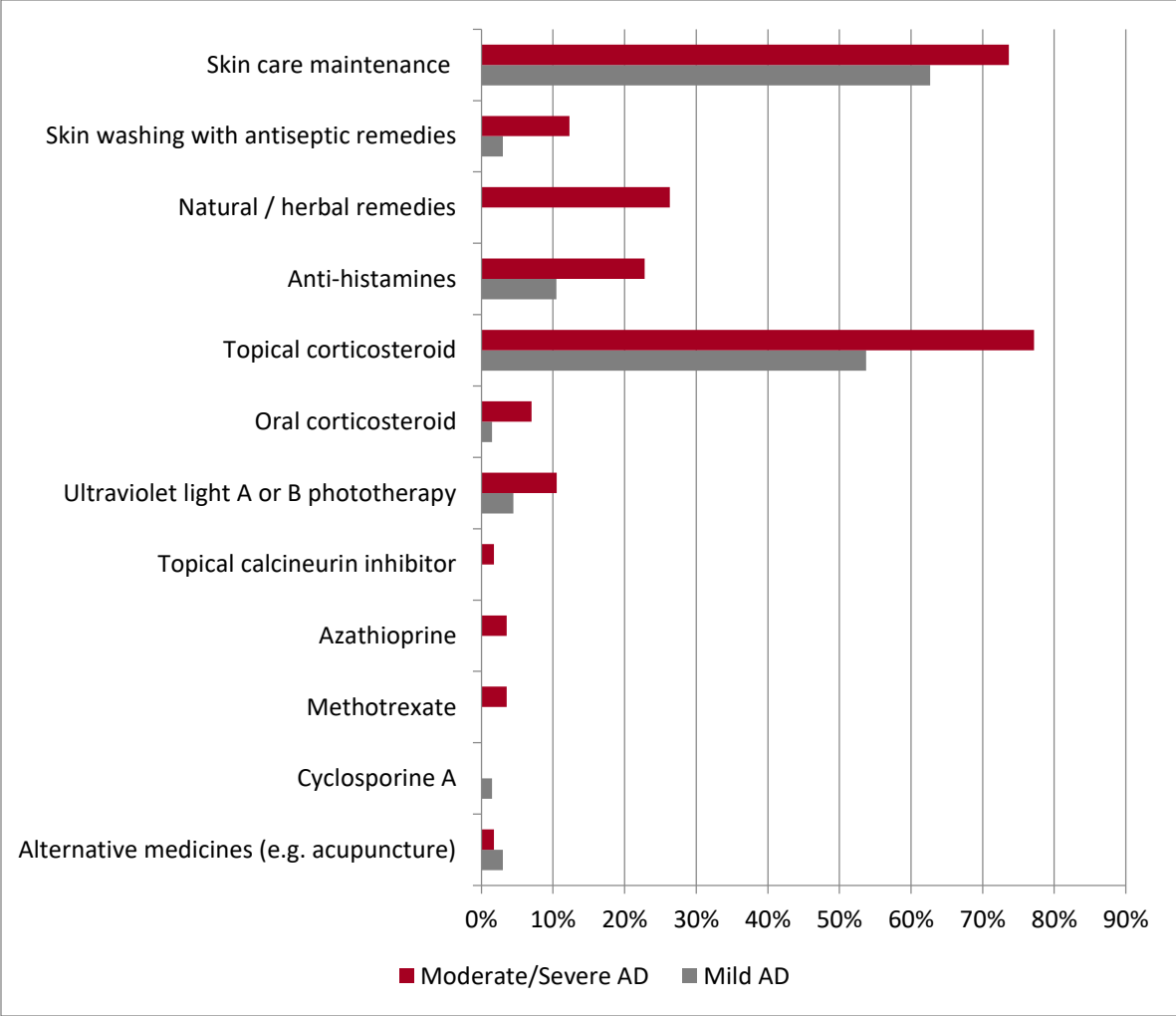


**Immunosuppressive medication use:** The majority of respondents have never used immunosuppressive medications (oral corticosteroids, cyclosporine A, azathioprine, methotrexate), though use was more prevalent in those with moderate/severe illness compared to individuals with mild atopic dermatitis. Use was mainly infrequent, though 15% of those with moderate/severe illness reported more regular use.

*“I’m less than thrilled about having to use a corticosteroid and am very concerned about it becoming less and less effective over time.”*



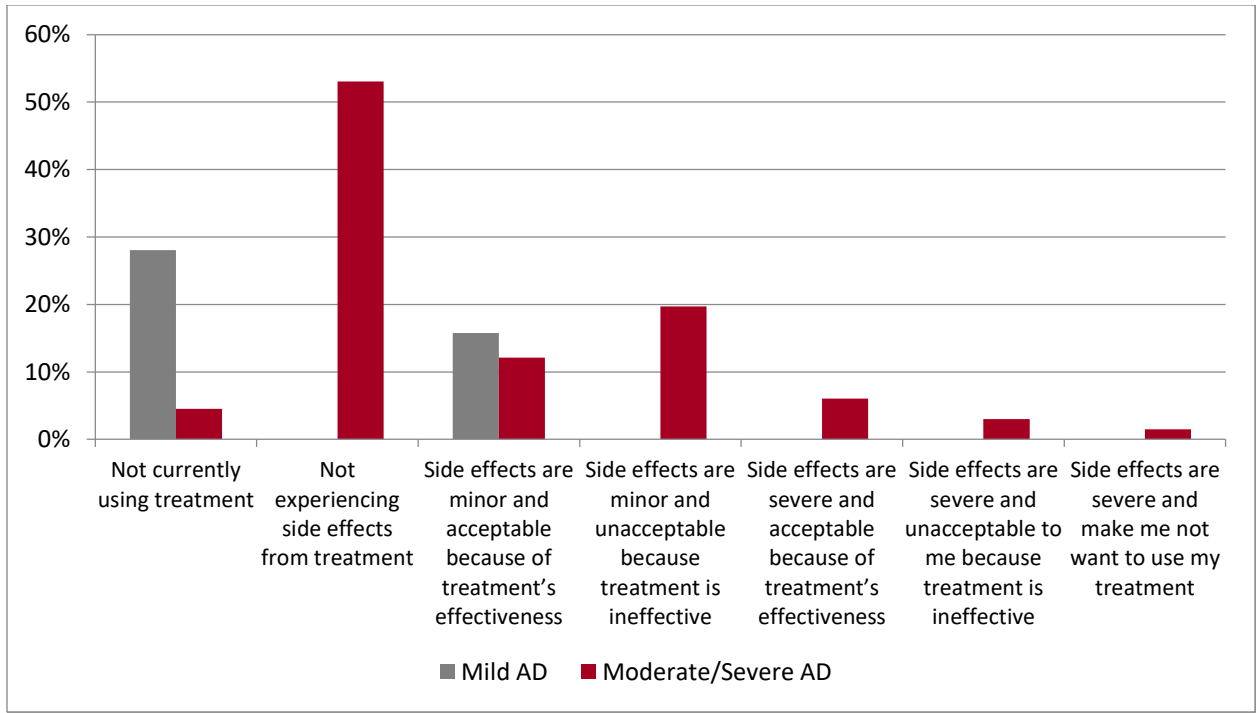
**Current medication use:** Respondents are currently using various non-prescription methods of controlling and preventing symptoms including skin care maintenance such as specific bathing routines and moisturizer application, natural and herbal remedies and acupuncture. For medicated treatments, topical corticosteroids are most commonly used by both those with mild and moderate/severe atopic dermatitis.



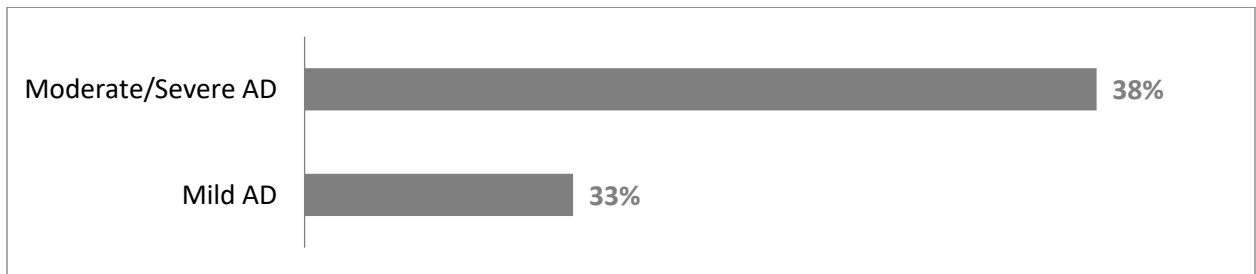
xi. **TREATMENT SIDE EFFECTS/ADVERSE EVENTS**

The majority of those with mild atopic dermatitis indicated that they are either not currently using any treatment or not experiencing side effects from their regimen. For the 16% of respondents with mild atopic dermatitis who are experiencing side effects/adverse events, all considered these to be minor enough to justify continued use.

However, for those with moderate/severe atopic dermatitis, 24% are experiencing side effects/adverse events which interfere with their willingness to take their medication.



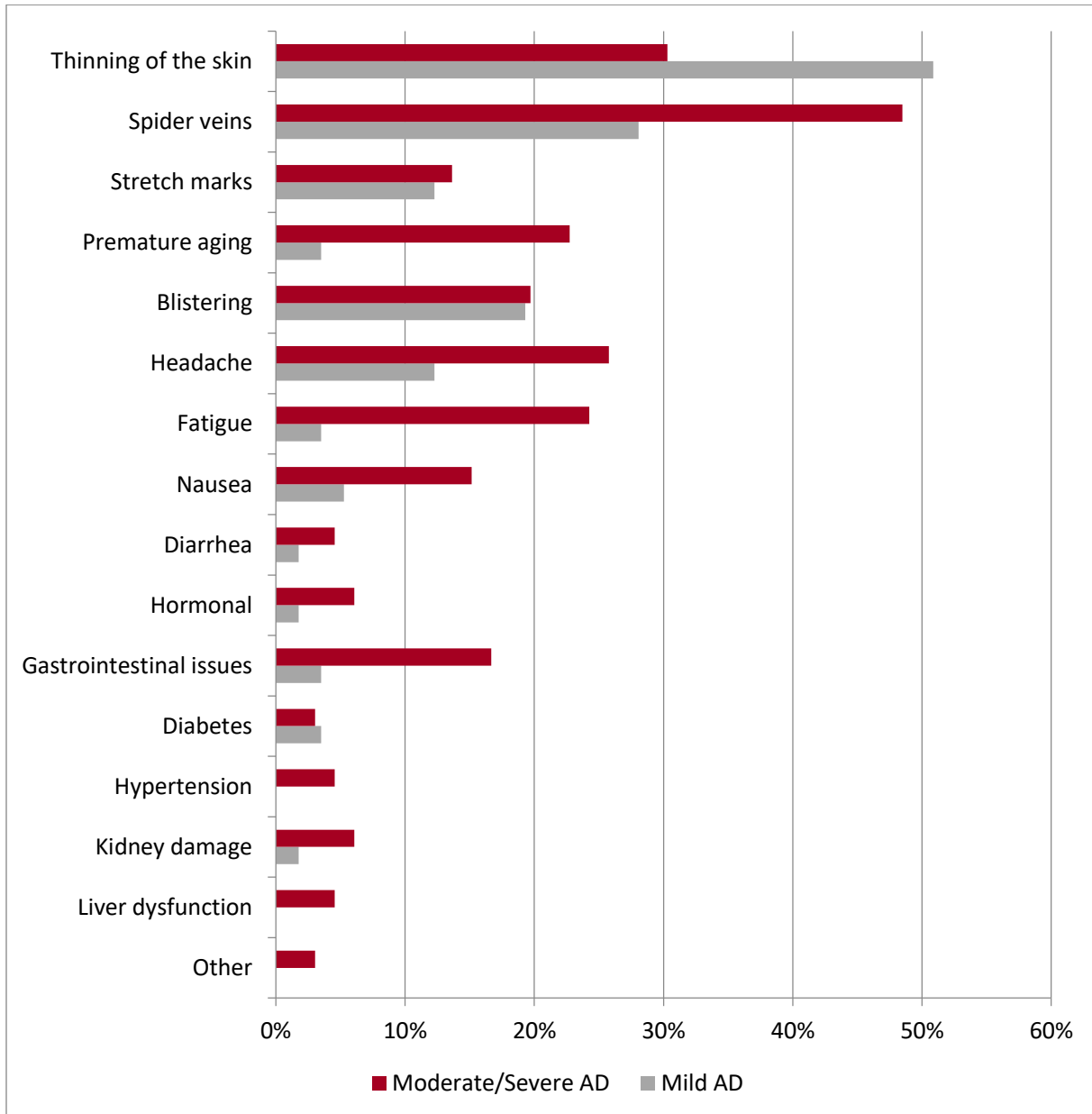
**Physician counselling on treatment side effects:** More than one-third of respondents with mild or moderate/severe atopic dermatitis reported that their physician had not adequately informed them about their medications, including what to expect in terms of effectiveness and side effects.



**Past experiences with treatment side effects/adverse effects:** Treatments commonly caused side effects for patients. For those with mild atopic dermatitis, more than half experienced skin thinning from a medication, while spider veins and blistering were the next most common effects.

For those with moderate/severe atopic dermatitis, spider veins was most common (47%), followed by thinning of the skin and headaches.

A small subset of patients also reported severe chronic adverse events such as diabetes, hypertension and liver damage. However, we did not specifically ask whether the respondent's physician had determined causation between the treatment and these chronic condition.



## xii. COST OF TREATMENTS

We asked Canadian respondents about their monthly out-of-pocket costs for atopic dermatitis treatments and therapies. There was a large variation in expenses including medications, other symptom treatments, and preventative measures.

Item*~	Mild AD			Moderate/severe AD		
	Median Monthly Cost (\$)	Range (\$)	n	Median Monthly Cost (\$)	Range (\$)	n
<b>Medications</b>						
Oral corticosteroid	24	11-50	4	18	10-25	2
Cyclosporine A	16	11-20	2	0	0	0
Methotrexate	21	20-21	2	45	45	1
Azathioprine	16	11-20	2	43	40-45	2
Anti-histamines	20	3-50	13	20	2-200	22
<b>Topical treatments</b>						
Topical corticosteroid	10	1-200	29	20	1-100	41
Topical calcineurin inhibitor	11	10-11	2	0	0	0
Ultraviolet light A or B phototherapy	22	10-40	4	0	0	0
<b>At-home symptom treatment/alternative therapies</b>						
Skin care maintenance <sup>1</sup>	12	1-52	45	20	5-200	53
Alternative medicines (e.g. acupuncture)	30	20-70	5	80	10-250	7
Natural / herbal remedies	20	5-50	9	35	1-200	18
Skin washing with antiseptic remedies	20	20-40	5	15	1-50	11

\*n varies per row because not every respondent uses all treatments and therapies; those who did not use a specific treatment/therapy or abstained from responding were excluded in the calculation of monthly cost.

~Other costs may be covered through a public or private insurance plan

<sup>1</sup>bathing routine, applying moisturizer

*“The costs associated with the trial and error nature of treatment regimens is very frustrating.”*

## xiii. IMPACT OF COST

A minority of patients reported that the substantial cost of a medication precluded them from being able to begin a course of treatment.

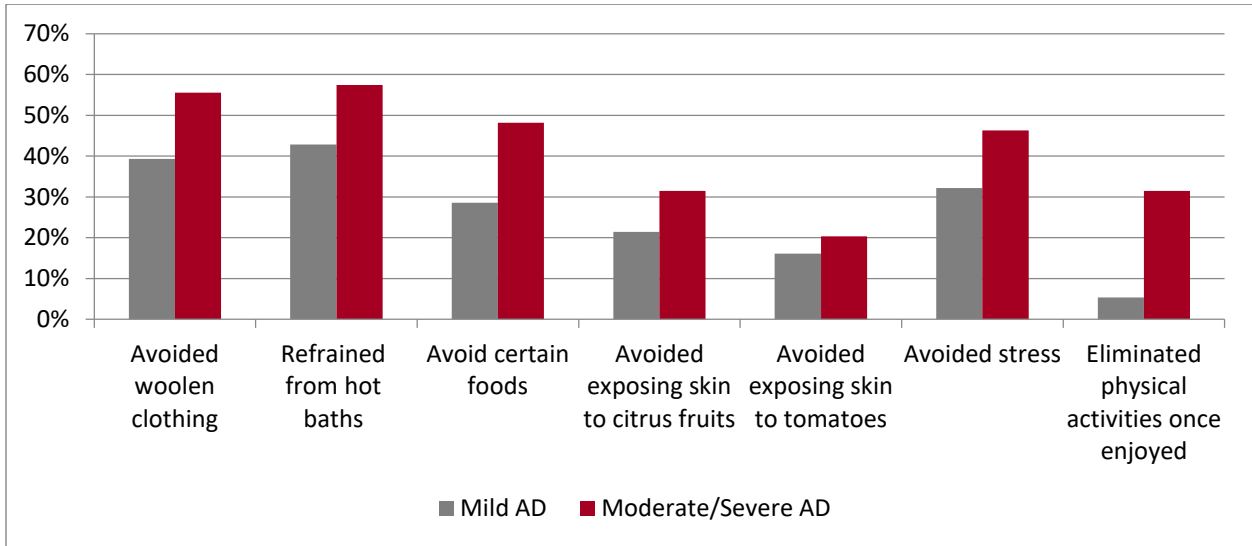
Mild AD	5%
Moderate/Severe AD	17%

A small percentage of patients also reported that they have previously stopped using a treatment due to cost.

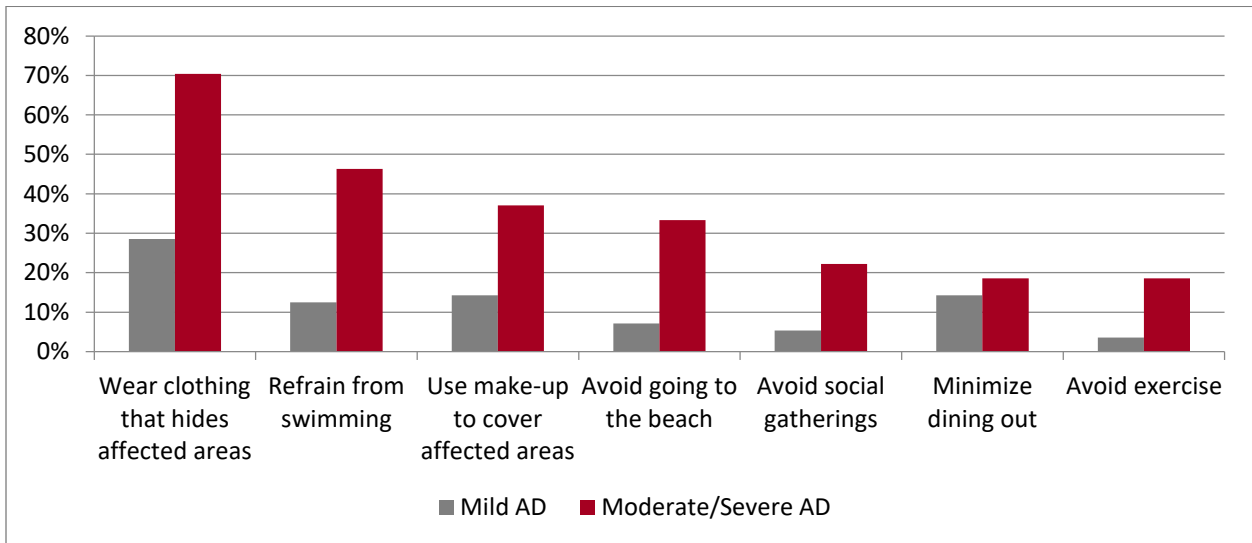
Mild AD	2%
Moderate/Severe AD	16%

**xiv. LIFESTYLE BEHAVIOURS TO PREVENT AND CONTROL SYMPTOMS**

Respondents are well-versed at eliminating or reducing behaviours which may aggravate their atopic dermatitis symptoms, most commonly avoiding itchy, woolen clothing and restricting skin exposure to hot water.



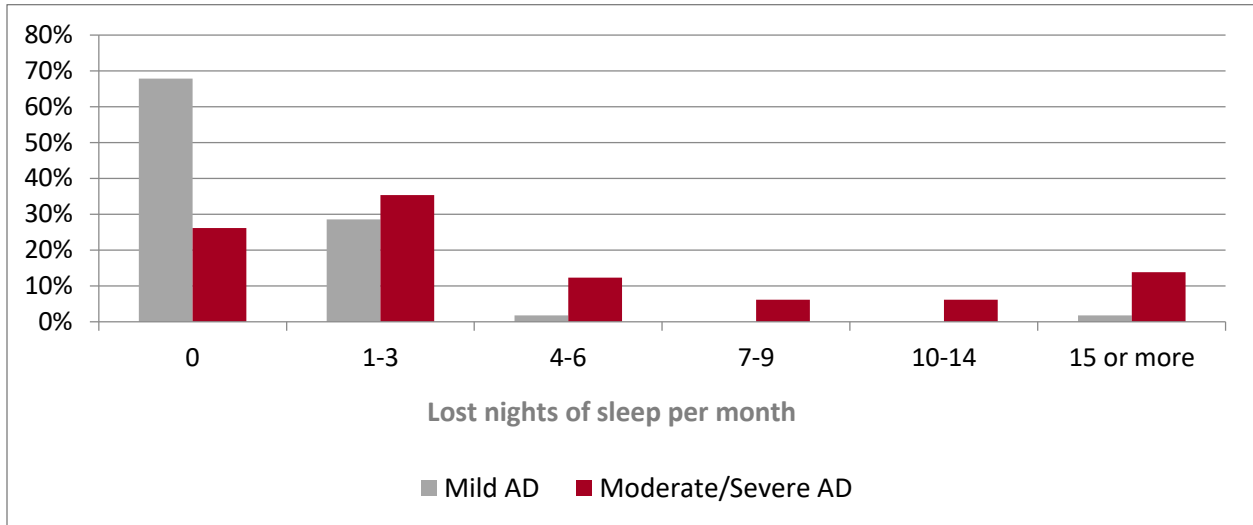
The most common lifestyle modification to accommodate atopic dermatitis was to wear clothing to hide affected areas.



**xv. IMPACT OF ATOPIC DERMATITIS**

The symptoms of atopic dermatitis can affect an individual's life in many ways including hindering their ability to sleep.

- 32% of those with mild atopic dermatitis lose one or more days of sleep every month
- 74% of those with moderate/severe atopic dermatitis lose at least one night of sleep monthly due to symptoms, while 20% lose 10 or more days a month

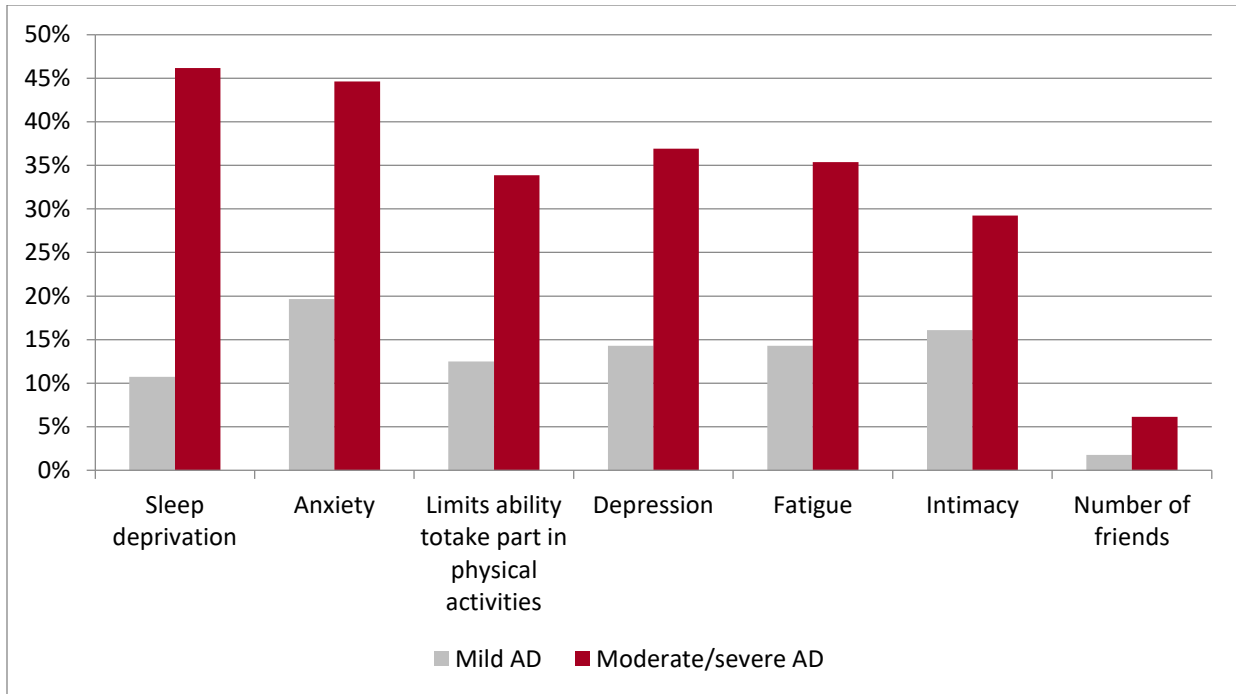


	Mild AD	Moderate/severe AD
Missed days of work/school per month	0.23 days (range = 0-10)	2.4 days (range = 0-30)
Individuals whose AD negatively affects ability to be in work/school	14%	46%
Individuals whose AD negatively affects personal life	18%	68%
Individuals who are concerned about their next flare	34%	80%

Atopic dermatitis impacts various aspects of a person’s life, manifesting in ways that can be detrimental to daily living. Of those with mild atopic dermatitis, the most common effects are anxiety (20%), negative effect on ability to be intimate with a partner (16%), and depression and fatigue (14% each). For those with moderate/severe atopic dermatitis, sleep deprivation is the most prevalent effect (46%), followed by anxiety (45%) and depression (37%).

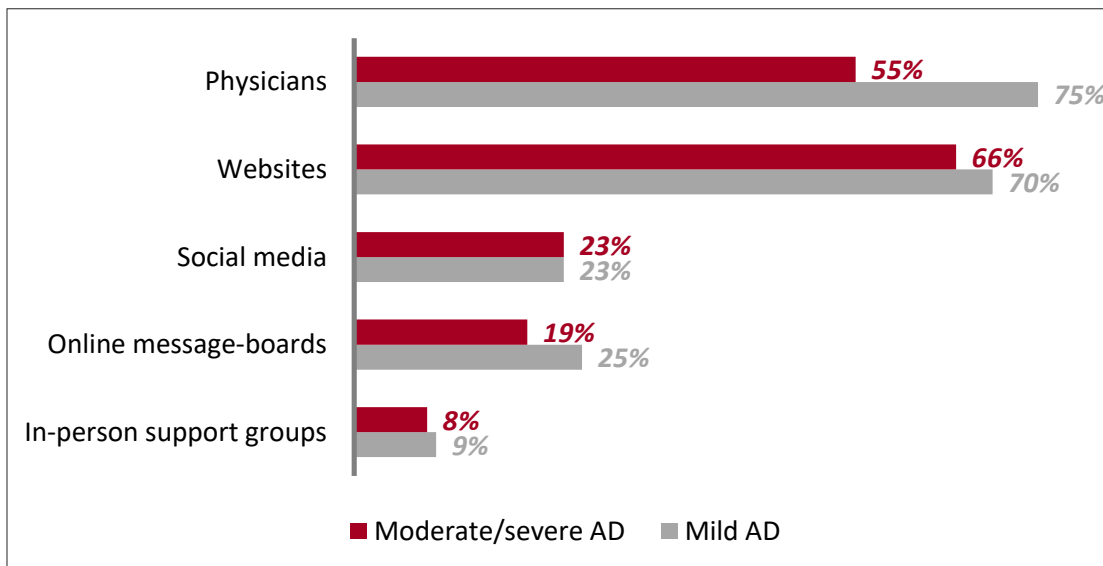
*“Damage and scarring to skin have caused me high anxiety.”*



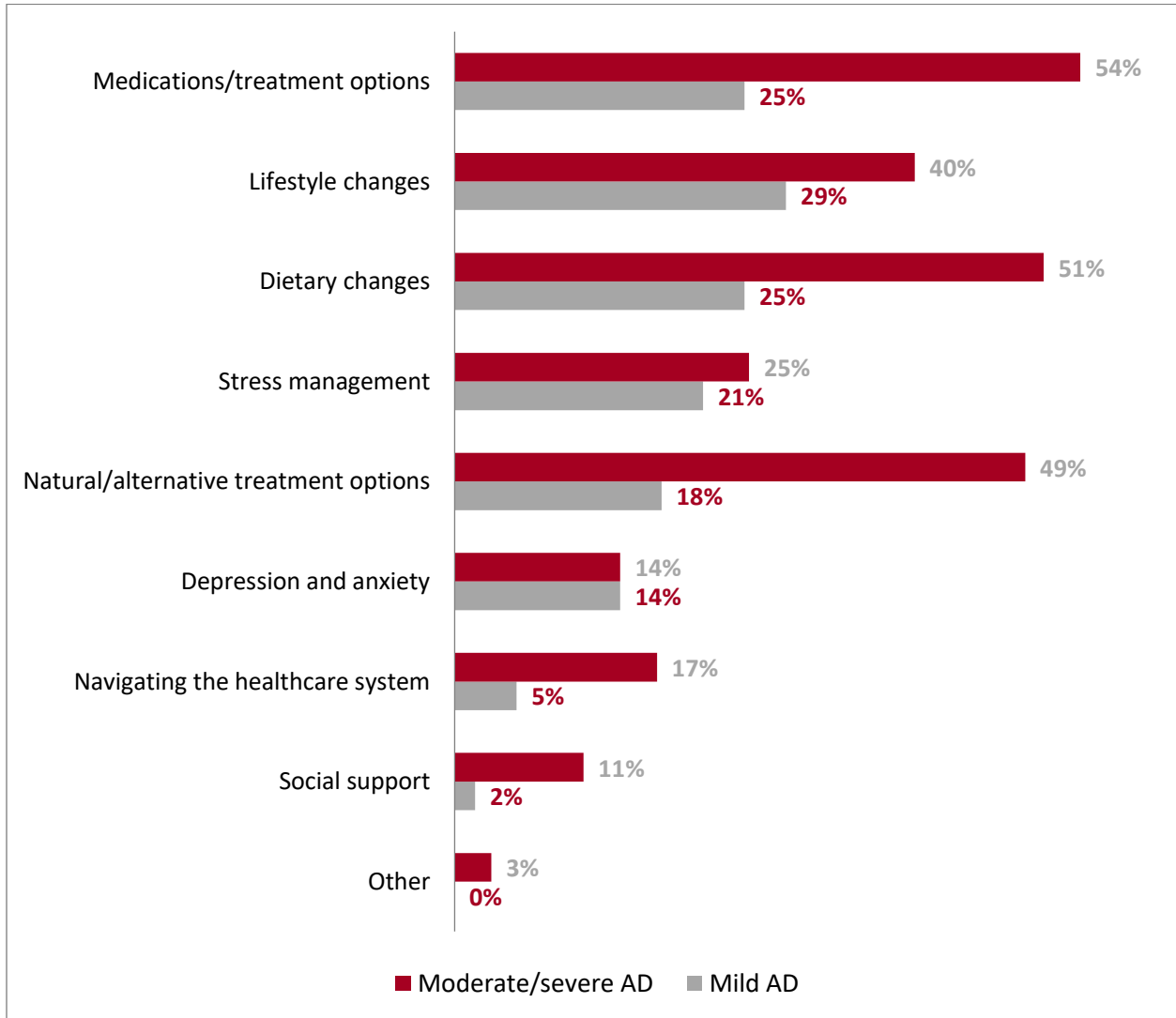


xvi. KNOWLEDGE AND PATIENT NEEDS

**Sources of information on atopic dermatitis:** The two primary sources of atopic dermatitis information are respondents' HCPs and health websites (<https://www.livestrong.com/>, <https://www.webmd.com/>, <https://eczemahelp.ca/>, <https://www.mayoclinic.org/>, <https://dermatology.ca/>, <https://itsan.org/>, <https://nationaleczema.org/>). Other online sources are also commonly sought, such as social media and online message-boards. Only a small percentage of respondents access information through in-person support groups.

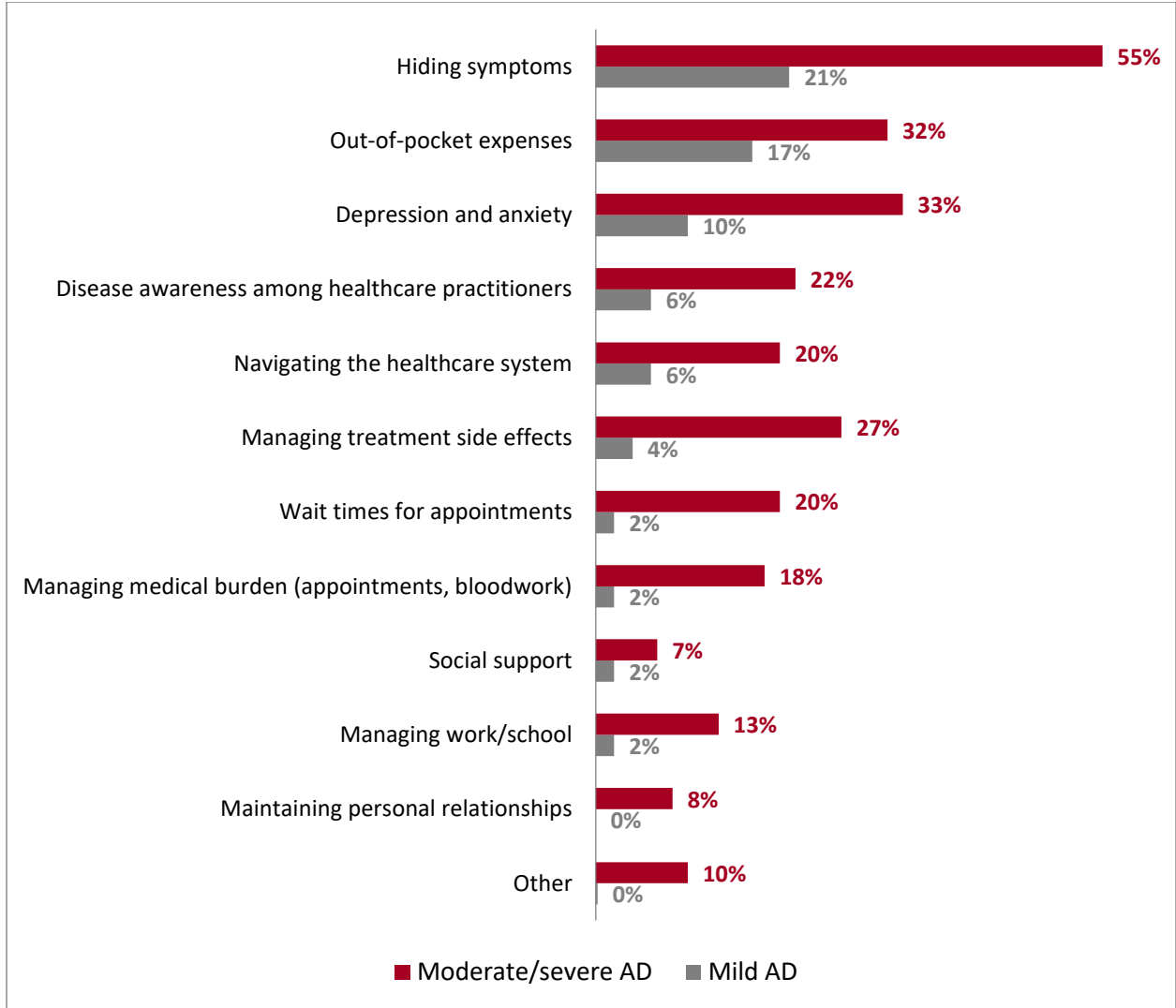


Respondents expressed the need for more information on various atopic dermatitis-related topics. For those suffering from mild illness, more than one-quarter want to know more about lifestyle changes to help with symptoms, dietary changes to reduce symptoms and medications/treatment options. Approximately half of those with moderate/severe illness want more information about medications/treatment options, dietary changes and natural/alternative treatment options.



*“It makes me hesitate to join people at gatherings and outings because I’m embarrassed to be seen with nasty rashes and flakes.”*

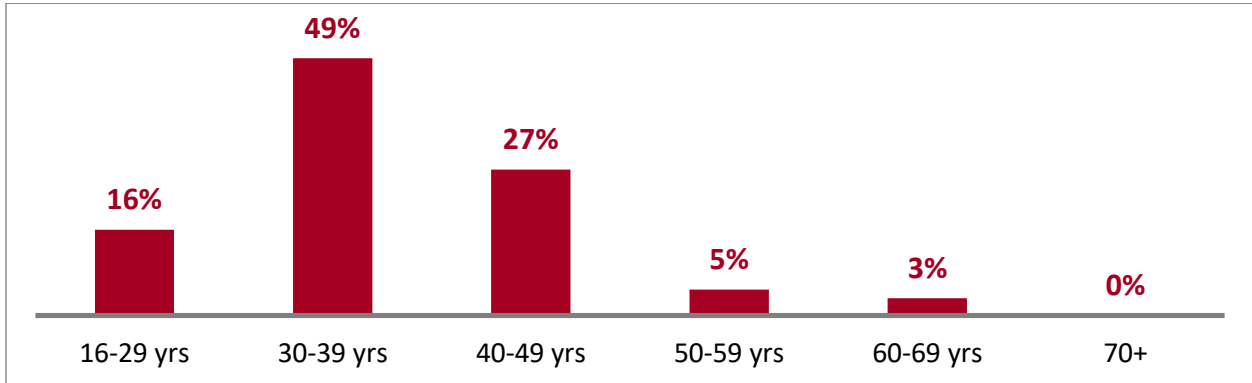
Those with atopic dermatitis and particularly those with moderate/severe illness struggle with more than one aspect of their condition. Hiding the visible symptoms was the most common struggle for all respondents, along with handling out-of-pocket expenses and depression/anxiety.



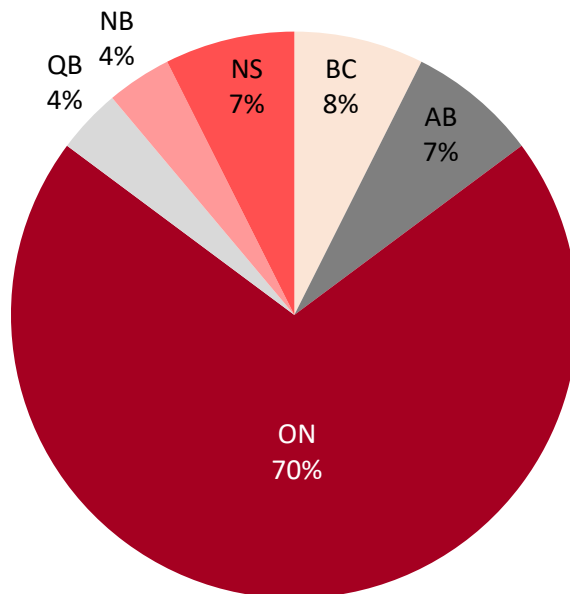
## Section II: Results from Caregivers to Individuals with Atopic Dermatitis

### i. DEMOGRAPHICS

The majority of the 62 eligible respondents were female (79%), and the average age was 36 years with a range of 23 to 65 years.



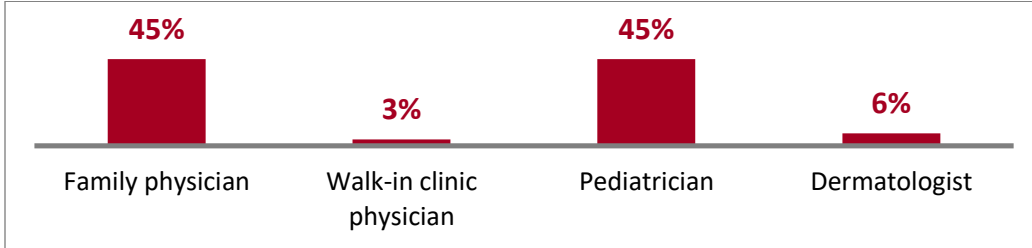
Fifty-four respondents were from Canada (87%), with more than half residing in Ontario. No surveys were received from PEI, Saskatchewan, Manitoba, Newfoundland or any of the Canadian territories.



The remaining eight respondents were from the United States.

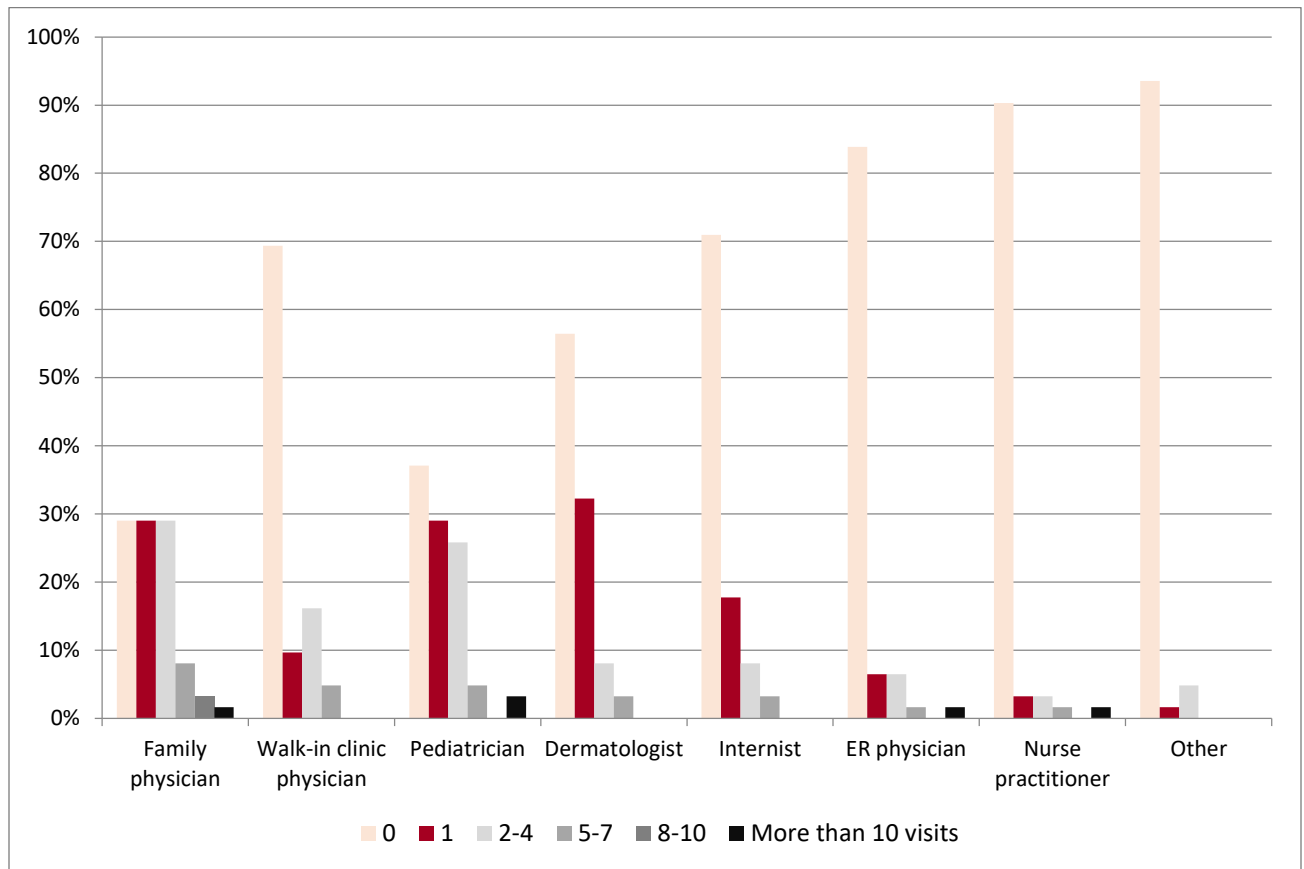
ii. HEALTHCARE UTILIZATION EN ROUTE TO ATOPIC DERMATITIS DIAGNOSIS

For 90% of respondents, the individual that they care for visited their family physician or pediatrician first for initial atopic dermatitis symptoms.



In seeking a diagnosis, 42% saw a family physician at least twice, and 5% visited at least 8 times

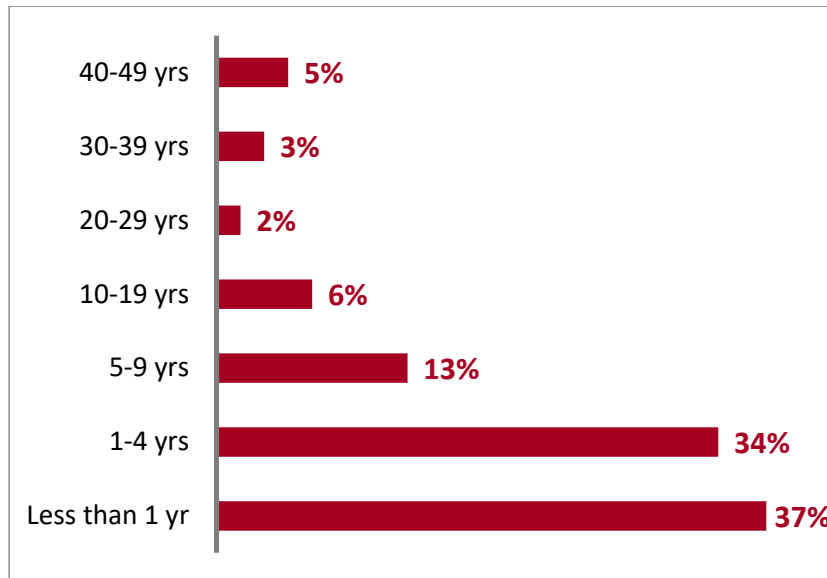
- 34% visited a pediatrician two or more times, and 8% visited at least 5 times
- 29% visited an internist at least once
- 21% visited a walk-in clinic at least twice
- 10% visited an ER at least twice



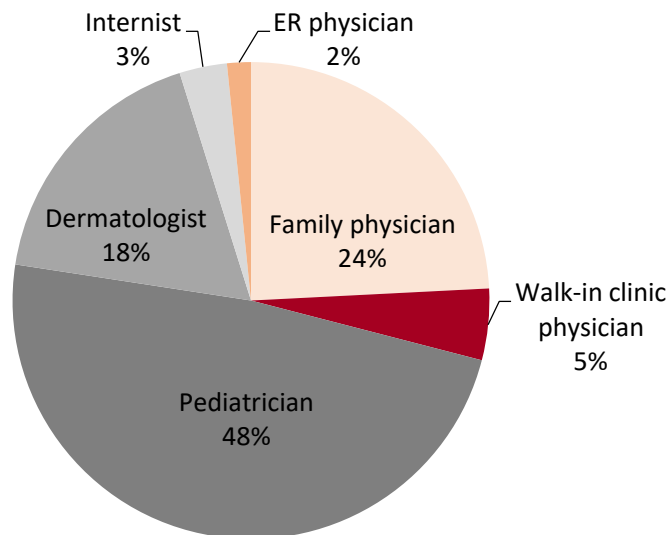
iii. **ATOPIC DERMATITIS DIAGNOSIS**

The average age at diagnosis was 5 years and 7 months, with a range of 2.5 months to 45 years.

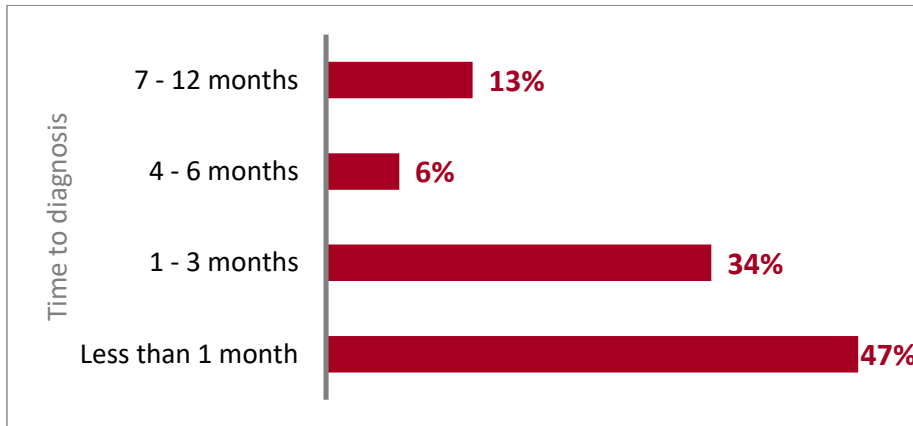
- 71% of all respondents reported that the person that they care for was diagnosed when they were less than 5 years old



The majority of respondents (72%) care for an individual who was diagnosed by their family physician or pediatrician.

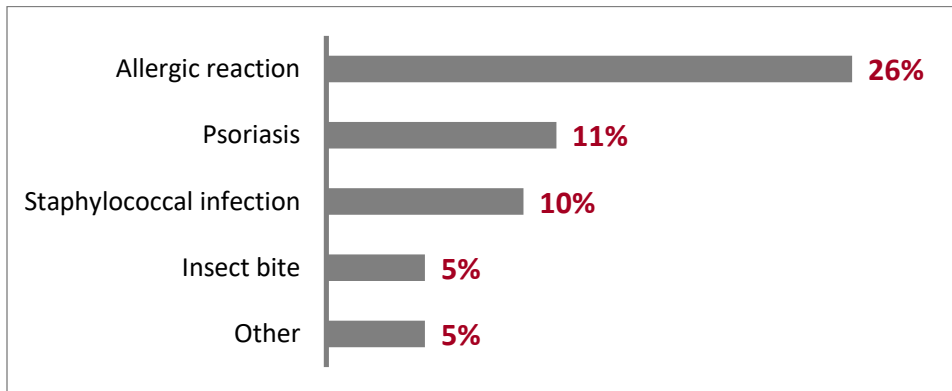


Nearly half of respondents reported that the person that they care for received a diagnosis of atopic dermatitis within 30 days, and all were diagnosed within one year of first experiencing symptoms.



#### iv. MISDIAGNOSES

Prior to those cared for being diagnosed with atopic dermatitis, 37% received at least one misdiagnosis, the most common being “allergic reaction”. Five percent were given a diagnosis that was not listed, namely dry skin.

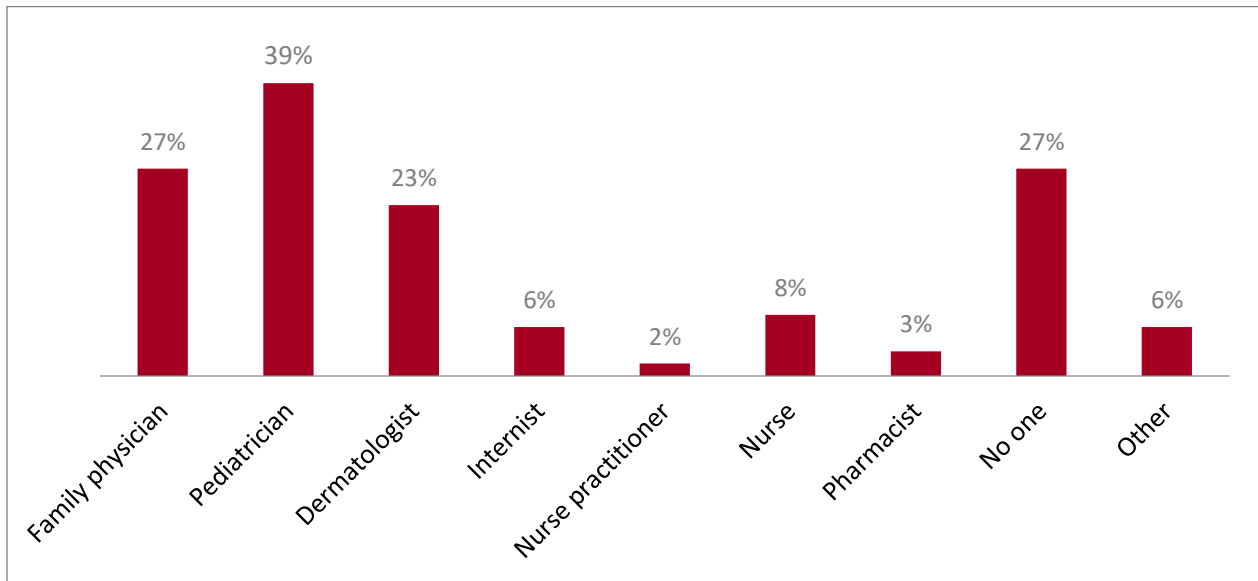


#### v. CURRENT HEALTHCARE TEAM FOR MANAGEMENT OF AD

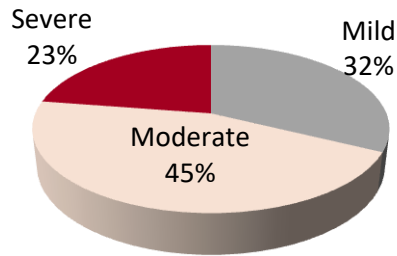
The majority of respondents (75%) reported that they seek HCP support for their loved one’s AD, with family physicians and pediatricians being the

*“I’m frustrated that our allergist, dermatologist and GP all have different theories as to why my son has atopic dermatitis.”*

most common sources, followed by dermatologists. A small percentage chose “other”, and either turn to HCPs such as naturopaths, or consider themselves to be responsible for management.

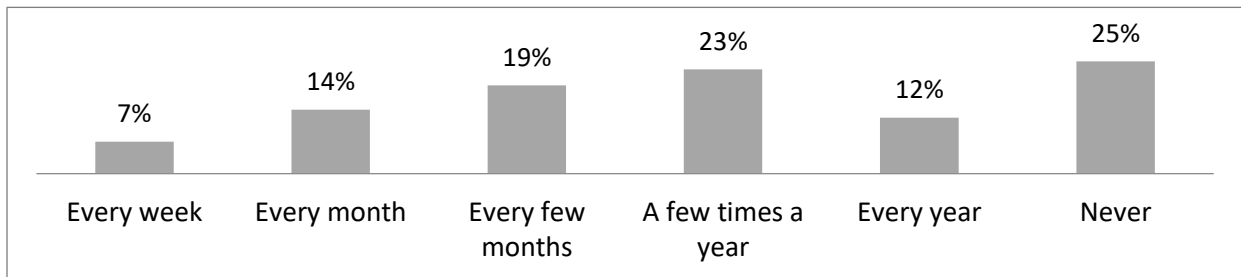


vi. SEVERITY OF AD



*“When my son’s flares are bad, we can’t fully live our lives or relax without worrying about what he’s touching, eating, etc. that could make it worse.”*

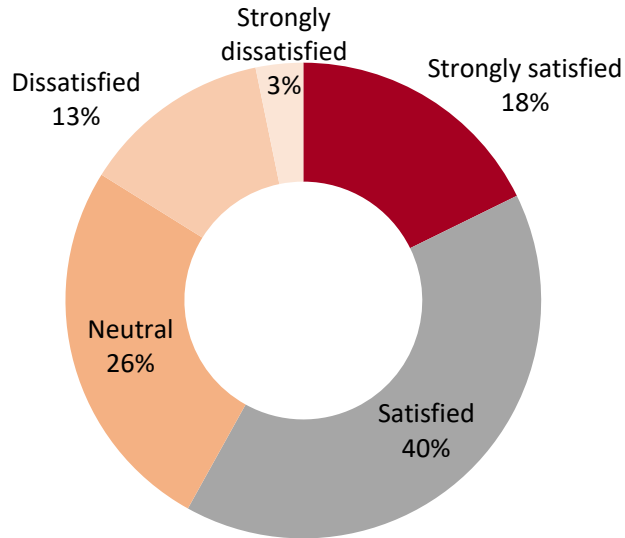
- 61% of respondents reported that the person they care for experiences intermittent flare-ups
- Of those, 21% of respondents reported that the person that they care for experiences flare-ups on a weekly or monthly basis





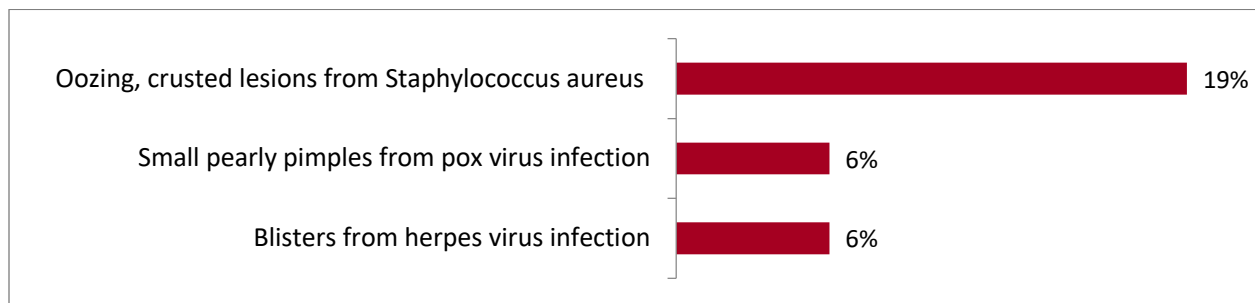
### vii. SATISFACTION WITH THE HEALTHCARE SYSTEM

Respondents seemed fairly satisfied with their healthcare system experiences for their loved one's condition to date.



### viii. COMPLICATIONS AND COMORBIDITIES

- 30% of respondents reported that the individual that they cared for experienced at least one complication of atopic dermatitis, the most common being lesions resulting from a *Staphylococcus aureus* bacterial infection



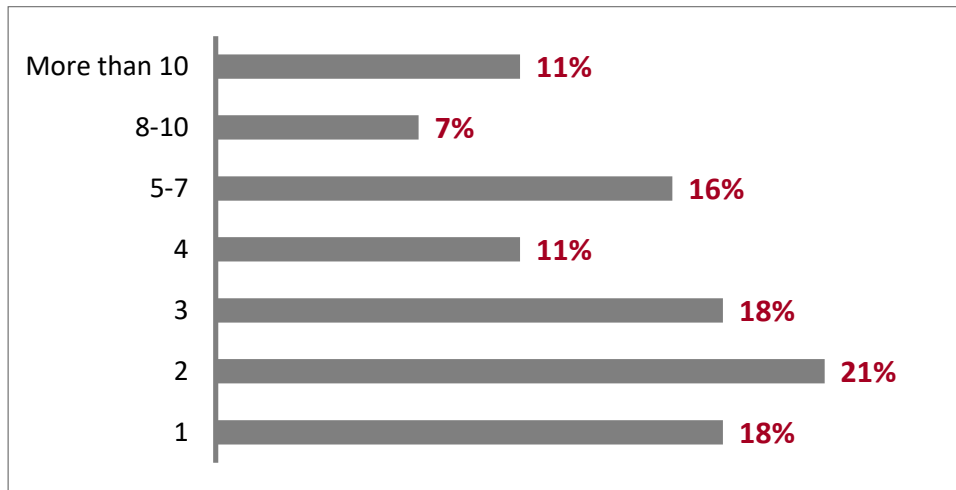
Many caregivers reported that the individual that they care for suffers from allergies as well: 31% have seasonal allergies while 48% have food allergies.

*“My son caught hand, foot and mouth disease. The area that he has his eczema (elbows) got covered in blisters/rash with his other areas unaffected. I did not realize that the area affected by the eczema would make it easier for other skin disorders to appear.”*

ix. **SEARCHING FOR AN EFFECTIVE TREATMENT**

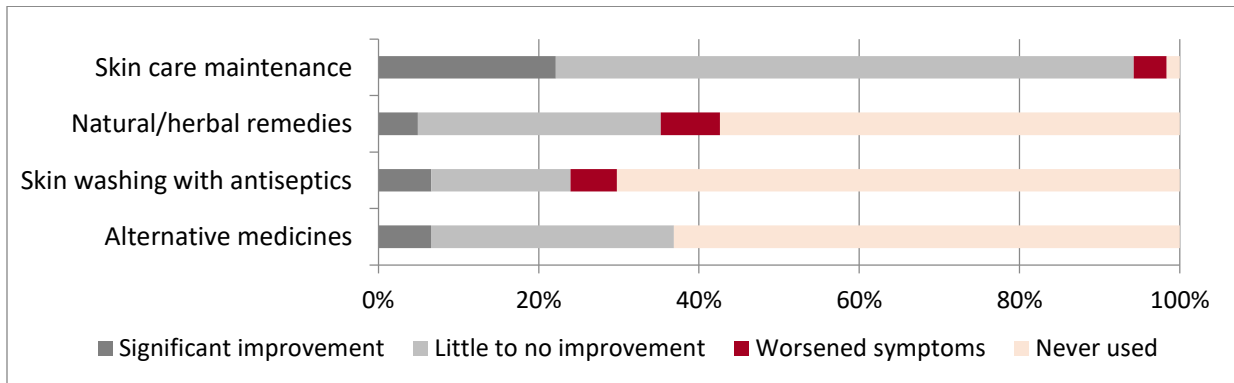
The majority of respondents (82%) indicated that the person they care for tried multiple treatments before finding relief.

- The most common number of treatments attempted was 2
- 11% tried more than 10 treatments
- 34% tried 5 or more treatments

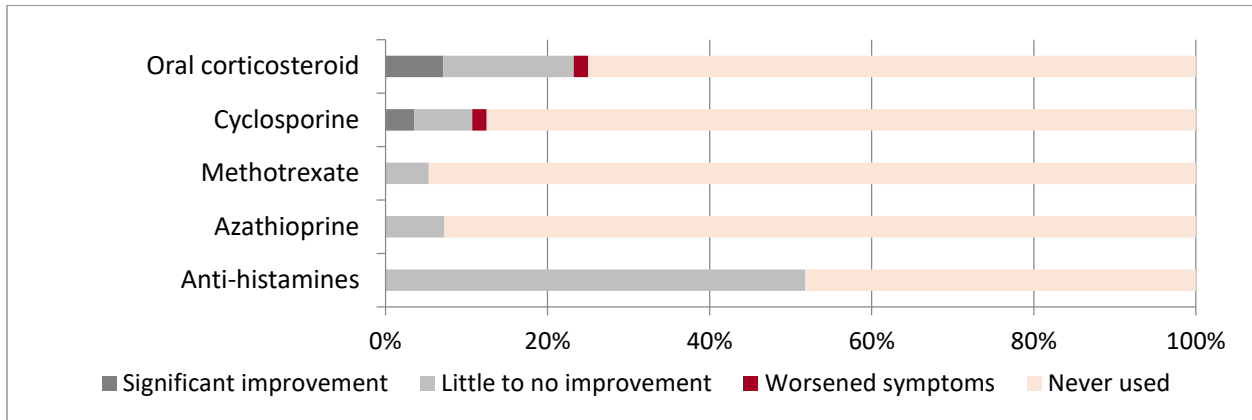


x. **TREATMENT EFFECTIVENESS**

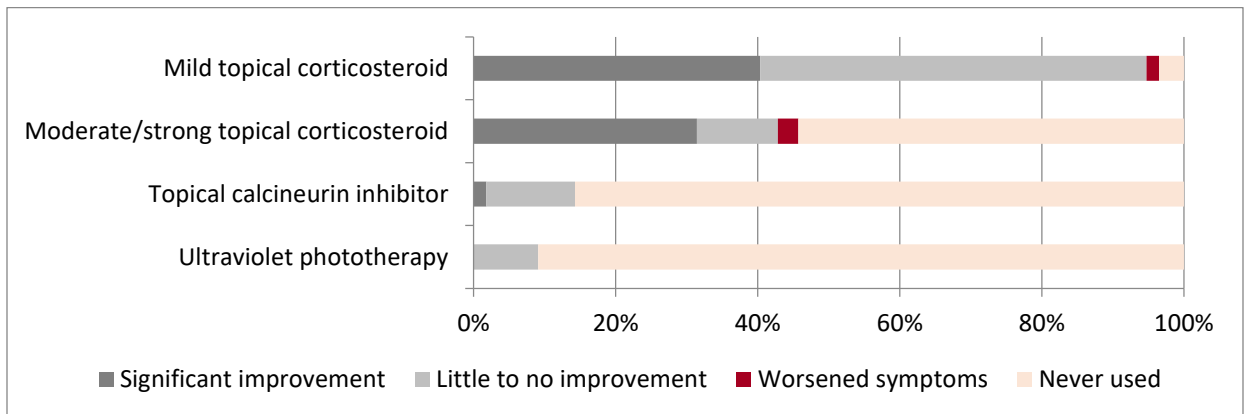
The vast majority of caregivers try non-medicated methods of preventing and controlling symptoms of those for whom they care, likely in part due to the younger age (and therefore sensitive skin) of those suffering. Skin care maintenance in the form of moisturizer offered significant relief to almost 25% of those who tried it, but other natural treatments were less likely to have been attempted.



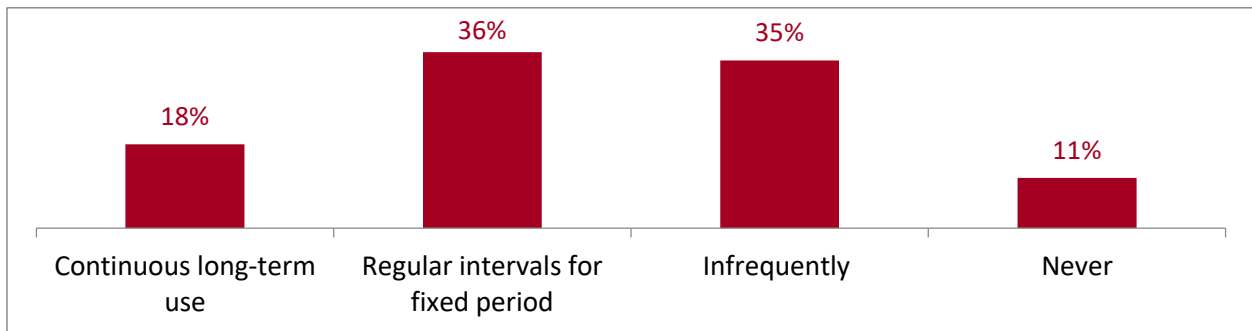
None of the oral medications had been tried by more than 52% of individuals looked after by caregiver respondents. Oral corticosteroids were found to provide significant improvement to approximately one-third of those who use them.



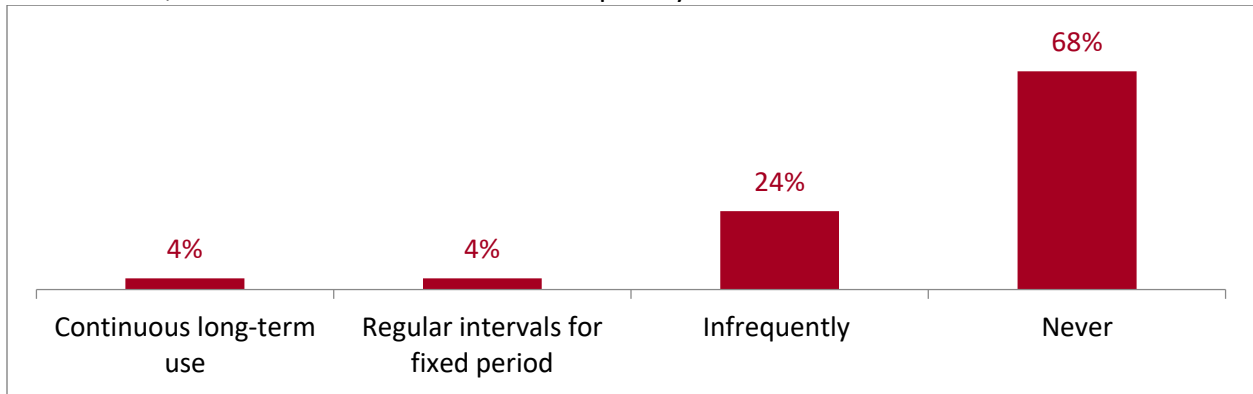
Topical corticosteroids have been commonly prescribed, and have offered the greatest effectiveness with more than 40% of respondents reporting significant improvement in symptoms.



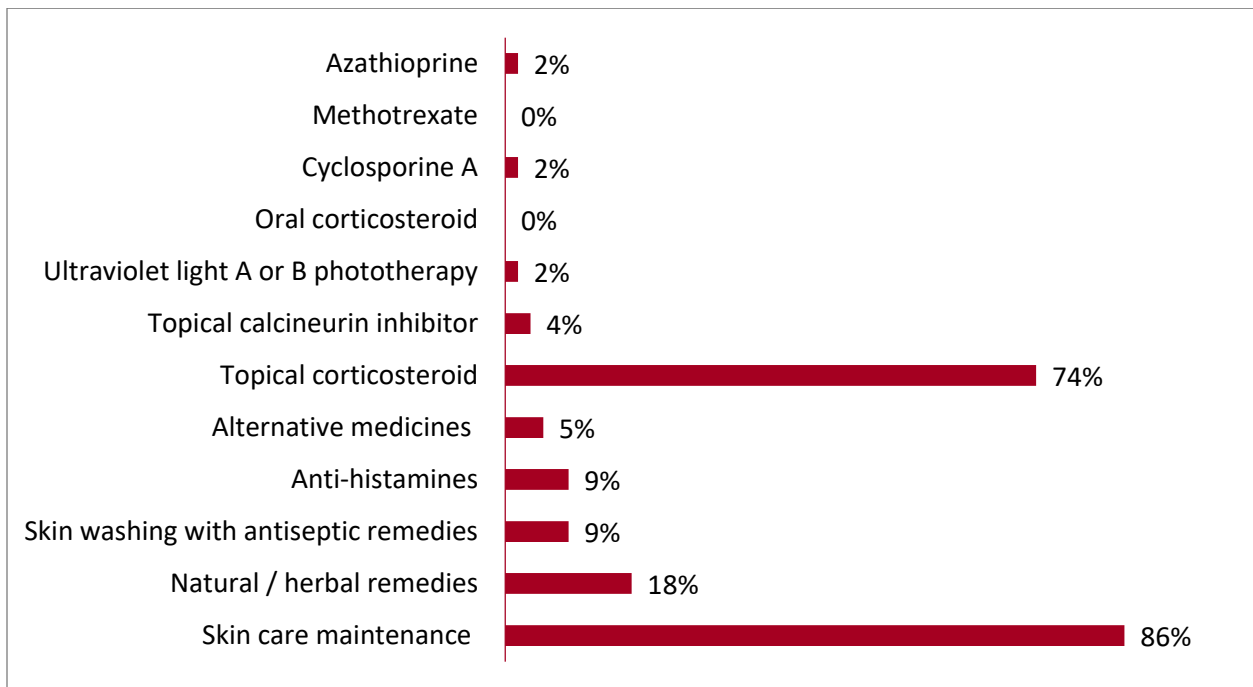
**Topical corticosteroid use:** The majority (89%) have tried corticosteroids for their symptoms, although dosing schedules varied.



**Immunosuppressive medication use:** The majority (68%) have never used immunosuppressive medications, and those who have use it infrequently.

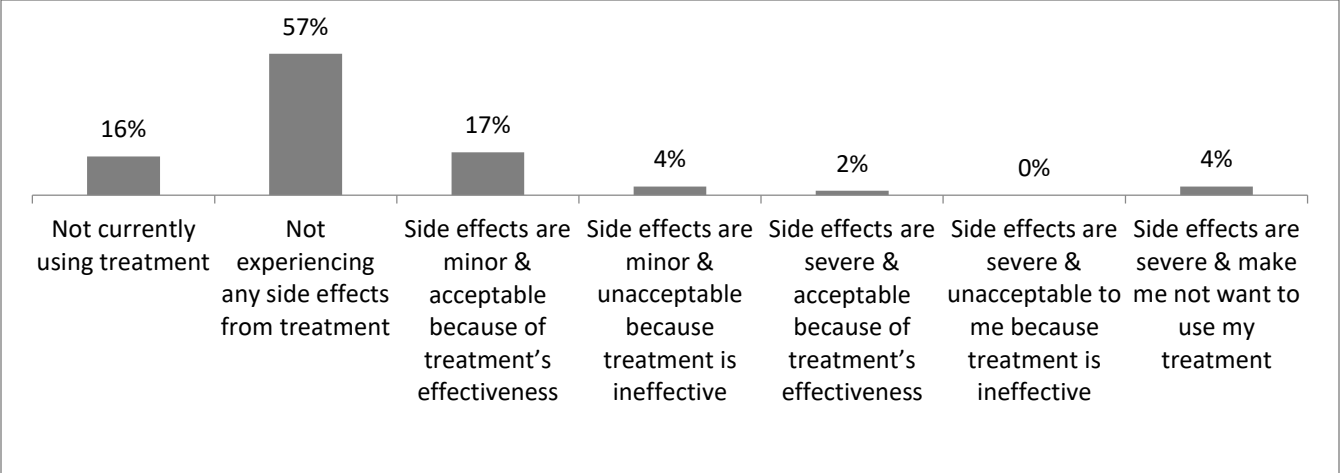


**Current treatments:** The majority of caregivers are opting for skin care maintenance to treat their condition, while the most common medication in current use is topical corticosteroids.



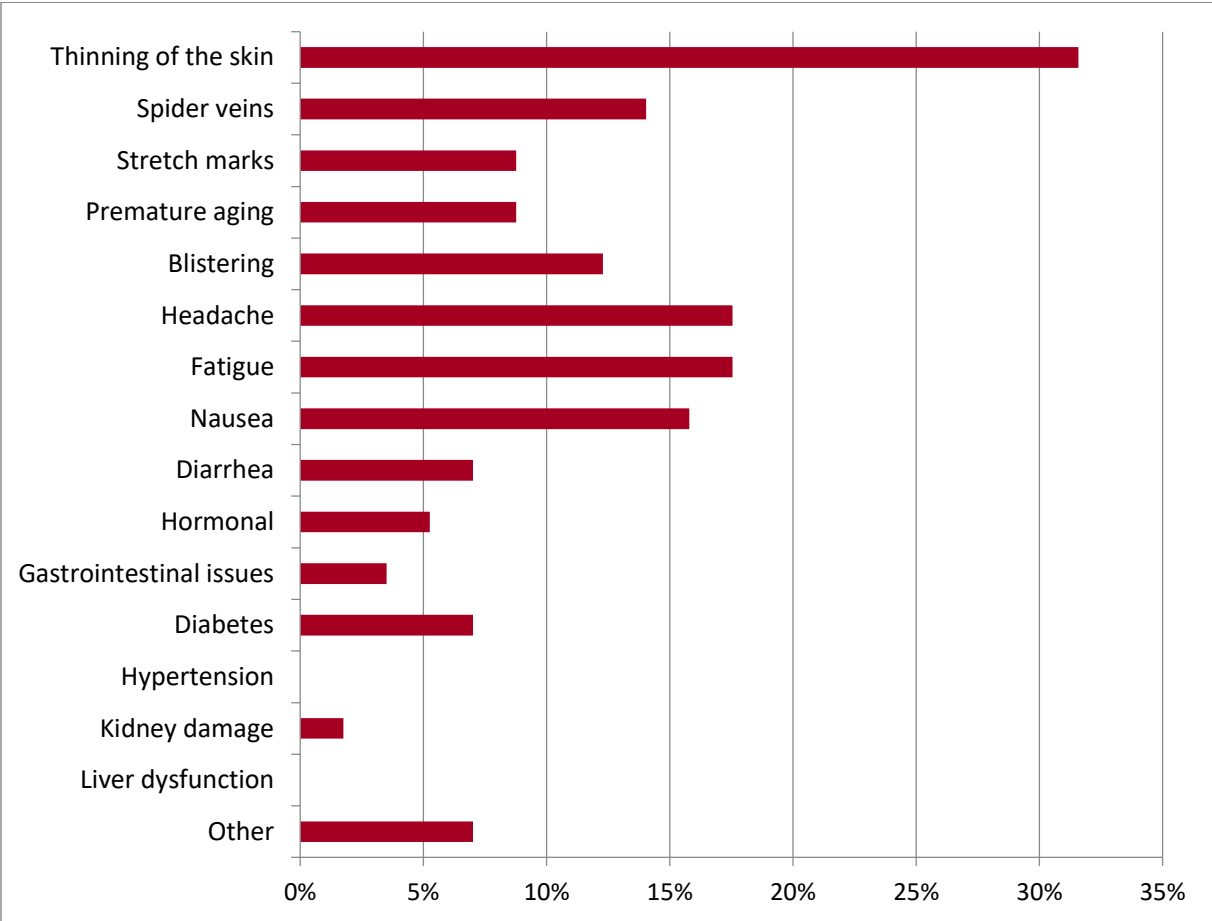
xi. **TREATMENT SIDE EFFECTS/ADVERSE EVENTS**

When caregivers were asked about their loved ones’ experiences with their current treatment, 8% reported severe side effects/adverse events. Of all respondents, 8% reported minor or severe side effects that led to concern over whether the treatment course should continue.



**Physician counselling on treatment side effects:** One-quarter of respondents reported that the physician of the person that they care for had not adequately informed them about their medications.

**Past experiences with treatment side effects/adverse events:** Caregivers reported that treatment side effects were commonly exhibited in those they cared for, the most common being skin thinning, headache and fatigue.



A small subset of patients also reported severe chronic diseases as potential treatment-related adverse events (we did not ask whether treatment and effect causation had been proven), with 7% reporting diabetes and 2% kidney damage.

- 7% reported symptoms not listed: itchiness, difficulty sleeping, slow developmental gains and skin discolouration (may actually be due to under-treating their condition)

## xii. COST OF TREATMENTS

We asked Canadian respondents about their monthly out-of-pocket costs per atopic dermatitis treatments and therapies, and noted considerable variations in expenses.

Item	Median Monthly Cost- (\$)	Range (\$)	n*
<b>Medications</b>			
Oral corticosteroid	23	15-50	4
Cyclosporine A	80	80	1
Methotrexate	0	0	0
Azathioprine	0	0	0
Anti-histamines	20	5-50	13
<b>Topical treatments</b>			
Topical corticosteroid	15	2-300	39
Topical calcineurin inhibitor	50	18-100	3
Ultraviolet light A or B phototherapy	0	0	0
<b>At-home symptom treatment/alternative therapies</b>			
Skin care maintenance <sup>1</sup>	30	5-300	53
Alternative medicines (e.g. acupuncture)	10	10	1
Natural / herbal remedies	20	3-250	13
Skin washing with antiseptic remedies	20	2-100	12

\*n varies per row because not every respondent uses all treatments and therapies; those who did not use a specific treatment/therapy or abstained from responding were excluded in the calculation of monthly cost.

<sup>1</sup>Other costs may be covered through a public or private insurance plan

<sup>1</sup>bathing routine, applying moisturizer

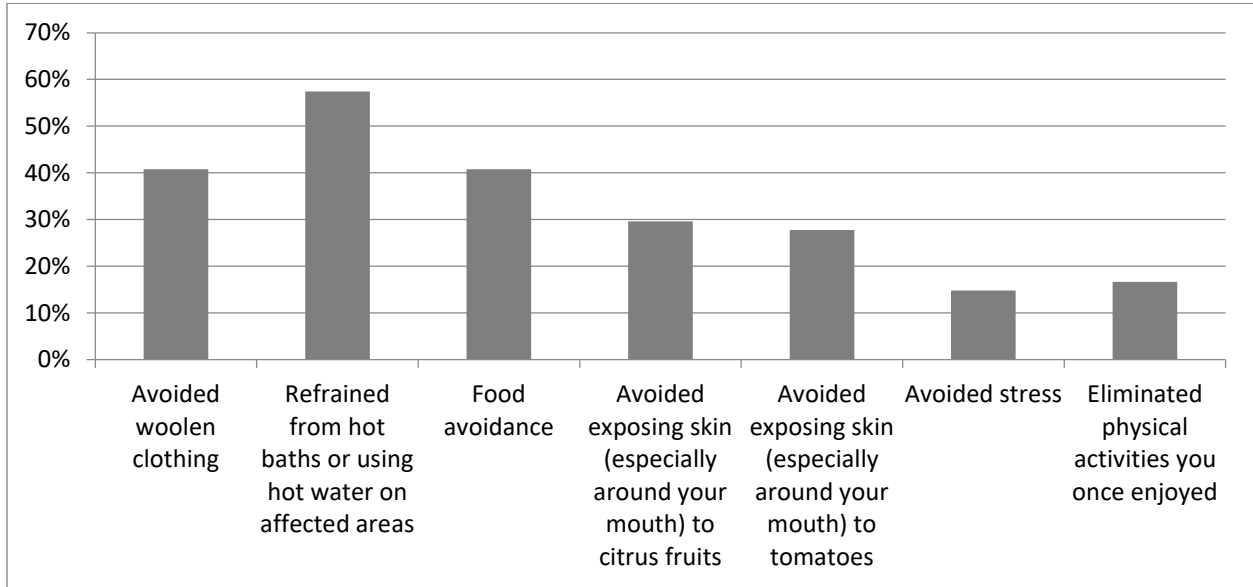
## xiii. IMPACT OF COST

*“I can’t always afford the monthly medications for my daughter because they aren’t covered by my insurance.”*

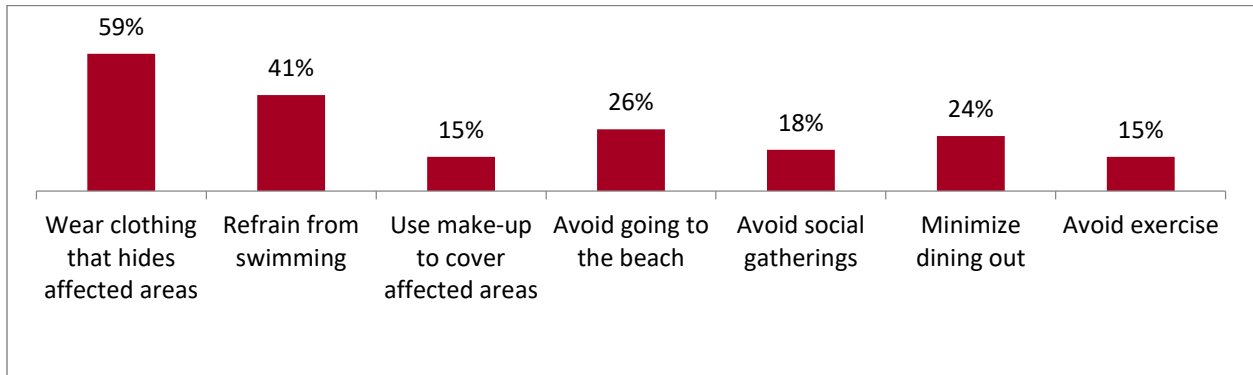
A sizable minority of caregivers (**11%**) reported that the substantial cost of a medication prevented those that they care for from being able to begin a course of treatment. Similarly, **11%** of caregivers also reported that in the past, the individual that they care for stopped using a treatment due to the cost.

#### xiv. LIFESTYLE BEHAVIOURS TO PREVENT AND CONTROL SYMPTOMS

Caregivers report various behaviours to avoid aggravating symptoms of atopic dermatitis.



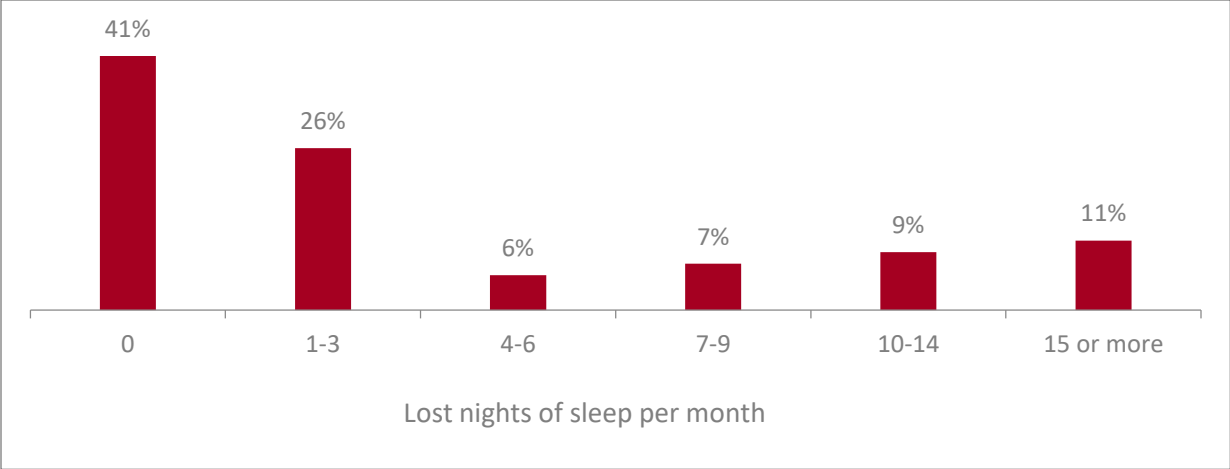
Those with atopic dermatitis have had to modify their lives in order to accommodate their condition, mostly commonly wearing clothing to hide affected areas.



*“Our family wears only cotton. We’ve removed stuffed toys, fabric furniture, carpets... it’s been a total life overhaul.”*

#### xv. IMPACT OF ATOPIC DERMATITIS

- 59% of caregivers reported that atopic dermatitis symptoms affected the sleep of those for whom they provide care



Individuals who missed at least one day of work/school per month*	22%
Individuals whose AD negatively affects ability to be in work/school*	28%
Individuals whose AD negatively affects personal life (social activities, etc.)*	38%
Caregivers who are concerned about their loved ones' next flare	34%
Caregivers whose personal lives are negatively affected by their loved ones' AD	68%

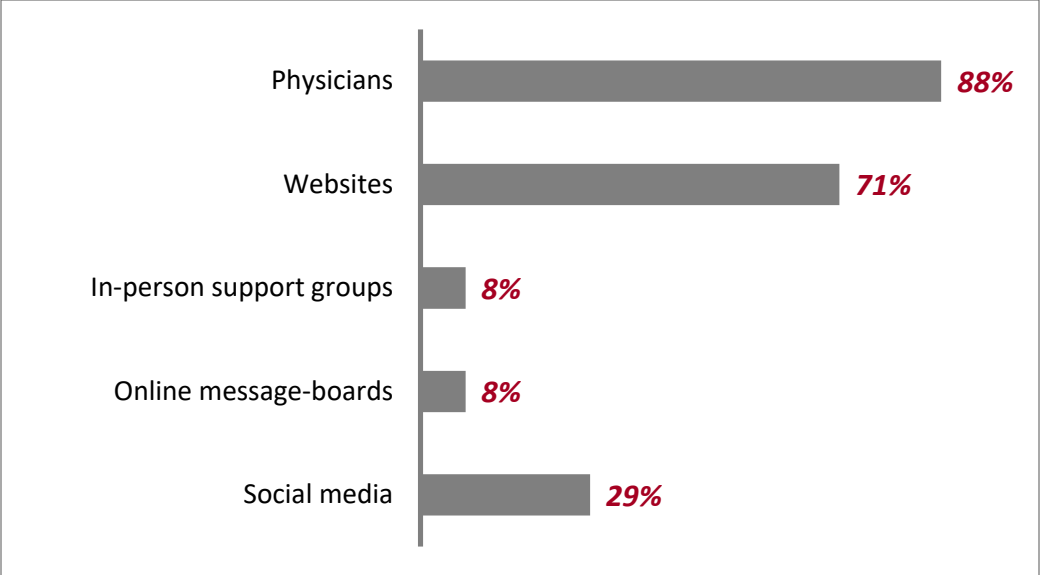
\*As reported by their caregiver

*"I worry about my child's development due to constant, interrupted sleep."*

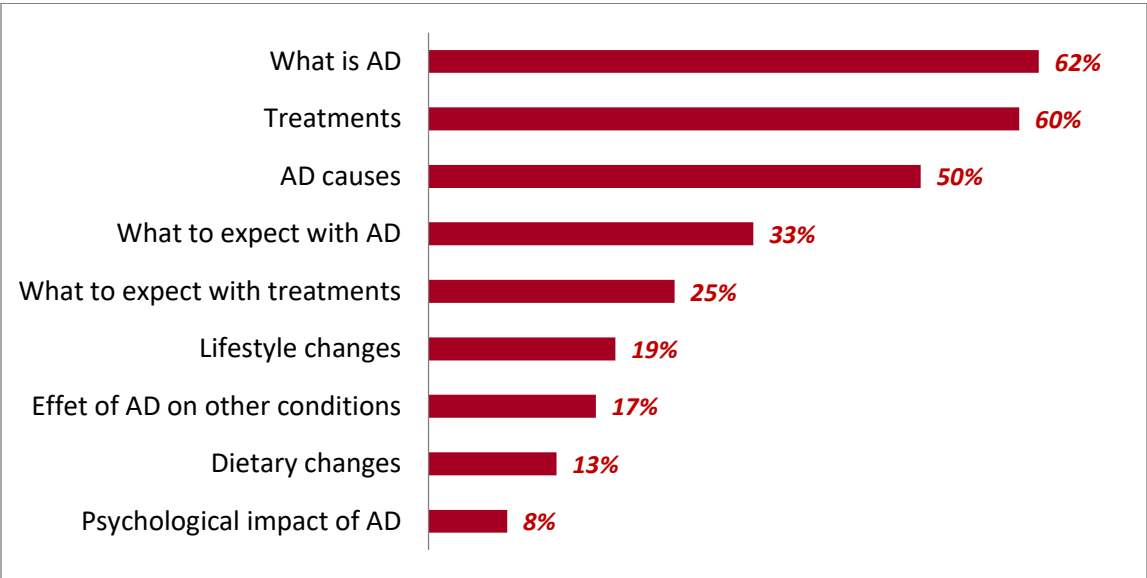
**xvi. KNOWLEDGE AND PATIENT NEEDS**

To gain information about the condition, caregivers primarily turned to their HCPs and also to health websites.

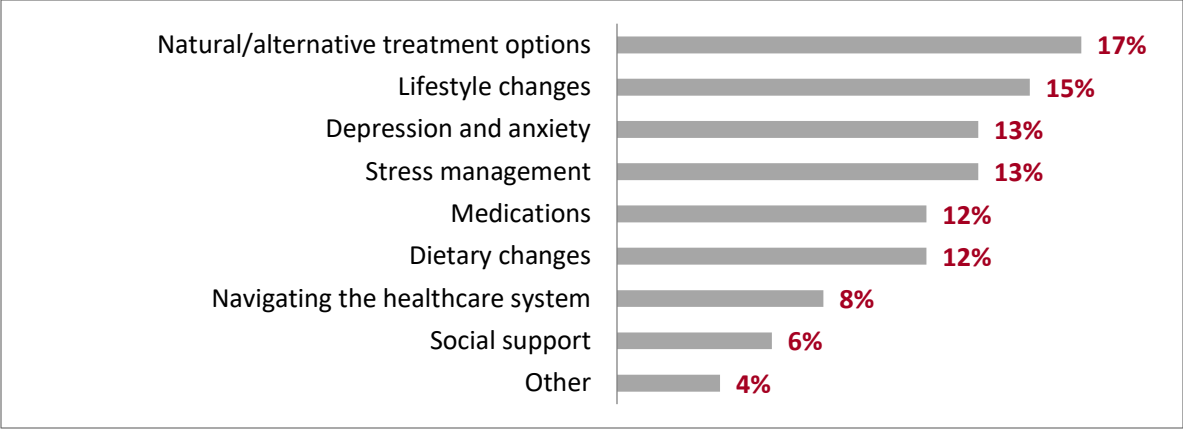




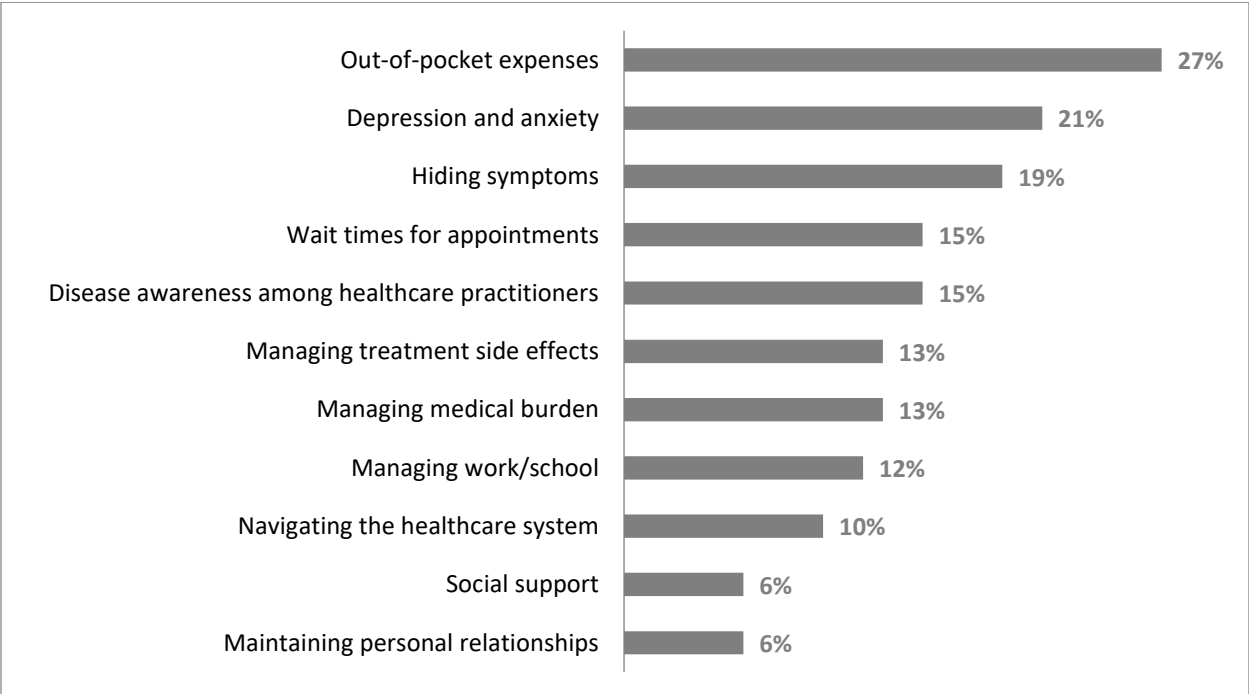
HCPs typically provided caregivers with information about atopic dermatitis background and treatments, but less so on non-medical treatments and dietary and lifestyle changes to prevent and control symptoms.



There were various topics for which respondents expressed the need for more information to help their loved ones, including non-medicated treatments such as natural remedies and lifestyle changes.



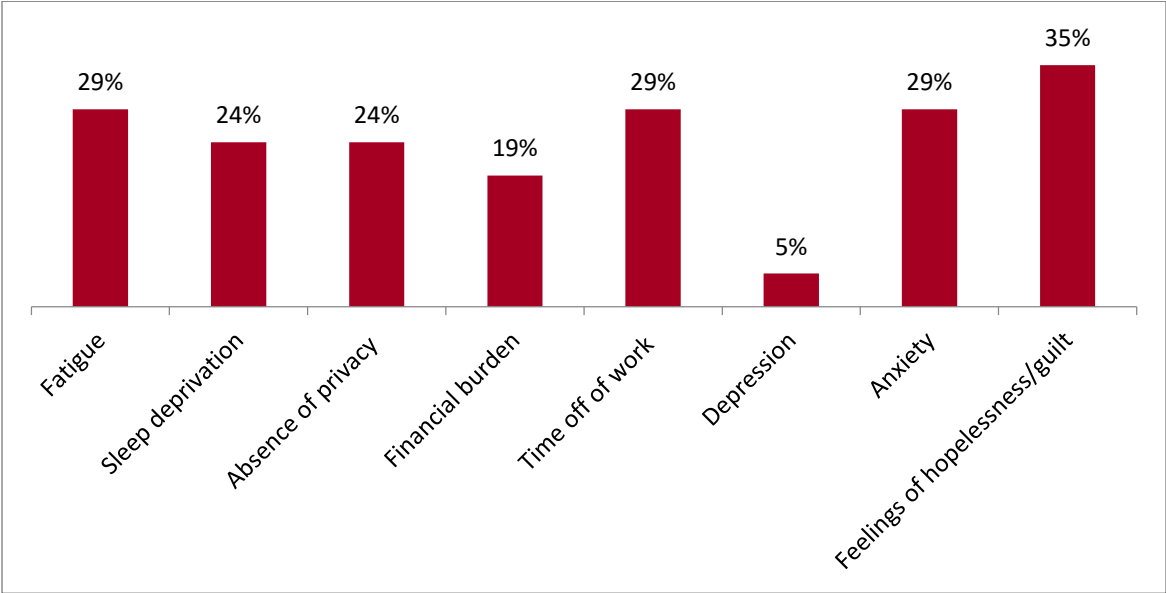
For caregivers, out-of-pocket expenses, depression and anxiety and hiding symptoms were the most common topics of struggle.



Caregivers also reported how caring for their loved ones' condition impacts their own well-being. Thirty-five percent are plagued with feelings of hopelessness and guilt, particularly if they themselves suffer from atopic dermatitis and are concerned that they may have passed it on to their child.

*“I am depressed and without hope because it is so sad to see my baby suffer without knowing how to solve the problem.”*

Nearly 30% are plagued with fatigue and anxiety and an additional 29% expressed that taking care of someone with atopic dermatitis affected their ability to work, requiring them to take time off as needed.



*“This condition affects every aspect of my life and I feel terrible that I’ve passed it down to my children and grandchildren.”*

## Discussion and Recommendations

The results of the ADPE Survey describe the patient journey from the first symptom of atopic dermatitis to ongoing disease management. Our breakdown of mild, moderate and severe patients was similar to the split that has been observed in the literature of 45%, 45% and 10%, respectively,<sup>3</sup> and our comprehensive survey characterized the challenges faced by patients with mild and moderate/severe disease and caregivers as they try to prevent and control the symptoms of this condition.

Atopic dermatitis is typically diagnosed within months, indicating strong HCP awareness of its clinical presentation. Patients and caregivers are generally satisfied with their experiences within provincial healthcare systems, perhaps partly due to their fairly quick diagnosis. Family physicians, pediatricians and dermatologists commonly comprise the patient's management team, as was also found in the ESC Survey results. Of note, we observed that more than half of respondents reported that no one helps them manage their condition, suggesting that for many, and most especially those with minor illness, care consists of mainly self-directed lifestyle and behavioural changes.

Those with mild atopic dermatitis were typically only minimally affected by their condition; they were able to find an effective treatment fairly quickly, if they required treatment at all, and the impact of their illness on their work/school and personal lives was reported as minor. However, for those with moderate/severe atopic dermatitis, the consequences on quality of life can be far more significant with the visible nature of this condition causing embarrassment and discomfort, affecting ability to sleep without disruption, to focus on work while experiencing persistent itching, and to socialize and be intimate during a flare-up. Caregivers also reported that the negative impact of atopic dermatitis on their own lives commonly included feelings of hopelessness, as well as fatigue and anxiety.

*“The eczema on my eyelids is disfiguring, and prevents me from wearing make-up or contact lenses. I am embarrassed to be seen during flare-ups which happen almost weekly.”*

Both patients and caregivers reported that the available treatments have limited effect. Caregivers in particular often opt for non-prescription options, possible due to fear of using potentially harsh medications on their children. They may also be instructed by their HCPs to be cautious of using such treatment in younger patients. Of prescribed treatments, topical corticosteroids seem to offer the most improvement, though they may not represent a long-term solution that is without side effects. Additionally, several patients described their experiences with steroid withdrawal after years of use. This corroborates a 2006 survey of Canadian patients which found that 71% were concerned about the safety profile of topical corticosteroids.<sup>8</sup> While patients and caregivers are clearly willing to try effective medications to treat this condition, safe, effective and long-term options are limited. It has been well over 10 years since Health

Canada approved a new treatment for atopic dermatitis and it is clear that there is a need for new and effective options.

Immunosuppressive medications have been used by 39% of those with moderate/severe atopic dermatitis and 18% of those with mild atopic dermatitis, despite their use being off-label only and that have the potential to cause significant side effects. Of caregivers, 32% also reported that those they look after have used these medications to manage atopic dermatitis. On a related note, the ESC Survey found that 63% of those who used such off-label medications reported that they did not provide a meaningful improvement.<sup>7</sup> The three most pressing needs for information were around medications and treatments with this condition, further illustrating the importance of developing medications for atopic dermatitis with improved risk:benefit profiles.

A small proportion of patients reported that they had either had to refrain from beginning a medication or discontinue a medication due solely to cost. Additionally, patients and caregivers named out-of-pocket costs as one of their biggest atopic dermatitis-related struggles. In a country where each province is responsible for its own healthcare decision-making including selecting which medications are publicly funded, this further highlights the inequities that patients experience when managing chronic conditions.

Our costing data show that depending on which regimen is being attempted, there is potential for considerable out-of-pocket costs for oral and topical medications, as well as natural and at-home treatments. We observed a large range in costs with patients spending up to \$300 per month on one medication alone. Given that individuals with atopic dermatitis often try more than one medication before finding one that helps to relieve their symptoms, this can be an expensive endeavor. A 2006 survey of 76 Canadian patients found that the annual cost per patient was \$282 for those with mild atopic dermatitis, \$454 for moderate atopic dermatitis, and \$1242 for severe atopic dermatitis, with a cost of \$4.1 billion to Canada's healthcare system.<sup>8</sup>

The impact of atopic dermatitis is evident. Twenty-seven percent of caregivers reported that the person that they care for loses 7 or more nights of sleep a month due to their condition. International studies have previously documented the association between the persistent itch of atopic dermatitis and sleep disturbance.<sup>9-11</sup> The short and long-term effects of interrupted sleep are challenging for anyone, but particularly unfortunate for children whose resulting fatigue has the potential to affect growth, emotional well-being and ability to learn.

We found that individuals with moderate/severe atopic dermatitis miss an average of 2.4 work days a month. This is consistent with findings from the 2010 U.S. National Health Interview Survey which reported that 12.2% of those with atopic dermatitis missed 1-2 days of work, and 2.3% missed 3 or more days.<sup>9</sup> The financial and emotional implications of absenteeism can be very detrimental on the well-being of those with this condition.

Our results corroborated many findings from the recent ESC survey.<sup>7</sup> However, there are several domains for which our results differed, with the ESC survey indicating a more severe impact of atopic dermatitis on quality of life; for example, the ESC survey found that 91% of respondents were negatively impacted daily by their condition while 67% of our respondents with moderate or severe atopic dermatitis indicated that their personal lives were negatively affected by their condition. Our survey found that 26% lost 7 or more nights of sleep monthly while the ESC survey reported a nearly doubled figure (50%). Sixty-four percent of ESC Survey respondents suffered from anxiety, and 44% from depression, compared to 45% and 37% of our survey's respondents, respectively. There could be several explanations for these differences, related to variations in sampling strategies. However, the primary reason is likely that a larger proportion of the ESC survey's sample had severe atopic dermatitis, compared to our moderate/severe sample (44% vs. 24%), which translated to their respondents reporting a more negative impact of their condition.

Given the atopic dermatitis is a prevalent condition in Canada, and that more than half of those plagued by it have a moderate or severe manifestation which impacts their emotional and physical well-being, it is important to determine how to better support these patients. We advocate for the following changes to patient care:

- Develop educational materials to ensure that those newly diagnosed with atopic dermatitis are given valuable information on prevention and control through both prescription and non-prescription means
- Provide funding for new treatments that show promise in managing symptoms and whose short- and long-term safety profile are acceptable
- Increase understanding of the impact of skin diseases, such as atopic dermatitis, on mental health, and create programs and services to address related patient and caregiver needs
- Empower patients and caregivers with the tools and mechanisms to support their journey and navigate the healthcare system once diagnosed
- Provide sufficient training for family physicians and pharmacists on available medications for atopic dermatitis, including dosing and side effects

## Acknowledgements

This study is supported by a grant from Pfizer Canada.

The CSPA is grateful for the expert contribution from Dr. Isabelle Delorme and Dr. Aaron Drucker, and from Ms. Goldie Putrym (<https://www.theeczemamom.com/>), as well as the assistance of JRL Research & Consulting Inc. for survey development and analysis.

## References

1. Thomsen SF. Atopic dermatitis: natural history, diagnosis, and treatment. *ISRN Allergy* 2014;354250.
2. Tollefson MM, Brucknew AL. Atopic dermatitis: skin-directed management. *Pediatrics* 2004;134(6):e1735-44.
3. Drucker AM, Wang AR, Li WQ, Sevetson E, Block JK, Qureshi AA. The burden of atopic dermatitis: summary of a report for the National Eczema Association. *J Invest Dermatol* 2017;137(1):26-30.
4. Ipsos-Insight Health. Eczema prevalence in Canada. 2003.
5. Williams H, Robertson C, Stewart A et al. Worldwide variation in the prevalence of symptoms of atopic eczema in the International Study of Asthma and Allergies in Childhood. *J Allergy Clin Immunol* 1999;103:125-38.
6. McAlister RO, Tofte SJ, Doyle JJ et al. Patient and physician perspectives vary on atopic dermatitis. *Cutis* 2002;69:1-6.
7. Eczema Society of Canada. Atopic dermatology quality of life report: 2016/2017 survey results. [https://eczemahelp.ca/wp-content/uploads/2017/08/ESC\\_QUALITY\\_OF\\_LIFE\\_REPORT\\_2017.pdf](https://eczemahelp.ca/wp-content/uploads/2017/08/ESC_QUALITY_OF_LIFE_REPORT_2017.pdf)
8. Barbeau M, Lalonde H. Burden of atopic dermatitis in Canada. *Int J Dermatol* 2006;45:31-36.
9. Silverberg JI, Garg NK, Paller AS, Fishbein AB, Zee PC. Sleep disturbances in adults with eczema are associated with impaired overall health: a US population-based study. *J Invest Dermatol* 2015;135(1):56-66.
10. Chamlin SL, Frieden IJ, Williams ML, Chren MM. Effects of atopic dermatitis on young American children and their families. *Pediatrics* 2004;114(3):607-611.
11. Zuberbier T, Orlow SJ, Paller AS et al. Patient perspectives on the management of atopic dermatitis. *The Journal of allergy and clinical immunology* 2006;118(1):226-232.