

# The Skin I'm In

---

2022 UPDATE

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

**November 2022**

Canadian Skin Patient Alliance

Eczéma Québec



Canadian Skin Patient Alliance  
Alliance canadienne des  
patients en dermatologie



## SURVEY TEAM

---

The survey team consisted of the following:

- Rachael Manion (Canadian Skin Patient Alliance)
- Sabrina Ribau, R.Kin (Canadian Skin Patient Alliance)
- Charlie Bouchard (Eczéma Québec, McGill University Health Center - Center of Excellence for Atopic Dermatitis)
- Gaurav Isola M.Sc. (Eczéma Québec, McGill University Health Center - Center of Excellence for Atopic Dermatitis)
- Dr. Carolyn Jack (Eczéma Québec, McGill University Health Center - Center of Excellence for Atopic Dermatitis)
- Douglas Michael Lebo (Eczéma Québec, McGill University Health Center - Center of Excellence for Atopic Dermatitis)
- Dr. Jennifer Pereira (JRL Research & Consulting Inc.)

Translated by : Benjamin Forget (Eczéma Québec, Université de Montréal)

## ACKNOWLEDGEMENTS

---

This report was supported by funding from AbbVie, LEO Pharma, Pfizer, and Sanofi.

Survey incentives in the form of skin products were provided by Galderma (Cetaphil), Beiersdorf (Eucerin) and La Roche Posay.

abbvie



# CONTENTS

---

EXECUTIVE SUMMARY .....	5
RECOMMENDATIONS.....	8
BACKGROUND .....	11
METHODS .....	13
RESULTS.....	14
i. Demographics.....	14
ii. Discussion .....	14
SECTION I: Symptom Onset and Diagnosis .....	15
i. History of atopic dermatitis symptoms and diagnosis.....	15
ii. Discussion .....	16
SECTION II: Severity of Atopic Dermatitis.....	17
i. Symptoms .....	17
ii. Diagnosis of other atopic diseases .....	18
iii. Discussion.....	18
SECTION III: Experiences with Medical Care for Atopic Dermatitis After Diagnosis .....	19
i. Healthcare visits for symptom management.....	19
ii. Satisfaction with medical care for atopic dermatitis .....	20
iii. Discussion.....	21
SECTION IV: Use of Treatments for Atopic Dermatitis .....	22
i. Experiences with atopic dermatitis treatments.....	22
ii. Concerns with topical corticosteroid use.....	23
iii. Side effects of treatments for atopic dermatitis.....	24
iv. Cost of treatments as a barrier to use.....	25
v. Treatment goals.....	26
vi. Discussion.....	27
SECTION V: Behaviours and Activities to Manage Symptoms of Atopic Dermatitis.....	28
i. Avoidance of behaviours and activities.....	28
ii. Discussion .....	29
SECTION VI: Impact of Atopic Dermatitis on Overall Quality of Life and Daily Life.....	30
i. Dermatology Life Quality Index findings .....	30
ii. Impact of atopic dermatitis on daily life .....	31
iii. Time spent on activities related to symptom management.....	32
iv. Struggles in the management of atopic dermatitis symptoms.....	33
v. Discussion .....	34

SECTION VII: Primary Sources of Information on Atopic Dermatitis..... 34

SECTION VIII: Impact of Caregiving on Well-being ..... 34

    i. Impact on productivity and quality of life ..... 34

    ii. Discussion ..... 36

SECTION IX: Healthcare Resource Utilization for Atopic Dermatitis..... 37

    i. Emergency room visits ..... 38

    ii. Hospitalizations..... 41

REFERENCES ..... 45

# EXECUTIVE SUMMARY

---

**Atopic dermatitis (AD), also known as atopic eczema, is the most common and burdensome skin condition globally. Patients with AD suffer terrible itch and open sores due to chronic inflammation.**

**Extensive research has highlighted how significantly AD can impact the lives of patients and caregivers, impairing sleep, attention, concentration, and daily functions as simple as wearing clothes, all of which profoundly influence health-related quality of life and productivity. The burden of AD, which may affect up to 20% of Canadians, was explored in a 2018 survey by the Canadian Skin Patient Alliance, a not-for-profit patient organization formed to support Canadians impacted by skin, hair, and nail conditions.**

**The resulting report illustrated the considerable effects of this condition on daily activities, as well as emotional and mental health. The survey findings also demonstrated that patients perceive a gap in the availability of safe and effective treatment options.**

**Based on these results, recommendations were made to key healthcare stakeholders, calling for the provision of funding for new treatments and the creation of services and support to address the mental health needs of individuals with AD and their caregivers.**

**Since that time, several new medications have been approved for use in Canada, including two biologics and two oral Janus kinase (JAK) inhibitors, for the treatment of moderate to severe AD. Given the evolution in the treatment landscape, CSPA collaborated with Eczéma Québec on a new survey to build on the previous body of work and further understand the current experiences of individuals with AD and their caregivers. Eczéma Québec is an evidence-based network of patients and healthcare providers that develop AD-related resources based on international best practices and is affiliated with the internationally accredited McGill University Health Center, Center of Excellence for Atopic Dermatitis.**

## SURVEY HIGHLIGHTS

---

The survey was disseminated in November 2021, and 118 survey responses were received: 108 from individuals with AD, and 10 from caregivers.

Of the 118 survey respondents:

- **99% were from Canada**
  - **49% from Quebec**
- **83% were female**
- **62% were adults between the ages of 16 and 49**
- **81% reported symptoms consistent with moderate to severe AD**

Most respondents first started having symptoms of AD as a child (64%) although for nearly one-third, symptom onset began in adulthood, consistent with an increased recognition of adult-onset disease. Accessing the healthcare system for support with their AD was challenging.

Receiving a diagnosis took up to one year for most survey participants, with 27% diagnosed within 30 days, and 23% waiting more than 12 months. For half of the respondents, their family physician was the first person to diagnose their condition; diagnosis by a dermatologist was made in less than one-third of patients (28%). One-fifth of respondents see their family physician or dermatologist at least five times a year for AD, indicating significant healthcare use.

In contrast, one-quarter (23%) of respondents reported that they do not have healthcare support for their AD symptoms, and instead manage their condition entirely on their own. The majority of respondents have been disappointed with their healthcare experiences for AD, with 30% reporting that they were dissatisfied and 11% strongly dissatisfied.

Respondents have tried numerous ways of managing their condition. While 87% of respondents reported using steroid creams, only 28% indicated significant improvement with them, while 59% reported little improvement. Half of respondents expressed reservations around the use of topical corticosteroids (TCS), reporting concerns for risk of skin damage and even long-term impact on health.

Patients report stopping TCS treatment as soon as possible and using such therapy when deemed absolutely necessary, indicating potential barriers to effective use of treatments.

The majority of respondents reported having never attempted oral JAK inhibitor drugs (96%), immunomodulating agents (methotrexate, mycophenolate mofetil, and cyclosporine) (86%), phototherapy (74%), or oral/injectable corticosteroids (73%).

Only 12% of respondents reported that they had used biologics to treat their manifestations of AD. However, within the small sample of biologic users, two-thirds reported significant improvement in symptoms, making this treatment the most effective one for those surveyed. Among respondents who have used treatments for AD in the last year, 37% reported experiencing adverse events, most commonly thinning of the skin (topical therapy) and worsening of symptoms.

Costs of medications are important to people living with AD. For 29% of respondents, the cost of a treatment for AD has impacted their decision of whether to take it (14% have abstained from a treatment altogether) and/or cost has impacted the duration of use (10% have taken a prescribed treatment less frequently than prescribed to make it last longer).

Given each federal, provincial and territorial public drug plan in Canada is responsible for its own decisions around which medications are publicly funded for its residents, not all medications indicated for AD are covered by public health plans across the country, and out-of-pocket fees can be significant. Access to medications for AD through private plans is not always robust and can present barriers for patients.

Living with AD is associated with a constant need for vigilance in the management of what can be a lifelong condition. Patients suffer from the costs of time and energy spent attempting to identify triggers that exacerbate their symptoms. The majority of respondents (89%) indicated that they avoid activities such as taking long baths, and wearing clothes made from specific fabrics, such as wool.

Respondents also used various techniques to hide their bodies, a behaviour associated with shame: 81% of patients report that they covered afflicted areas of their skin under makeup and clothing, or even avoided certain social or outdoor activities entirely due to their condition.

The negative impact of AD on daily life was assessed using the Dermatology Life Quality Index, which indicated a large or very large effect by 47% of respondents, while only 4% reported that their lives were unaffected. Detrimental effects on mental health and sleep were common, with one-quarter of patients reporting that their sleep was disturbed every night, half (43%) reporting that it impacted relationships with others, and nearly one-third (29%) having impaired capacity to engage in social and leisure activities.

Management of AD symptoms was challenging for three-quarters of respondents. The most commonly reported impacts were hiding symptoms (62%), suffering through wait times for medical appointments (49%), and difficulty accessing a specialist (46%).

Of the ten caregivers who responded to the survey, six reported that they provide care to a child, and four indicated they provide care to an adult.

Forty percent of this group reported that caring for someone with AD had a very negative effect on their lives, manifesting as feelings of guilt and hopelessness, anxiety, fatigue and disturbed sleep. Further research is needed to fully explore these results in a larger population of individuals who provide care to those with AD.



## CANADIAN INSTITUTE OF HEALTH INFORMATION AND HEALTHCARE UTILIZATION ASSOCIATED WITH AD

---

We examined Canadian Institute of Health Information data on healthcare utilization associated with AD, and found considerable burden of disease, ER visits and hospitalizations.

There is no laboratory or imaging-based diagnostic test for AD; instead, diagnosis requires attentive examination of skin for disease distribution over the whole body and a lengthy history, particularly in adults.

Limited expertise by healthcare providers may have influenced use of diagnostic coding of AD at this point of care; the majority of burden was found coded as dermatitis and eczema rather than specifically as AD.

With regards to ER visits for AD as main problem, specifically labelled cases are found mostly in the 0-11 and 18-64 age groups, which is consistent with prevalence of AD in childhood and adulthood.

Interestingly, national data shows that hospitalizations for dermatitis and eczema are mainly found for adults, highlighting the burden beyond childhood. Additionally, females are hospitalized more than males for eczema and dermatitis.

This may be due to women being more likely to seek treatment, and possible sex-differences that increase or decrease the burden on a person's quality of life. Although AD may be slightly more prevalent in females, there is currently weak evidence to suggest that sex hormones strongly influence the development or worsening of the disease.

We found significant limitations in available data and in the quality of data collected on health-care utilization for patients with AD.

Importantly, data on health-care usage in Quebec was not available in time for this report. As such, it remains difficult to estimate the true burden of AD in Canada.

Nonetheless, our findings uncover important patient needs and opportunities for improvement in the treatment and management of AD and can be used to inform research and policy directions. CSPA and Eczéma Québec have outlined 7 recommendations to improve the lives of individuals with AD.

## RECOMMENDATIONS

---

Based on the survey findings, we have developed recommendations to improve the disease management and quality of life of individuals with atopic dermatitis (AD). As shown below, we have also identified key stakeholders who can lead the charge in improving health outcomes and quality of life for people in Canada living with atopic dermatitis.

### **I. Increase access to new treatment options for atopic dermatitis that are safe and effective.**

Atopic dermatitis is an incredibly variable condition across time, lifespan, and patient background. This is commonly referred to as "endotype", describing how disease and immune system factors may be different for different patients and highlighting the need for a range of treatments that can address these differences. There is a clear need for treatments that control disease rapidly; yet, as a lifelong condition, rapid control must be balanced with exposure risks over time. We are only just beginning to witness important advances in tailored treatment options for patients but many remain inaccessible to patients because of their out-of-pocket costs. As the most burdensome skin disease globally, it is important that individuals with AD have access to a range of affordable, safe and effective treatment options that allow them to achieve long-term skin clearance, manage their symptoms and improve their health and wellbeing throughout their entire lives.





**II. Increase awareness around the relationship between atopic dermatitis and other related diseases and screen those at risk.** Family physicians are typically the first clinician visited by people with the initial symptoms of AD and are part of their medical team to manage this condition. It is important to educate clinicians who are the first point of contact for patients on how to diagnose AD, how to measure disease severity, and how to recognize common comorbidities of eczema (such as asthma, allergies that affect the eyes and nose, anxiety, and depression) to ensure that those who are diagnosed with one are screened for the others. In this way, appropriate treatment can begin sooner.



**III. Establish a Project ECHO to support continuing education for interdisciplinary health care providers who support patients with atopic dermatitis.** Project ECHO is an avenue for interdisciplinary health care providers to share and learn best practices and receive advice on managing care for various conditions. Continuing education and collaborative relationships among primary care providers, dermatologists, allergists, and other providers involved in caring for people with AD and other atopic conditions may support improved knowledge and awareness of effective disease management strategies and the administration of new treatment options.



**IV. Ensure that individuals diagnosed with atopic dermatitis and their caregivers are offered recognition and support for the impact the disease has on their wellbeing.** People with AD and their caregivers very frequently experience sleep disturbances, anxiety, depression, and feel self-conscious about their skin. Support for managing these issues must be part of a comprehensive treatment strategy for each individual with AD. A first step would be to conduct a mental health screening and an assessment of sleep quality for every patient with AD, and offer support, care, access to resources, and referral to a specialist, when appropriate. It is important to recognize that the detrimental effects of AD are not purely physical.



**V. Ensure that employers and schools recognize that atopic dermatitis is a serious disease and support accommodations for patients.** The symptoms of AD include physical and emotional manifestations and can lead to absences and lower productivity at work and school. Increased education about disease and skin health should be integrated into schools, and increased awareness of this condition, and the need for accommodations – such as uniform modifications which do not exacerbate the skin, and sun avoidance activities – is needed for both schools and workplaces.










**VI. Increase awareness of sex and gender differences in the prevalence of atopic dermatitis.** Women are more likely to suffer greater impacts on their health-related quality of life due to their AD. This was also demonstrated in our survey's respondents, the majority of whom self-reported as female. It is important to be conscious of, and sensitive to, increased prevalence in women when developing screening programs as well as educational and support tools. Additionally, further research is needed to explore sex-differences and to optimize equitable health trajectories across the lifespan for patients in Canada.



**VII. Implement national data collection practices for atopic dermatitis across the country.** There appears to be a large gap in clinician capacity to identify and diagnose AD, especially in adult patients; this is compounded by the lack of laboratory and/or imaging-based tools. Clinicians need improved training and/or tools to help diagnose and measure severity of AD. This is required to support appropriate diagnostic coding which is urgently needed to study and to build evidence-based management in Canada.



-  **ORG:** Patient groups, including the CSPA and Eczéma Québec
-  **FED:** Federal government
-  **PRIV :** Private payers
-  **RS:** Scientific researchers and funding organizations, such as the Canadian Institutes of Health Research
-  **CADTH, INESS, pCPA:** Canadian Agency for Drugs and Technologies in Health, Institut national d'excellence en santé et en services sociaux (INESSS)
-  **HCP:** Healthcare providers
-  **P/T:** Provincial and Territorial governments

## BACKGROUND

---

Atopic dermatitis (AD) is the most common type of eczema. AD is also known as atopic eczema and commonly referred to as eczema. It is a chronic inflammatory condition characterized by a weakened or damaged skin barrier, resulting in flares of itchy and dry skin, with a propensity to ooze and crust.<sup>1,2</sup>

In light skin, AD often presents as red skin, while in dark skin, it may appear as brown, purple or ashen grey.<sup>2</sup> It is estimated that up to 17% of Canadians experience AD at some point in their lives.<sup>3</sup>

While there is a common misconception that AD is a mild childhood disease that is outgrown, many people with AD have moderate to severe symptoms, reflecting varying degrees of severity and frequency.

Symptoms can be ever-changing, fluctuate over time, and are potentially life-long.<sup>4</sup> People with AD are at increased risk for other atopic conditions including asthma and allergies as well as mental health impacts.<sup>5-7</sup> Patients with AD suffer from dysregulated immune responses that are seen in both the skin and in the blood; this dysregulation increases with severity.

There are treatment options available to help achieve disease control and long-term remission at various stages of disease severity that aim to reduce the frequency and severity of flares and symptoms.<sup>8</sup>

Topical corticosteroids (TCS) and topical calcineurin inhibitors (TCI), as well as newer topical therapies (PDE4i) are considered effective first-line treatment when used alongside behavioural changes and general measures for promoting skin health.

Topical Steroid Withdrawal Syndrome (also known as Red Skin Syndrome), a condition characterized by a red rash from the original site of TCS application and extending to other areas, can develop after prolonged use of TCS.<sup>9</sup>

Extensive therapeutic education may be required to mitigate concerns and/or risks of adverse effects and the burden of treatment must also be considered, especially in situations where the disease affects >10% of the body surface or when someone has the disease for life.

Many patients suffer from topical treatment failure, relapse and/or rebound effects, especially when topical therapies are needed to be used often or for a long time over large areas of the body; challenges with adherence to these treatments is common.<sup>10-12</sup>

For those with moderate to severe disease and for whom topical therapy is ineffective, other treatments, including phototherapy and/or systemic therapy – prescription drugs that work through the entire body - may be required to reduce skin inflammation and accompanying symptoms. Biologics and Janus kinase (JAK) inhibitors represent promising treatment options for AD, and since 2017, four have been approved for use in Canada.<sup>13-15</sup>

Implications of AD on daily life have been documented worldwide, including depression and anxiety,<sup>16,17</sup> increased risk of suicide,<sup>18</sup> attention deficit/hyperactivity disorder,<sup>19</sup> poor sleep quantity and/or quality,<sup>20,21</sup> and decreased productivity at work.<sup>22</sup>

Given both the prevalence and chronic nature of AD, the impacts of this condition have the potential to be very difficult and long-lasting and affect a large number of Canadians.

In 2017, the Canadian Skin Patient Alliance released a report based on the Atopic Dermatitis Patient Experience Survey entitled “The Skin I’m In: A National Report of the Patient and Caregiver Experience with Atopic Dermatitis.”<sup>23</sup> The survey was completed by 194 individuals – 132 from individuals with AD and 62 from caregivers – and the findings showed:

- Those with moderate/severe AD 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 heavily impacted: 68% indicated that this condition negatively affects their lives

Given that the treatment landscape for AD has changed considerably since 2017, it is important to understand how patients currently interact with the healthcare system.

The aim of this report is to contribute to our understanding of the lived experiences of people in Canada with AD and their caregivers.

Survey respondents were asked to share their experiences spanning from diagnosis to ongoing disease management, including symptom severity, impact on quality of life and overall wellbeing, treatment effectiveness, and satisfaction with the health care system.

The findings outlined in this report uncover important patient needs and opportunities for improvement in the treatment and management of AD in Canada and can be used to inform research and policy directions.

# METHODS

---

CSPA and Eczéma Québec collaborated to create the survey following a scoping review of the literature on methods for surveying AD in adult populations.

In order to address the treatment experiences and impact on quality of life, scientifically tested (validated) questions concerning patient-reported AD severity were included: the Patient Oriented Eczema Measure (POEM)<sup>24</sup> and the Dermatology Life Quality Index (DLQI).<sup>25</sup>

POEM is a validated tool used to score the severity of AD based on responses to seven questions about frequency of symptoms in the past week. Based on the responses, scores are categorized as clear or almost clear, mild, moderate, severe, and very severe.<sup>24</sup>

The DLQI is a 10-question tool designed to measure the health-related quality of life of individuals with dermatological conditions. This measurement asks about the emotional impact of their condition, as well as its effect on their ability to be social, be productive, and be active.<sup>25</sup>

The overall goal of the survey was to more comprehensively examine how all aspects of daily lives are affected by AD. The majority of the survey asked questions of individuals with AD; those acting as caregivers were invited to answer questions on behalf of the individual for whom they provide care. There was also a caregiver-specific set of questions about their own experiences.

The survey was created in RedCap (<https://www.project-redcap.org/>) and designed to be completed within 25 minutes. The survey was composed of sections, and upon completion of a section, respondents became eligible for prizes including skin care samples, subscriptions

to an online mindfulness program, draws for skin care products, participation in a live question and answer session with Dr. Carolyn Jack (dermatologist), and access to the EczemaQ self-management app in its beta phase.

## Eligibility criteria

Either diagnosed with AD by a healthcare provider or self-diagnosed with AD based on symptoms or acting as a caregiver to an individual with AD

Although recruitment was very Canada-focused, all individuals with AD were eligible to participate, regardless of geographical location, since many patient experiences regarding the impact of this condition are likely to be irrespective of place of residence.

## Survey dissemination

We disseminated the survey link through a number of methods:

- CSPA's website, newsletter, social media channels, and email lists
- Eczéma Québec's email list and social media channels
- Network of dermatologists

The survey was open from November 1 to 30, 2021.

We supplemented the survey results with data from the Canadian Institute for Health Information (CIHI) on AD-related ER visits and hospitalizations from 2016 to 2020, to gain a fuller understanding of healthcare utilization associated with this condition.

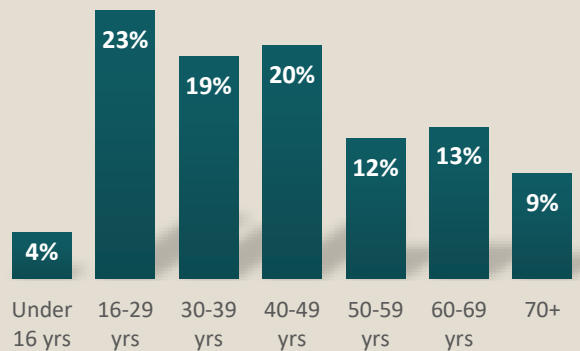
# RESULTS

In total, survey responses were received from 118 eligible respondents: 108 individuals with AD and 10 caregivers. Results are presented below.

## i. Demographics

Of the 118 eligible respondents, 96% were adolescent-adult; 83% self-identified as female, 12% as male, 4% as non-binary, and 1% preferred not to specify. The respondents represented a spectrum of ages, with more than half between the ages of 16 and 49 years.

**Respondents in each age group (n = 118)**



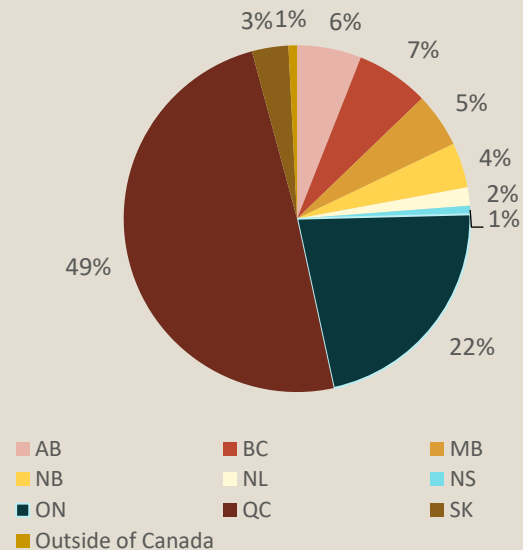
Of all respondents, 103 identified as Caucasian/White (87%) and the second most represented group was Indigenous/Aboriginal (8%).

**Respondents of each cultural, ethnic or racial background (n = 118)**

<b>White</b>	<b>87%</b>
<b>Indigenous/Aboriginal</b>	8%
<b>East Asian</b>	3%
<b>Don't know</b>	3%
<b>Arab / Middle Eastern</b>	2%
<b>Filipino</b>	2%
<b>Southeast Asian</b>	2%
<b>South Asian</b>	2%
<b>Other*</b>	2%
<b>West Asian</b>	1%
<b>Black/African American</b>	1%
<b>Latin/Hispanic/Latin American</b>	1%

All but one respondent was from Canada, with approximately half (49%) residing in Quebec. The sole non-Canada resident was from the Czech Republic and was included in our results.

**Respondents, by geographical location**



## ii. Discussion

The survey was disseminated in November 2021, with 118 responses received from 108 individuals with AD, and 10 caregivers. The majority of respondents were females from 16-49 years from Canada, primarily from Quebec and Ontario. Given our respondent profile, our results may be most representative of how adult women within these two provincial health systems have experienced AD.

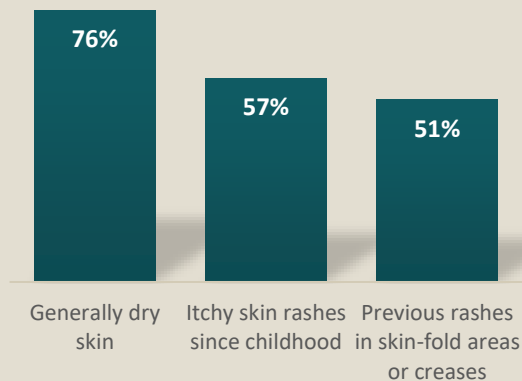
# SECTION I: Symptom Onset and Diagnosis

This section describes the experience of people with AD as they interacted with the healthcare system while seeking a diagnosis. We have presented results across all survey respondents for each question. Where possible, we have included comparisons to 2017 survey findings.

## i. History of atopic dermatitis symptoms and diagnosis

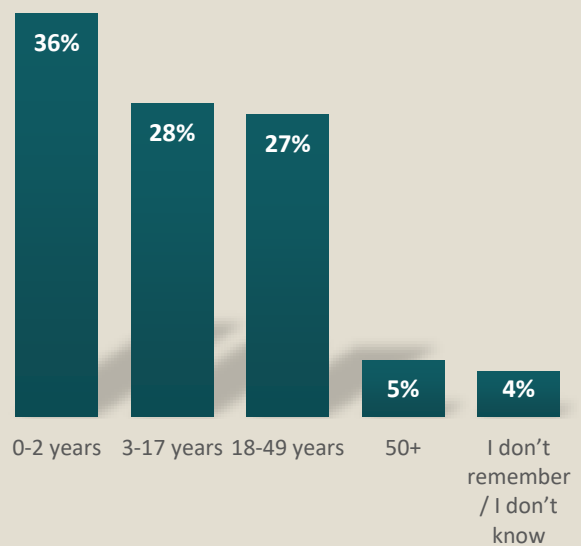
Individuals with AD often share similar dermatological characteristics, including a history of skin-related ailments from childhood. More than three-quarters of individuals (76%) surveyed indicated that they have had a history of generally dry skin.

**Respondents with atopic-dermatitis related history of symptoms (n = 118)**



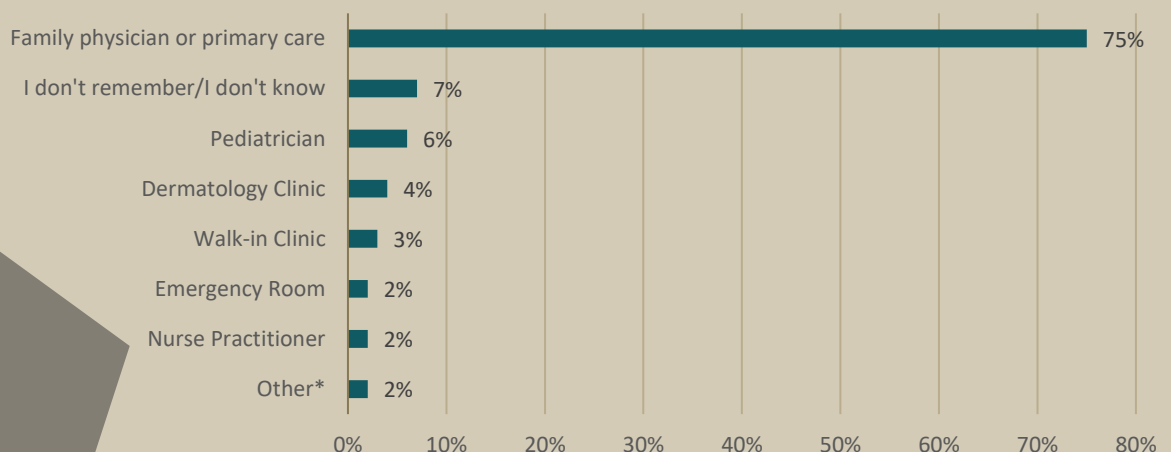
Most respondents first started having symptoms of AD (e.g., repeated rashes, redness, or itching) very early on, with 36% experiencing symptoms in the first years of life and 28% experiencing symptoms in their childhood and adolescence (3 to 17 years). However, AD is clearly a condition that can manifest at any age, with one-third of respondents reporting that their first symptom occurred in adulthood.

**Age of initial symptoms of atopic dermatitis (n = 118)**



For 75% of respondents (83% in the 2017 survey), the first stop on their healthcare journey for symptoms of AD was their family physician.

**First healthcare provider/clinic visited for symptoms of atopic dermatitis (n = 103)**

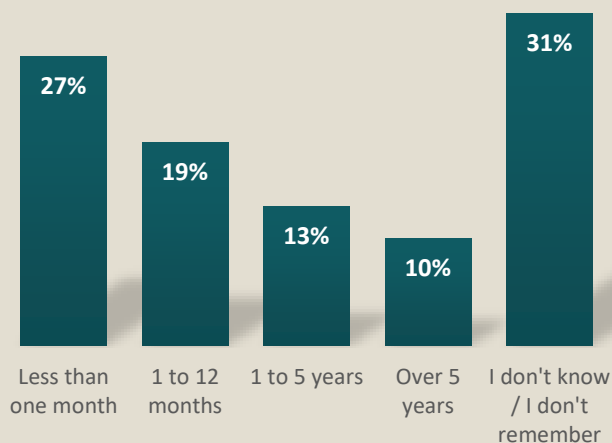


*Other\*: pharmacy, parent who also suffers from AD*

**"I wish my dermatologist had better availability."**

From the time of their first symptom, nearly one-quarter of respondents received a diagnosis of AD in less than one month, 19% in one month to one year, and 23% waited more than one year.

**Duration from initial symptom of atopic dermatitis to diagnosis (n = 103)**



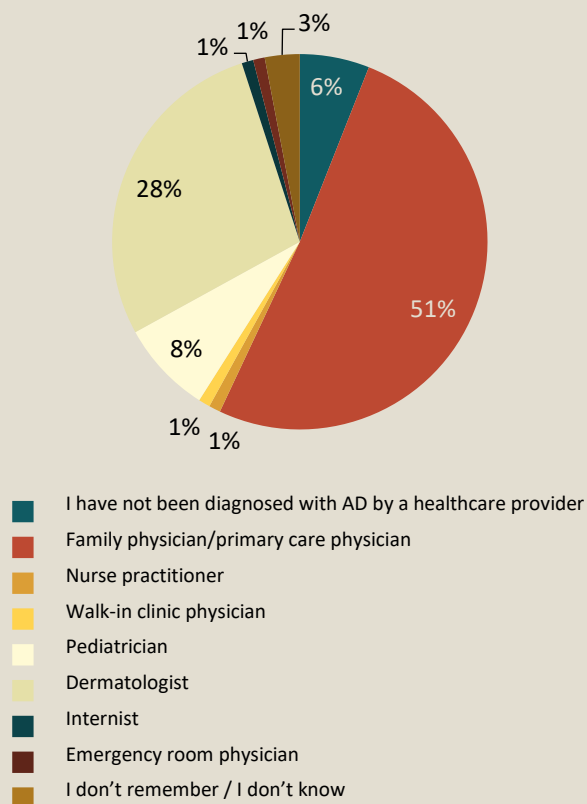
In 2017, nearly 80% of respondents reported they were diagnosed within 30 days of their first symptom.

This large difference in findings may be attributed to inter-provincial differences in wait times for care, since in 2017, the majority of respondents were from Ontario (22% in this survey).

When asked about which clinician type – if any – was the first to provide them with a diagnosis of AD, about half of respondents (51%) reported that it was their family physician, while for 28% a dermatologist made the first diagnosis.

This is fairly similar to our 2017 findings, where 59% were diagnosed by their family physician, while more than one-quarter received a diagnosis from their dermatologist. Our results highlight the important role of family physicians and dermatologists in diagnosing this condition.

**First healthcare provider to diagnose respondents' symptoms of atopic dermatitis (n = 103)**



When asked about whether they had ever been diagnosed with AD by a dermatologist at any point during their healthcare journey, 62% of respondents responded that they had. The remaining respondents had either only been diagnosed by other provider types including family physicians and pediatricians or had been self-diagnosed only.

## ii. Discussion

Family physicians and pediatricians are typically the main entryway into the health care system, the most long-standing relationship with a health care provider that patients have, and the primary avenue for referral to specialty care when required. Therefore, it is critical that they remain well-informed about best practices for providing care and facilitating access to specialists for the management of AD.



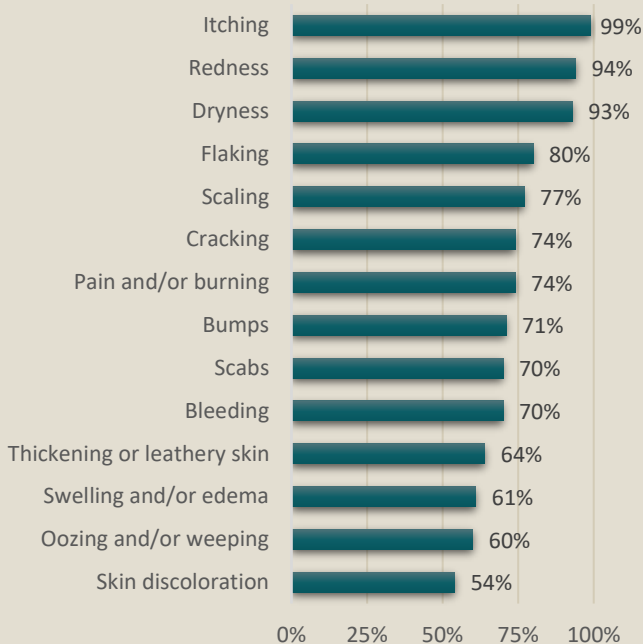
## SECTION II: Severity of Atopic Dermatitis

This section summarizes the symptoms of AD experienced by the survey respondents, the severity of these symptoms based on the POEM scale, as well as the prevalence of other atopic conditions.

### i. Symptoms

There are a host of symptoms associated with AD, and the most common ones of itching, redness and dryness were reported by nearly all respondents.

#### Atopic dermatitis symptoms experienced by respondents (n = 118)

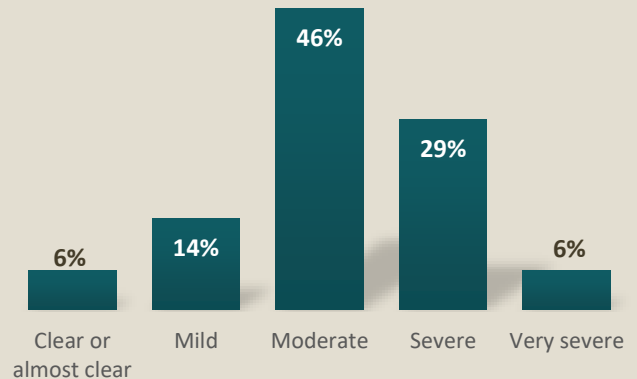


*"I am stuck in a body that is constantly burning or itching. It's like a constant sunburn without having been able to benefit from vitamin D [from the sun]."*

We used POEM, a validated measure of AD severity, to better understand the survey population based on their symptom frequency.

Nearly half of the respondents had overall POEM scores indicating moderate AD severity, while 35% had symptom frequency indicative of greater severity.

#### Severity of atopic dermatitis symptoms, based on POEM scores (n = 110)

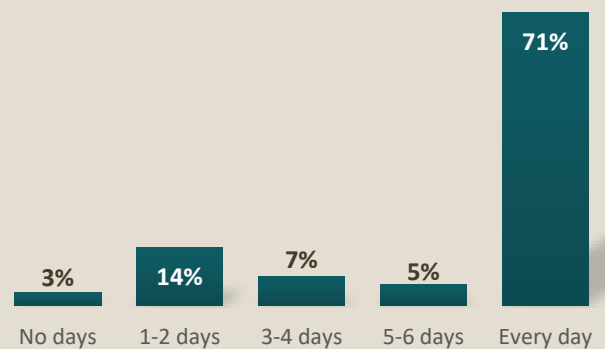


In 2017, we asked respondents to self-report their disease severity, and more indicated mild symptoms (45%), than moderate (42%) or severe (13%).

It is not clear whether they truly had a less severe condition overall than the current respondents, or just did not consider their symptoms to be as severe as what validated measures such as POEM (this was not used in the 2017 survey) would have classified.

We examined responses to two key POEM questions to further understand experiences with symptoms. When asked about frequency of itchy skin, most respondents (71%) reported that it was a common symptom, occurring daily over the past week.

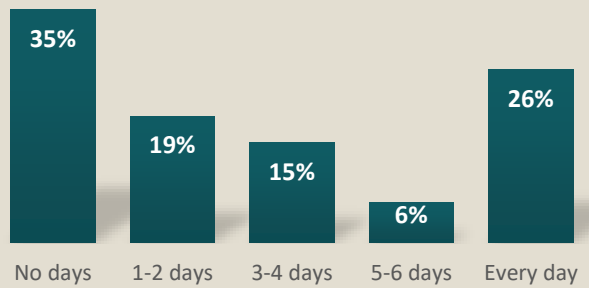
#### Frequency of itchy skin in the last week (n = 110)



*“My 7-year-old son’s eczema has a huge impact on his mood and his sleep, as he is constantly uncomfortable in his own skin.”*

Respondents frequently suffered from disturbed sleep due to AD, with 65% reporting at least one night affected in the past week, and more than one-quarter of respondents indicating disturbed sleep every night.

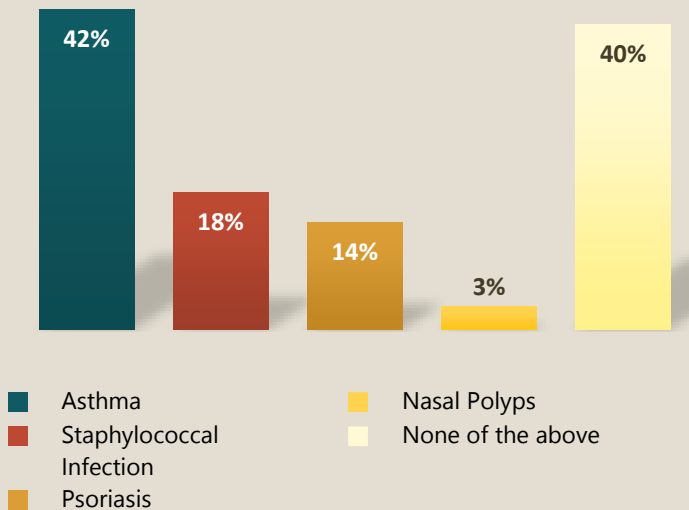
**Frequency of disturbed sleep in the last week (n = 110)**



**ii. Diagnosis of other atopic diseases**

Nearly half (42%) of respondents reported an asthma diagnosis, and almost one-fifth reported a previous staphylococcal infection, likely due to bacteria entering the skin through AD wounds and rashes.

**Diagnosis of other atopic dermatitis-related conditions (n = 118)**



Due to having an overactive immune response to allergens, those with AD often have one or more allergies. Nearly seven out of ten survey respondents reported having allergies, and of those individuals, 71% indicated they had been formally tested: 93% by skin prick testing (allergist) and 37% by patch tests (dermatologist). The most frequently reported allergens were cats, dogs, and dust.

**iii. Discussion**

Most respondents reported symptoms consistent with moderate to severe AD which undoubtedly impacts their perception of the burden of this condition, compared to those who have a milder presentation of AD. In addition to managing their symptoms of AD, individuals with AD also have an increased risk of other atopic diseases, which was reflected in our findings.

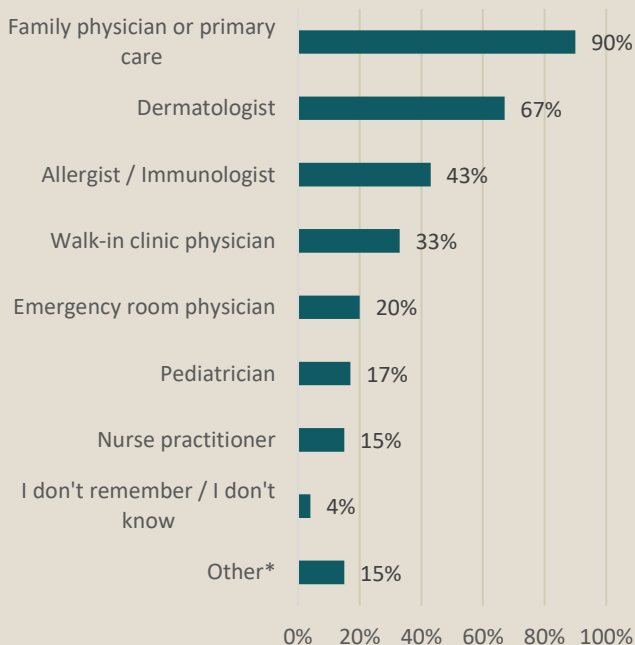
# SECTION III: Experiences with Medical Care for Atopic Dermatitis After Diagnosis

This section describes the various types of healthcare visits that survey respondents had for symptoms of AD, post-diagnosis, as well as satisfaction with their healthcare experiences.

## i. Healthcare visits for symptom management

When asked about the types of medical care they have obtained for their symptoms of AD, almost all respondents (90%) reported that they had visited their family physician, and approximately two-thirds had received care from a dermatologist. One-fifth of respondents reported that they went to an emergency room for help with their AD symptoms, providing evidence of the often acute and distressing symptoms of this condition and reflecting their unmet needs with available treatment options.

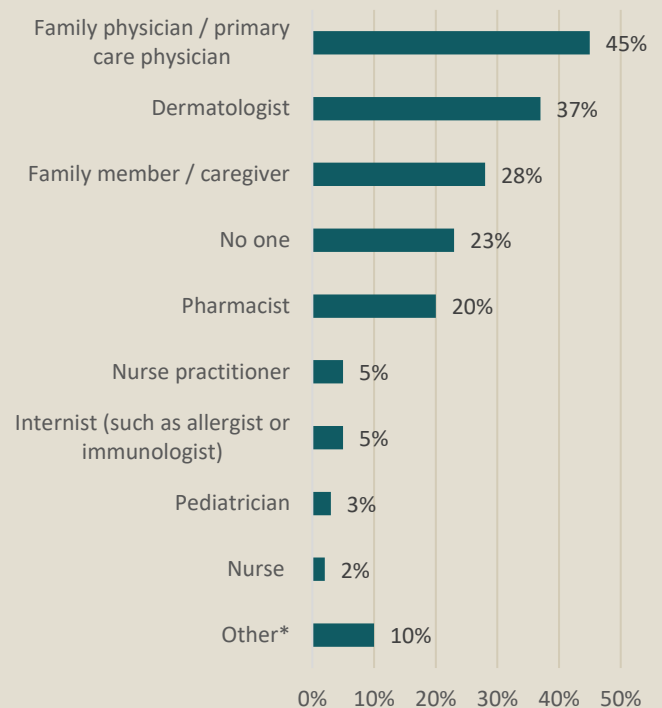
**Healthcare providers seen by respondent for treatment of atopic dermatitis (n = 103)**



*Other\*: naturopath, pharmacist, nutritionist, acupuncturist, osteopath, gynecologist, traditional Chinese medicine practitioner, massage therapist, healer, psychologist, phagotherapy practitioner*

Many respondents indicated that, in the past year, their team for managing symptoms of AD included their family physician (45%), dermatologist (37%), and/or family member/caregiver (28%). Nearly one-quarter noted that they did not receive help from anyone, and instead were managing their symptoms on their own.

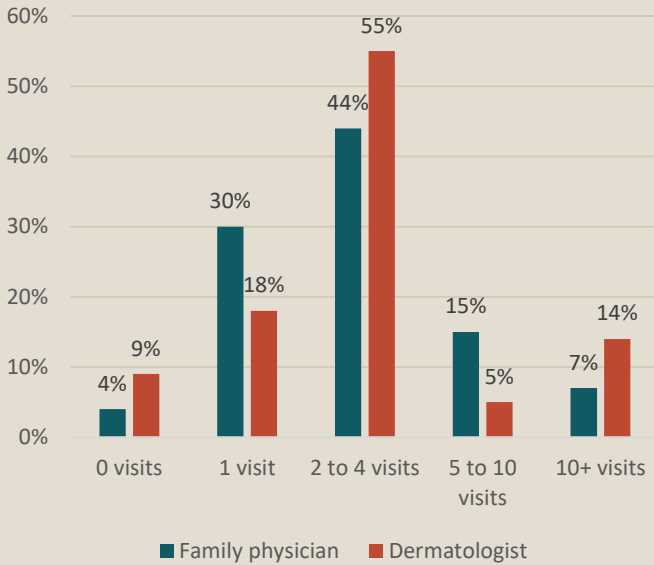
**Individuals that have helped respondents manage atopic dermatitis in the last year (n = 60)**



*Other\*: work colleague, acupuncturist, osteopath, naturopath, a friend*

When asked about the number of times they had seen their family physician and dermatologist in the past year for symptoms of AD, the most common response was two to four visits. Of note, 22% visited their family physicians five or more times in the last year and 19% visited their dermatologist as often, indicating significant healthcare use for this condition.

**Number of visits to family physicians and dermatologists in the last year, for atopic dermatitis (n = 27)**



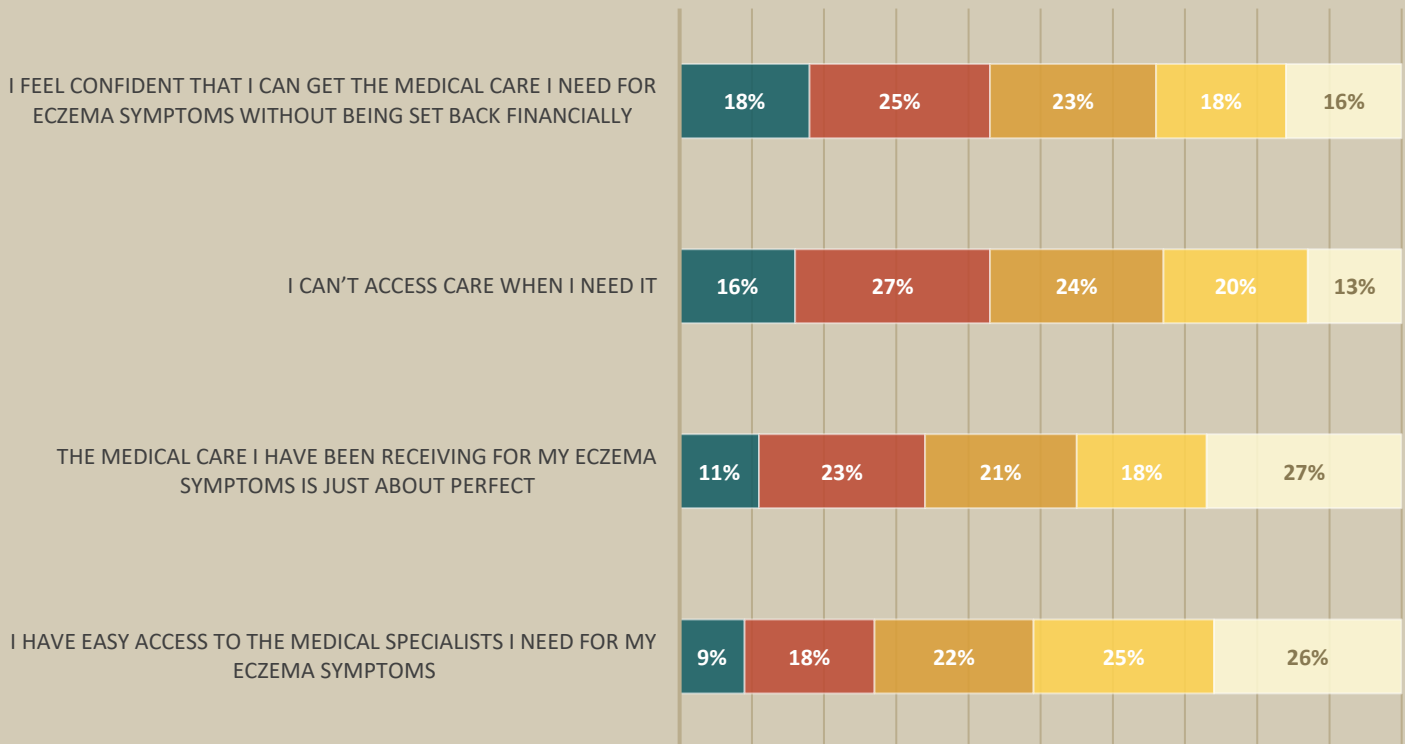
*“With chronic diseases like eczema, you need to listen to the patient experience. We live with our skin 24/7.”*

**ii. Satisfaction with medical care for atopic dermatitis**

Respondents were asked about their satisfaction with the quality of their medical care for AD, and responses were varied. Forty-three percent agreed/strongly agreed that they could access the care they needed for their symptoms of AD while 34% disagreed/strongly disagreed. More than half (51%) disagreed or strongly disagreed that they were able to easily access specialists as needed.

**Level of agreement to statements about satisfaction with medical care for symptoms of AD (n = 55)**

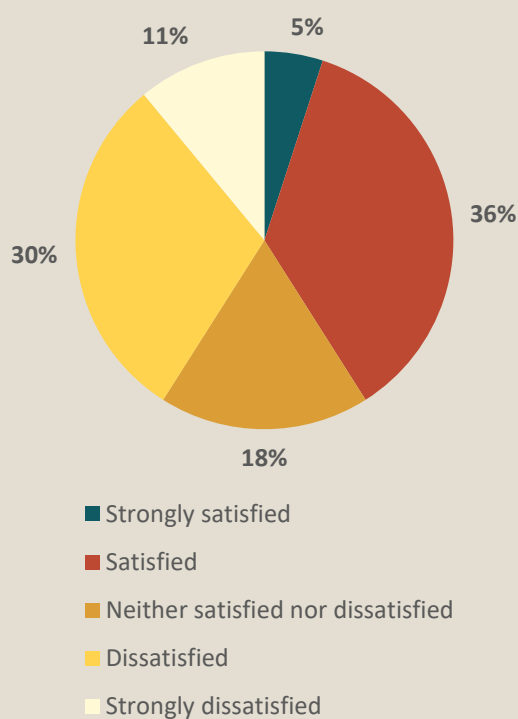
Strongly agree Agree Uncertain Disagree Strongly disagree



*“We have had a difficult time with the dermatologist. Communication has been less than ideal and we have not been able to improve my son's skin significantly with the current treatments.”*

Two-fifths of respondents (41%) indicated that they were dissatisfied or strongly dissatisfied with the care they have received from the health care system for the management of their AD symptoms.

#### **Current level of satisfaction with healthcare system for management of atopic dermatitis symptoms (n = 56)**



Satisfaction rates were higher in 2017, possible due to those respondents' quick diagnosis, or milder symptoms.

In 2017, 37% of those with moderate/severe AD were dissatisfied or severely dissatisfied, compared to 5% of those who reported having mild AD.

*“Whenever I have made an appointment for my eczema, at the time of the medical visit, my sores are never obvious enough to be taken seriously. It is so frustrating. I would have to be able to see a specialist when I am in the middle of a crisis, otherwise I'm not taken seriously, and nothing is moving. This has been going on for 45 years. I cannot stand it anymore.”*

#### **iii. Discussion**

Our findings indicate that the respondents have seen multiple providers for their AD symptoms, but many have very mixed feelings regarding satisfaction with medical care. It is important to note that the majority of our survey respondents identified as female. Prior studies have documented the tendency for females to engage in healthcare-seeking behaviours more frequently than males,<sup>26,27</sup> which may be a contributing factor to our respondents' ability to receive a diagnosis fairly quickly or willingness to seek out multiple types of health care providers to manage their condition. The male experience may be markedly different, with less physician visits, longer delays to diagnosis, and possibly even lower satisfaction with their healthcare experience.



## SECTION IV: Use of Treatments for Atopic Dermatitis

### i. Experiences with atopic dermatitis treatments

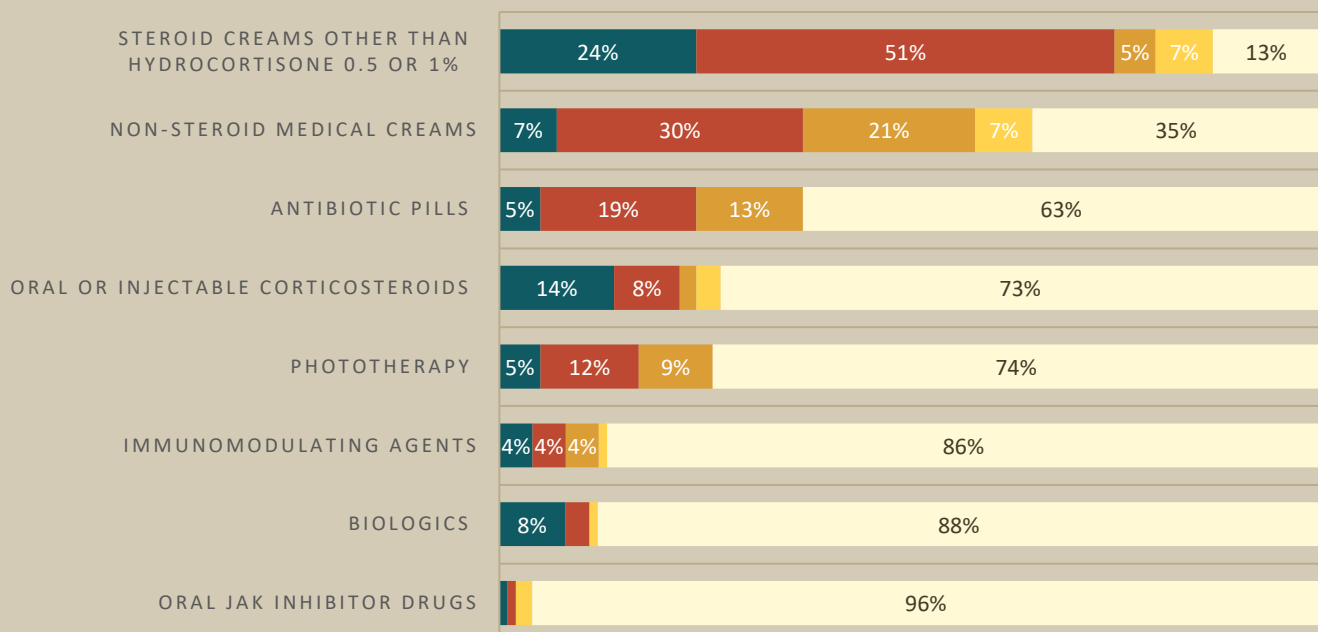
Respondents were asked to rate the level of AD symptom improvement they experienced when using a variety of treatments available by prescription.

- Steroid creams (excluding hydrocortisone 0.5% and 1%) were much more commonly used than any other treatment for AD, with 87% of respondents reporting that they had tried this option for their symptoms
  - Of those, 28% reported significant improvement and 59% reported a little improvement
- Sixty-five percent of respondents indicated they had used non-steroid medical creams, of which 11% reported significant improvement and 46% reported a little improvement
  - For one-third of respondents who tried these creams, no effect was observed

- Only 12% of respondents reported that they had used biologics to treat their manifestations of AD. However, for those who had tried these treatments, 67% reported significant improvement in symptoms, making this option the most effective option for those surveyed
- The majority of respondents reported having never attempted oral JAK inhibitor drugs (96%), immunomodulating agents (such as methotrexate, CellCept® [mycophenolate mofetil], and cyclosporine) (86%), phototherapy (74%), or oral/injectable corticosteroids (73%)
  - Oral/injectable corticosteroids were the second most effective treatment option for those surveyed. Of those who reported having used them, 52% had significant improvement in their symptoms of AD

### Experiences with prescription treatments for atopic dermatitis symptoms (n = 96)

■ Significant improvement ■ A little improvement ■ No improvement ■ Worsened my symptoms ■ I've never tried this



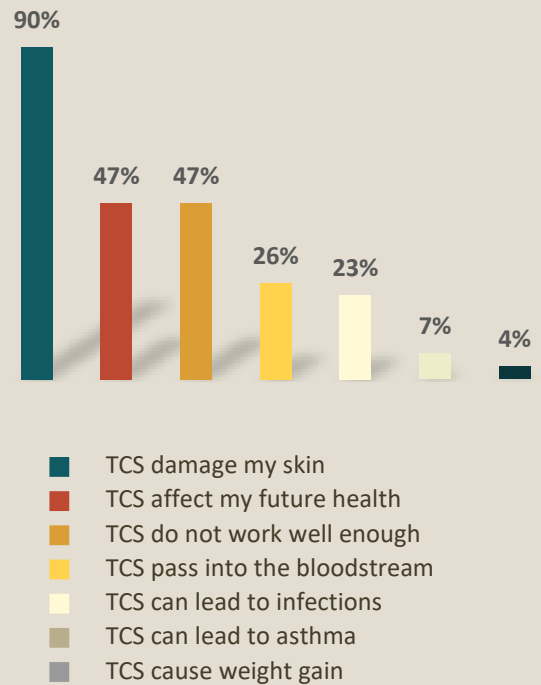
## ii. Concerns with topical corticosteroid use

Approximately half of all respondents (48%) reported they had concerns about using topical corticosteroids (TCS) for their itchy, red, rough skin.

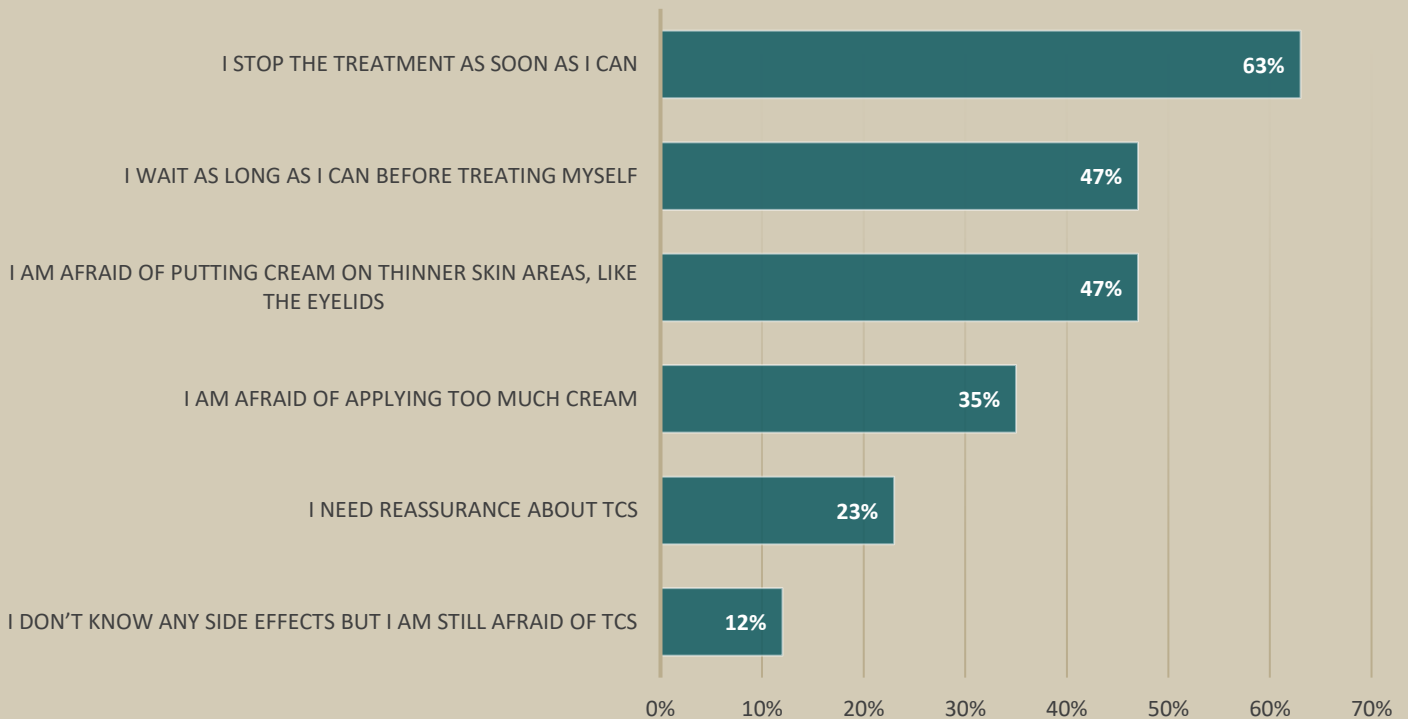
The most common worries centered around fears about potential adverse events such as skin damage, or a detrimental impact on their health. Nearly half (47%) of respondents concerned about TCS use did not believe that these medications would have a worthwhile positive effect.

Respondents reported that using TCS was often the cause of fears, and that they implemented strategies to self-protect, and eliminate as much risk as possible: stopping treatment as soon as the individual felt that enough of a benefit was achieved, and avoiding treatment until deemed absolutely necessary were the most common actions.

## Concerns with topical corticosteroid use (n = 57)



## Fears, concerns, and strategies associated with TCS (n = 57)



### iii. Side effects of treatments for atopic dermatitis

Among respondents who have used treatments for AD in the last year, 37% reported experiencing side effects. Two-thirds of these individuals reported thinning of the skin, while nearly half felt that their treatment for AD worsened their symptoms.

#### Adverse effects of atopic dermatitis treatments in the last year (n = 30)

Thinning of the skin	66%
Worsening of atopic dermatitis	48%
Thickening of the skin	28%
Fatigue	28%
Spider veins	24%
Premature aging	24%
Infections	17%
Stretch marks	10%
Headache	10%
Hormonal imbalance	10%
Conjunctivitis	7%
Nausea	7%
Gastrointestinal problems	7%
High blood pressure	3%
Other*	17%

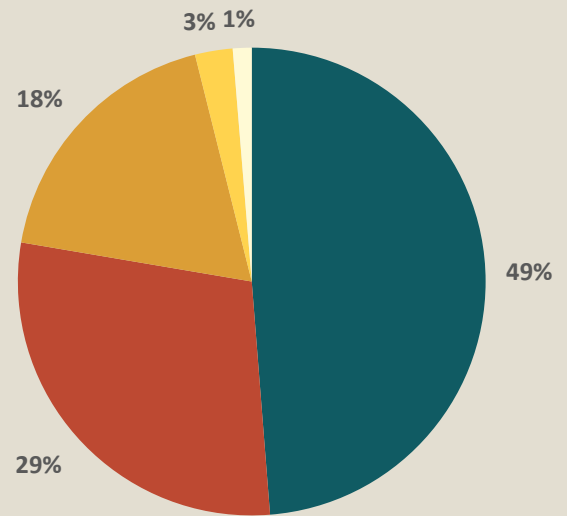
*Other\*: red skin syndrome, topical steroid withdrawal, bleaching of the skin*

We asked whether respondents were currently using a treatment for AD, and 78% of respondents reported that they were using one or more.

Of these, approximately half (49%) reported no side effects and 29% reported minor side effects that were acceptable to them because the treatment had been effective.

Four percent of individuals reported severe side effects, but their willingness to tolerate them was based on whether the treatment was effective.

#### Experiences with current treatments for atopic dermatitis (n = 76)



- No side effects from my treatment
- Side effects are minor and acceptable because of the treatment's effectiveness
- Side effects are minor but unacceptable because the treatment is not effective
- Side effects are severe but acceptable because of the treatment's effectiveness
- Side effects are severe and unacceptable because the treatment is not effective

---

*"The doctors I've spoken to this year heavily relied on medical interventions and didn't consider much about my preferences of care. I do not want to be on medical treatments long term especially given that I was recently told by my pharmacist that the medication I was given increases the risk of cancer."*

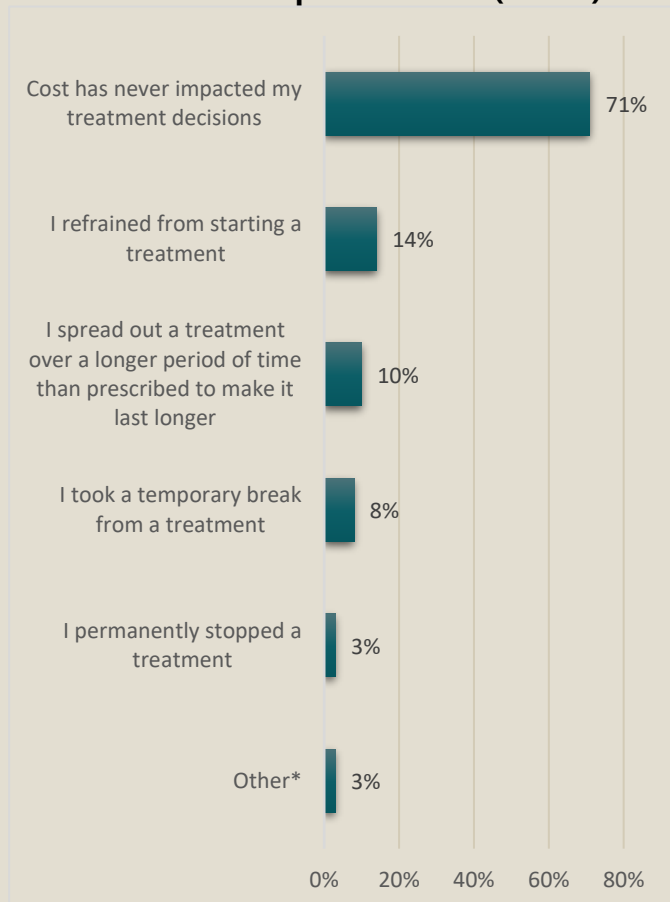


**iv. Cost of treatments as a barrier to use**

Many patients must pay partial or full out-of-pocket fees, depending on which treatment they have been prescribed. For 29% of respondents, there has been at least one instance when the cost of a treatment for AD has impacted their decision of whether or not to take it and/or the duration of use, despite the potential for benefits in terms of symptom relief.

The most common impacts were that the respondent did not start that treatment at all (14%), attempted to make the treatment last longer by spreading it out for longer than prescribed (10%), and took breaks from treatment (8%).

**Impact of cost on respondents' treatment decisions for atopic dermatitis (n = 97)<sup>1</sup>**



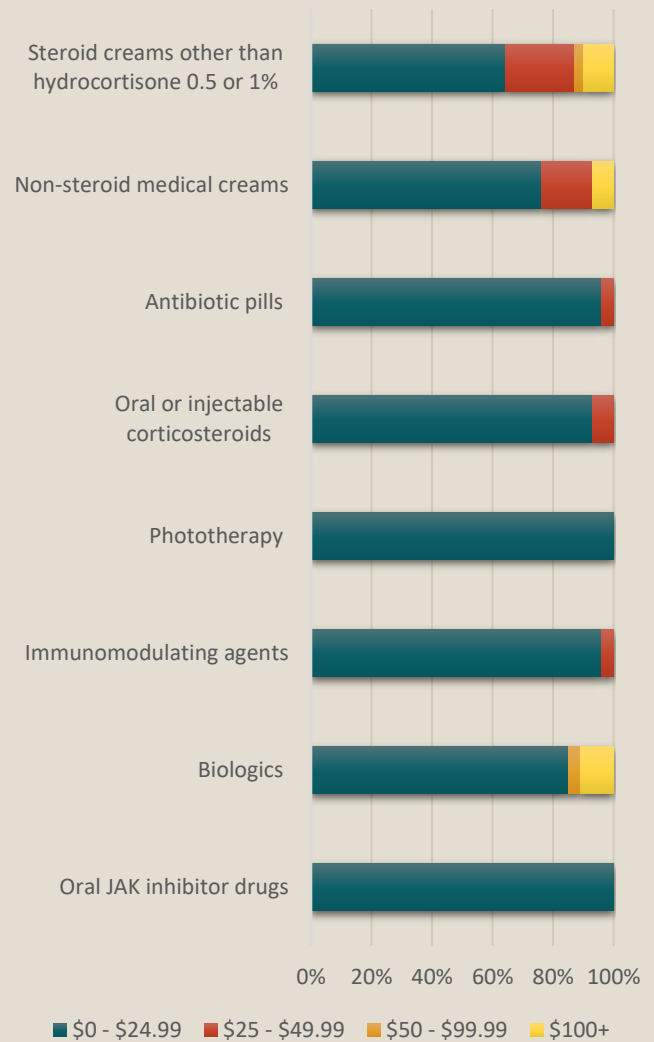
<sup>1</sup> Respondents were asked if cost had ever impacted their treatment decisions for AD. No specific time frame was specified.

*Other\*:* adapting household spending to adjust to the cost, checking in with insurance/benefits before starting a treatment to see if it is covered

Respondents reported that steroid creams, non-steroid medical creams, and biologics were the prescription treatment options that they spent the most money on.

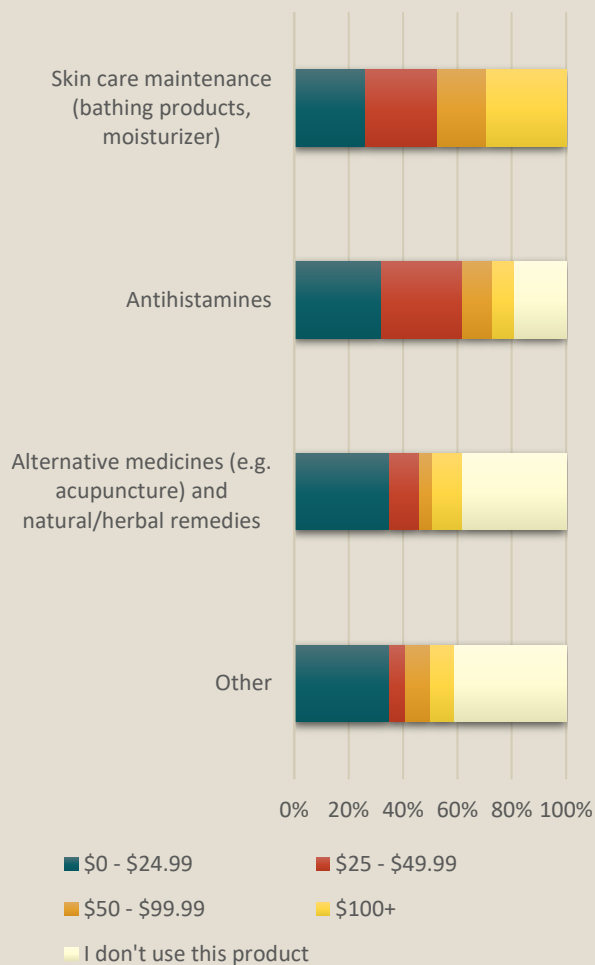
Ten percent of respondents reported spending over \$100 on steroid creams, 7% reported spending over \$100 on non-steroid medical creams, and 11% reported spending over \$100 on biologics.

**Monthly out-of-pockets costs associated with prescription treatments (n = 32)**



When asked to estimate their average out-of-pocket monthly cost for non-prescription AD treatments, respondents reported that they spent the most money on skin care maintenance (e.g., bathing products or moisturizer), with 29% spending over \$100 monthly.

### Monthly out-of-pockets costs associated with non-prescription treatments (n = 32)



### v. Treatment goals

Respondents reported that they had several goals they hope for with treatments for AD, with the three most common being to eliminate itch, control symptoms and improve sleep.

### Expectations of atopic dermatitis treatments (n = 56)



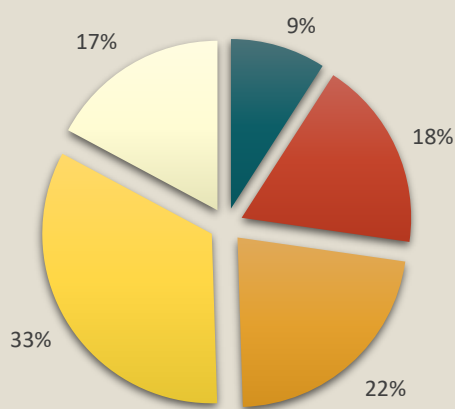
*Other\*: stop the symptoms altogether, find the root cause and be overall healthier, have no side effects*

*“I would love to not have to think about my skin on a daily basis and just live a normal life.”*

There is a clear disconnect between patient treatment goals and the ability of many of the current treatments to meet these goals. Half of all respondents reported dissatisfaction/strong dissatisfaction with current treatments, while only 27% reported that they were satisfied/strongly satisfied.

Given that the majority of respondents previously indicated that they had not tried many of the newer treatments (immunomodulating agents, biologics and oral JAK inhibitors), the reported satisfaction levels may be indicative of a lack of effectiveness of the treatments they have tried as well a lack of accessibility and affordability of the more recently available treatments.

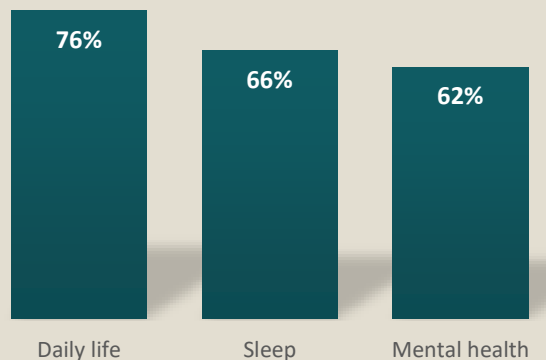
### Satisfaction with ability of current treatments to meet treatment goals (n = 55)



- Strongly satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Strongly dissatisfied

When asked how they thought a new treatment for AD that met all of their treatment goals might impact their lives, the majority of respondents reported that they believed that they would experience significant improvement in multiple aspects of their lives including sleep and mental health.

### Anticipated improvements if atopic dermatitis treatments met goals (n = 55)



### vi. Discussion

There are a number of treatments available for AD, and a survey conducted by the Eczema Society of Canada found that 43% of their respondents tried 10 or more to manage their symptoms.<sup>28</sup> Among the various prescription treatment options available, topical corticosteroids (TCS) were the most commonly used and most effective option reported by our survey respondents, but not without some concern. Almost half of respondents were concerned that TCS could damage their skin and about a third endeavoured to stop the treatment as soon as they could. This finding is consistent with other literature about the widespread concern among patients and caregivers about TCS use.<sup>11-12,29</sup>

---

*“The hardest part of topical steroid withdrawal is that no doctor believes you and you end up going through this alone. Before red skin syndrome, I had always trusted doctors. It is also scary to realize red skin syndrome is real and doctors still prescribe steroids whereas we would need data to know exactly how risky it is to use them. It is hard for me to trust doctors anymore, to feel safe with them, especially dermatologists.”*

Respondents reported considerable dissatisfaction with the ability of current treatments to manage their symptoms and about one-third reported adverse effects such as thinning of the skin or worsening of AD. Many of the newer treatment options, including oral JAK inhibitor drugs, had low uptake. Respondents who had used biologics reported good effectiveness, corroborating a recent qualitative study of individuals from Canada and Europe.<sup>30</sup> However, these treatments were used by only a minority of respondents, which could be indicative of limited awareness, knowledge, or confidence among health care providers about

prescribing these medications, or inadequate access to specialists who may be more experienced in prescribing them. However, it also likely speaks to a financial barrier, as approximately one-third of respondents indicated that the cost of a treatment impacted whether or not they decided to try it and/or how long they decided to use it for. Given that many new prescription drugs for AD are not widely publicly funded and a significant proportion of adult Canadians do not have access to private insurance benefits, one's ability to pay out-of-pocket may present significant barriers and inequities in the ability to manage AD.

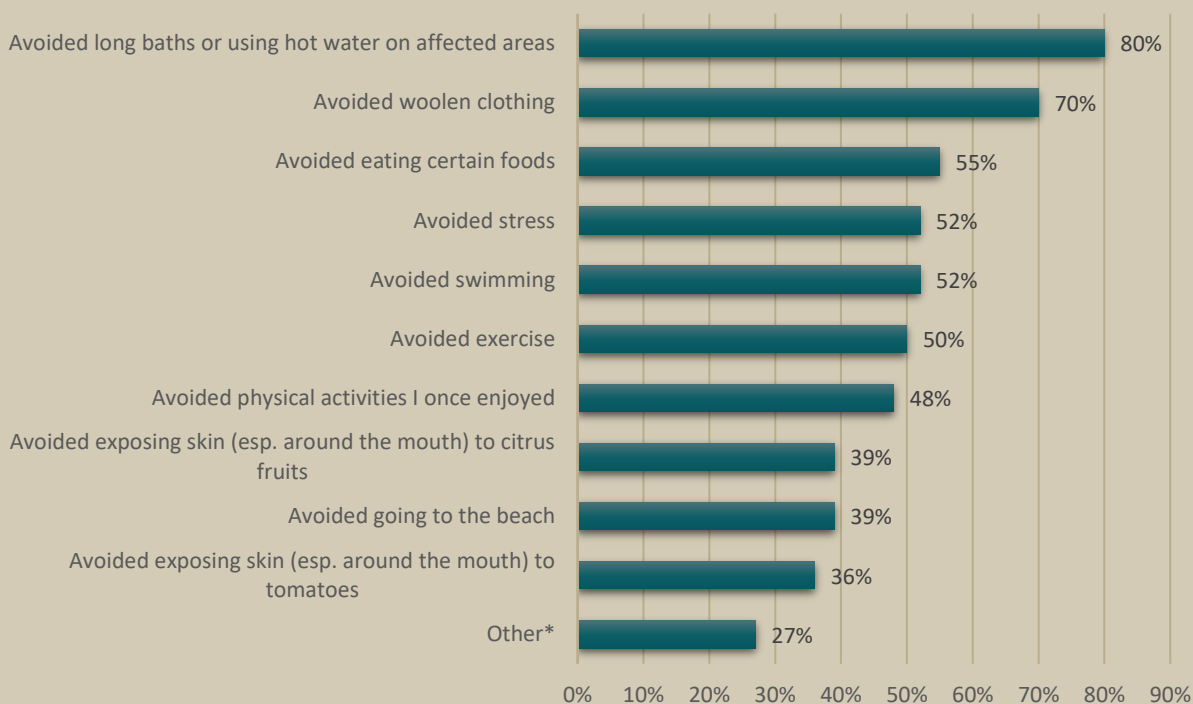
## SECTION V: Behaviours and Activities to Manage Symptoms of Atopic Dermatitis

Many individuals with AD adopt lifestyle changes to prevent exacerbation of their condition.

### i. Avoidance of behaviours and activities

The majority of respondents (89%) indicated that they have avoided certain behaviors and activities, with more than 70% avoiding long baths, and woolen clothing.

**Activities, food, and behaviours avoided due to atopic dermatitis (n = 56)**



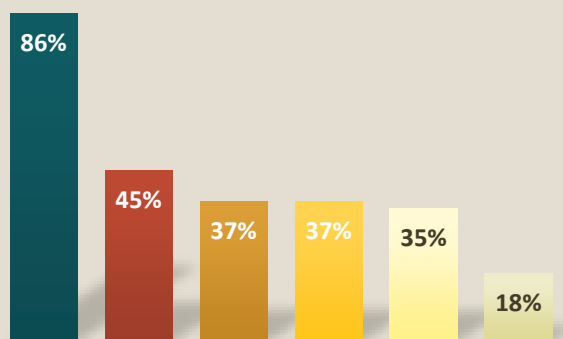
*Other\*: avoidance of going outside in winter/being in contact with animals/use of NSAIDs/washing dishes or getting hands wet*

---

*“The mandatory disinfectant gels in public places cause a burning sensation on my hands. To frequent a shop, for example, I have to put on cotton gloves covered with plastic gloves on which I apply the disinfectant gel to enter shops, sometimes having to keep these two pairs of gloves afterwards. It’s unpleasant.”*

Due to feeling embarrassed about how their condition looks, 81% of respondents reported feeling the need to “hide” in various ways, primarily through clothing to cover affected areas of the skin, but also by remaining inside more and avoiding gatherings.

### **Ways in which respondents have hidden their symptoms of atopic dermatitis (n = 51)**



- Wore long pants and/or long sleeves to hide affected areas
- Minimized going out
- Avoided social gatherings
- Avoided going to the beach
- Used make-up to cover affected areas
- Other\*

*Other\*: wearing hats/gloves, leaving hair down to hide outbreaks on the skin, wearing Band-Aids*

---

*“It took me years to start wearing rings, as I did not want to attract attention to my hands.”*

### **ii. Discussion**

A sizeable proportion of individuals experienced some degree of embarrassment or self-consciousness because of their skin, and felt compelled to make adjustments to how they live their lives, avoiding activities and hiding their skin, further illustrating the discomfort and/or shame associated with the disease.

---

*“I can’t count how many things I had to avoid because of random flare-ups that would force me to hide.”*

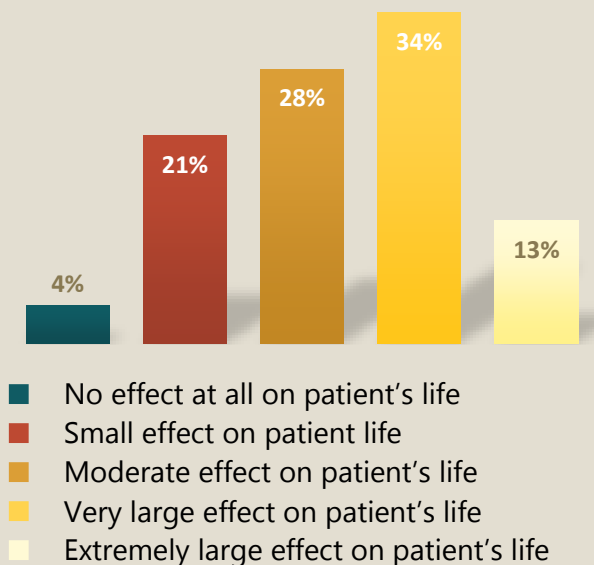
# SECTION VI: Impact of Atopic Dermatitis on Overall Quality of Life and Daily Life

To determine the effect of AD on health-related quality of life, we asked respondents to complete the Dermatology Life Quality Index (DLQI).

## i. Dermatology Life Quality Index findings

Of all respondents, nearly half (47%) reported that their AD symptoms significantly impacted their lives, reporting a “very large effect” or “extremely large effect”. Only 4% reported no effect.

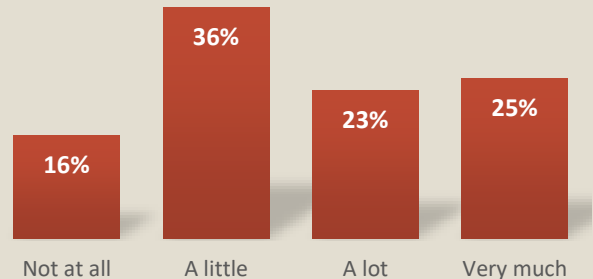
**Effect of atopic dermatitis symptoms on respondents’ lives (n = 103)**



We delved deeper into the more precise impacts of AD on quality of life, to identify which areas respondents felt were most negatively affected, and how this condition interferes with activities of daily living.

Nearly half of respondents (48%) reported feeling embarrassed or self-conscious frequently over the past week.

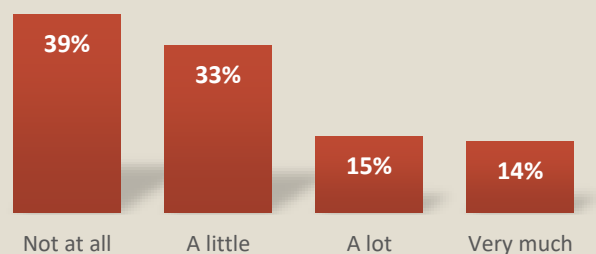
**Over the last week, how embarrassed or self-conscious have you been because of your skin? (n = 103)**



*“I am embarrassed and afraid that people will think I have a contagious condition.”*

When asked how much respondents’ skin has affected social or leisure activities over the last week, nearly one-third (29%) reported a significant negative impact.

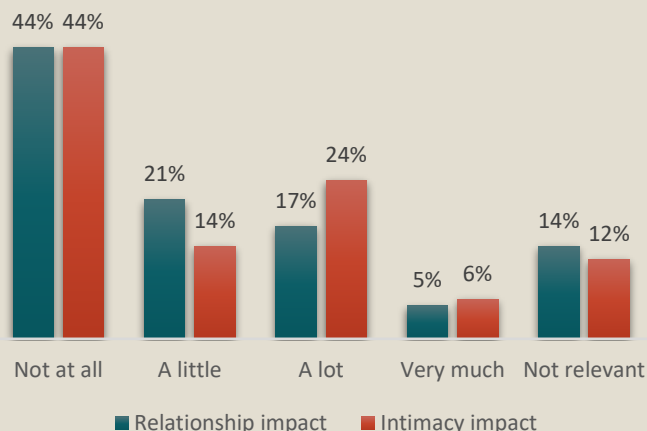
**Over the last week, how much has your skin affected any social or leisure activities? (n = 103)**



*“I am a senior. I would like to go back to my water aerobics, but I am embarrassed with the state of my back and neck areas.”*

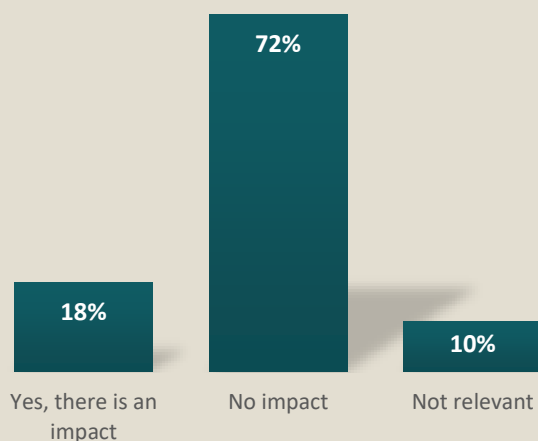
Of all respondents, more than two-fifths (43%) indicated that in the last week, their relationships with their partner or close friends had been impacted by their skin, and 44% reported that their skin had affected their ability to be sexually intimate.

### Impact of atopic dermatitis symptoms on relationships and intimacy (n = 103)



When asked whether respondents' skin had prevented them from working or studying over the last week, 18% reported that it had been an issue for them.

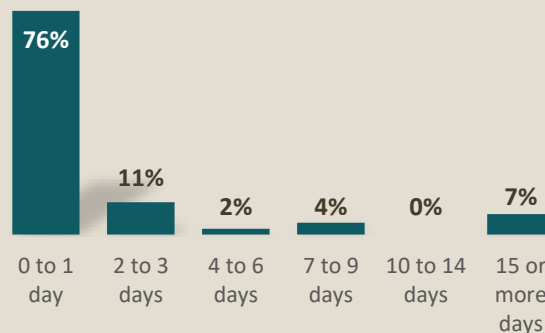
### Impact of atopic dermatitis symptoms on ability to work/study in the last week (n = 103)



*"Eczema has caused me an insurmountable delay in my studies and has affected my ability to be accepted into programs that interest me."*

When asked further about the impact of AD on their productivity, nearly one-quarter of respondents reported missing two or more days of school or work in an average month due to their condition (including for medical appointments, symptoms, etc.).

### Days of school/work missed monthly due to atopic dermatitis (n = 60)



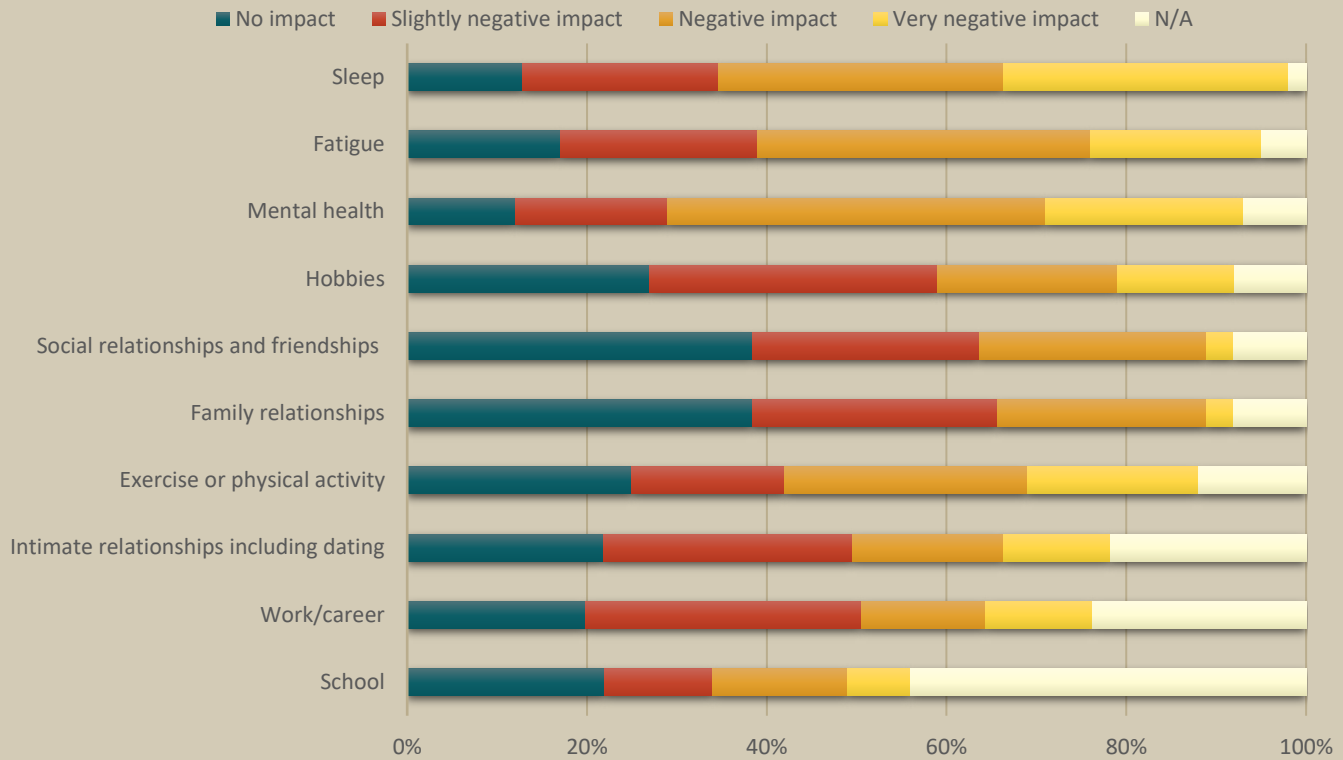
### ii. Impact of atopic dermatitis on daily life

When asked how AD impacts specific aspects of respondents' lives, respondents reported that their mental health, sleep quality, and fatigue levels were most affected:

- 64% reported a negative or very negative impact on mental health
- 64% reported a negative or very negative impact on sleep
- 56% reported a negative or very negative impact on fatigue

**"My anxiety flares up because of my eczema."**

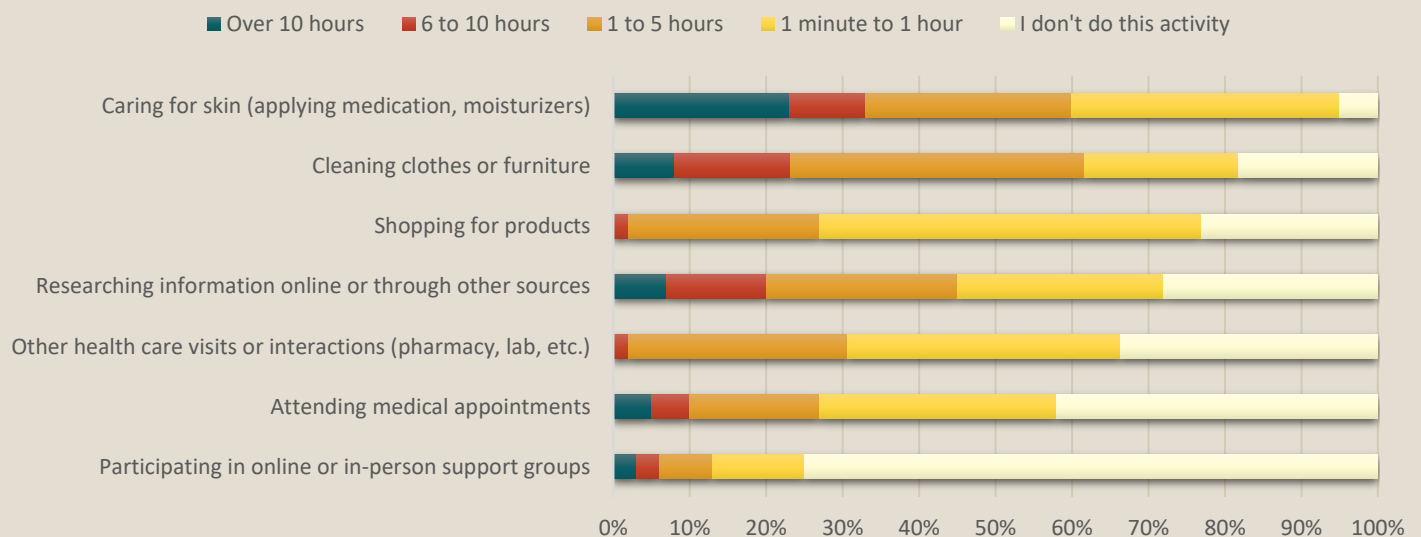
### Impact of atopic dermatitis symptoms on various aspects of respondents' lives (n = 59)



### iii. Time spent on activities related to symptom management

When asked how much time respondents spend on each of activities related to their condition in a typical month, caring for skin, cleaning clothes/furniture, and researching information were the activities that respondents dedicated the most time towards. Nearly all respondents indicated that they took time to apply moisturizers and treatments, and 23% reported spending 10 hours or more each month.

### Time spent on activities related to atopic dermatitis symptom management per month (n = 59)

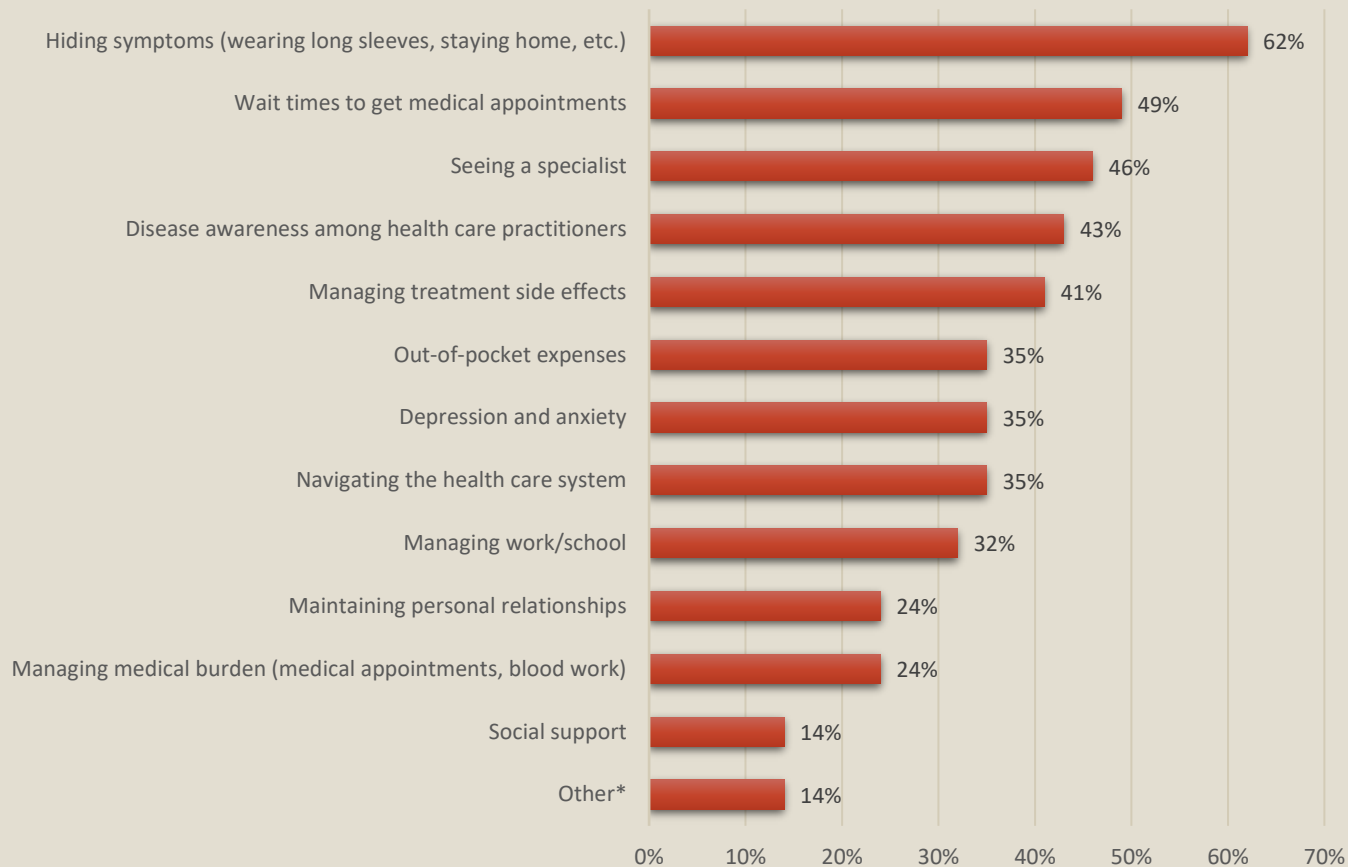




#### iv. Struggles in the management of atopic dermatitis symptoms

Seventy-three percent of respondents reported that they had difficulties with some aspect of managing AD. The three most common areas of struggle were hiding symptoms (62%), long wait times for medical appointments (49%), and gaining access to a specialist (46%).

**Causes of struggle related to atopic dermatitis (n = 37)**



*Other\*: remembering to apply treatment, dealing with itching; managing the time it takes to apply all the treatments, sleep, red skin syndrome awareness/support/treatment/prevention*

In 2017, hiding symptoms, out-of-pocket expenses, and depression/anxiety were the most common areas of struggle chosen by 55%, 33% and 32% of respondents, respectively. Out-of-pocket expenses and depression/anxiety were each selected by 35% of respondents in our current survey, indicating that they are still areas of difficulty for a significant proportion of individuals with AD, but that there are other aspects of this condition that many find even more problematic to manage.

---

**“A lot of management is needed from the patient’s perspective, such as managing orders of different medications from the pharmacy, updating the primary care physician on the evolving treatment plan, etc.”**

## v. Discussion

The detrimental effects of symptoms of AD are evident. When asked to consider how AD impacts ten different domains, respondents rated mental health, sleep, and fatigue to be the most negatively impacted compared to other areas of their lives. Other evidence demonstrates that a substantial proportion of individuals with AD experience symptoms of anxiety, depression and sleep disturbance.<sup>16,17,20,31</sup>

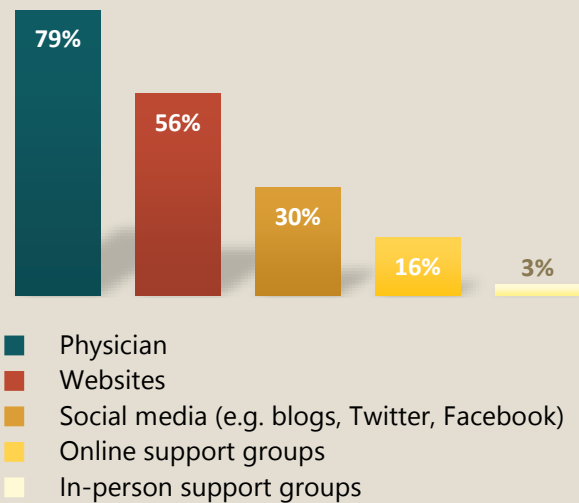
## SECTION VII: Primary Sources of Information on Atopic Dermatitis

Respondents seek out multiple sources for information regarding AD progression, symptom management, and treatment options.

The majority of respondents indicated that they obtain their information from their physician (79%) or from websites (56%). The most commonly used websites included Eczema Quebec (eczemaquebec.com), Google searches, WebMD, the Eczema Society of Canada (eczemahelp.ca), Topical Steroid Withdrawal Symptom Support (itsan.org), and the National Eczema Association (nationaleczema.org).

As patients and caregivers attempt to manage this disease, their access to knowledgeable health care providers, credible information, and supportive networks is key at every stage of their journeys.

**Primary sources of information on atopic dermatitis (n = 97)**



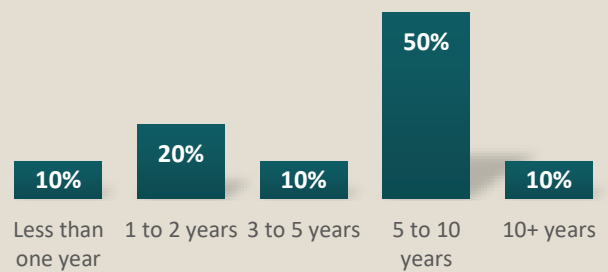
## SECTION VIII: Impact of Caregiving on Well-being

Of the 10 caregivers who responded to the survey, six reported that they provide care to a child, and four indicated that they provide care to an adult.

### i. Impact on productivity and quality of life

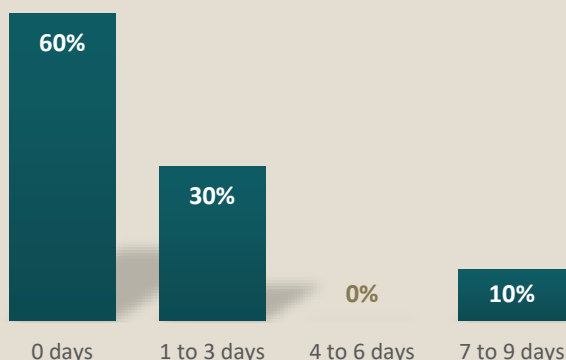
When asked how long the respondent had provided care to an individual with AD, half reported doing so for 5-10 years.

**Number of years the respondent has given care to someone with atopic dermatitis (n = 10)**



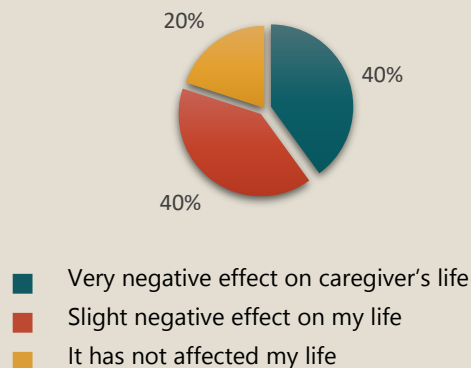
Most caregivers (60%) did not miss any days of school or work in an average month due to caring for someone with AD (including for medical appointments, symptoms, etc.), though 30% of caregivers missed up to 3 days.

**Missed days of work/school monthly due to providing care for someone with atopic dermatitis (n = 10)**



Caregiving is known to take a toll both mentally and physically. When asked how caring for someone with AD affected their lives, 40% of caregivers reported a very negative effect and 40% reported a slightly negative effect.

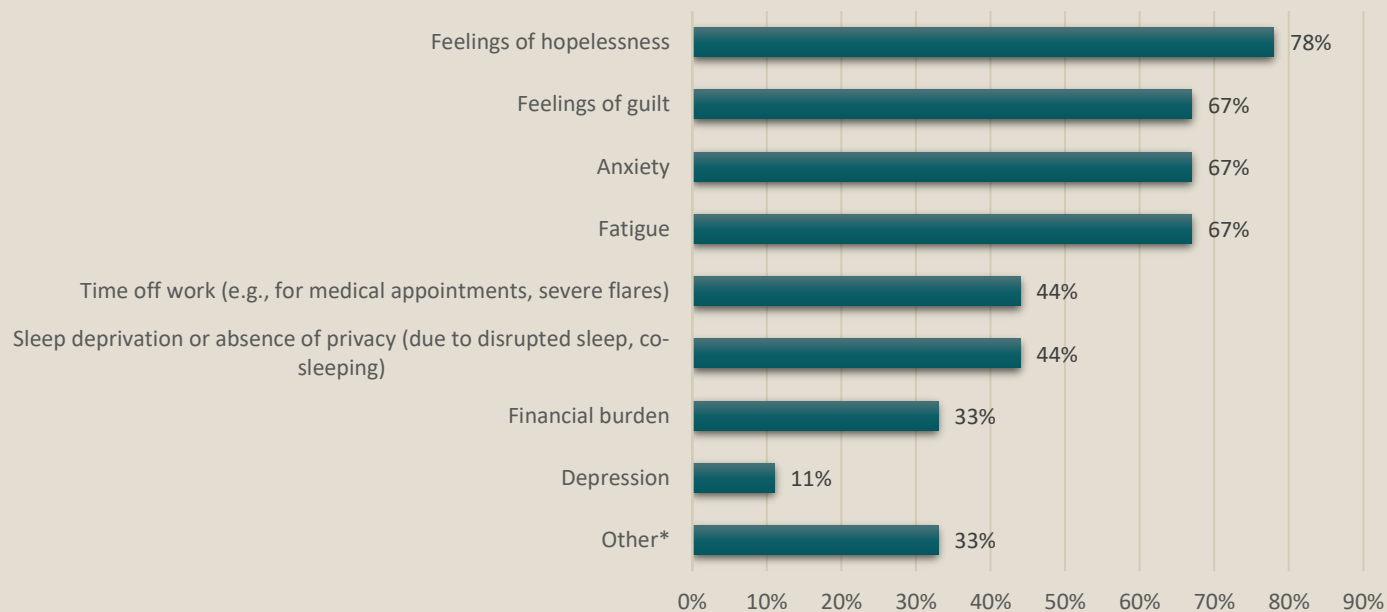
**Effect on respondents of providing care for someone with atopic dermatitis (n = 10)**



Caregivers reported multiple ways in which taking care of someone with AD was negatively impacting aspects of their lives.

The emotional effect is clearly difficult, with the majority of respondents expressing feelings of hopelessness and guilt. Two-thirds of caregiving respondents also reported that their own health had been affected, through anxiety and fatigue.

**Struggles experienced by respondents due to providing care for individual with atopic dermatitis (n = 9)**



*Other\*: bearing the full brunt of household chores and childcare, feeling powerless*

## ii. Discussion

Caregivers play an important role in a patient's circle of support and should not be overlooked when examining the impact that AD can have on quality of life. In our survey, caregivers reported playing this role for a significant number of years, perhaps unsurprising given the chronic nature of the condition, but an important implication for their overall health and wellbeing. While caregivers did not report that caring for someone with AD led to a significant impact on their ability to attend school or work, the majority of them have experienced some

degree of a negative effect on their lives, and they expressed feelings of hopelessness, guilt, anxiety, and fatigue.

In considering the generalizability of our results, it is important to recognize potential limitations, including a small sample of caregivers. However, our survey respondents report that providing care has a considerable impact on their lives, corroborating findings from the Eczema Society of Canada's 2017 survey.<sup>28</sup>

## SECTION IX: Healthcare Resource Utilization for Atopic Dermatitis

---

To supplement our survey data and provide a more comprehensive look at the burden of AD in Canada, we obtained provincial data on healthcare utilization – specifically, the number of AD-related ER visits, and number of AD-related hospitalizations/lengths of stay – from the Canadian Institute for Health Information (CIHI).

Both types of healthcare resource use represent AD that is either uncontrolled altogether or controlled inadequately. We obtained data from 2016 to 2020 in order to observe trends across these five fiscal years.

Recognizing that, when caring for a patient with AD, clinicians may not always use the AD-specific International Classification of Disease (ICD)-10 code (L20) and opt for another code within the broader dermatitis and eczema category (L20-L30) instead, we have included data for both condition codes. We have also presented numbers for the following group of comparator dermatological diagnoses: cellulitis (L03) / other local skin infections (L08) / rash and non-specific skin eruptions (R21) / impetigo (L01).

These conditions are widely considered to be common and impactful, leading to considerable healthcare utilization including high rates of both ER visits and hospitalization. We compared AD-specific data to comparator diagnoses data to demonstrate the magnitude of the burden of AD compared to other common dermatological reasons that an individual may visit the ER or be hospitalized.

The CIHI data have various limitations. CIHI does not have ready access to provincial data from Quebec, and data for PEI, Nova Scotia, Manitoba, Saskatchewan, and British Columbia are likely to be incomplete given that not all facilities in these provinces are required to submit data to CIHI. Additionally, for privacy reasons, CIHI cannot provide specific data counts for one to four people (we have not included this suppressed data in our graphs). For the purposes of this presentation, we have shown data for four regions: British Columbia/Alberta, Prairie provinces, Ontario, and Atlantic provinces (the Atlantic region excludes Newfoundland for emergency room visit data since no facilities report these data to CIHI). We opted to combine provinces into regions in order to avoid data suppression due to low counts.

### i. Emergency room visits

The number of ER visits with AD documented as the main problem per 100,000 people was fairly low across all provinces.

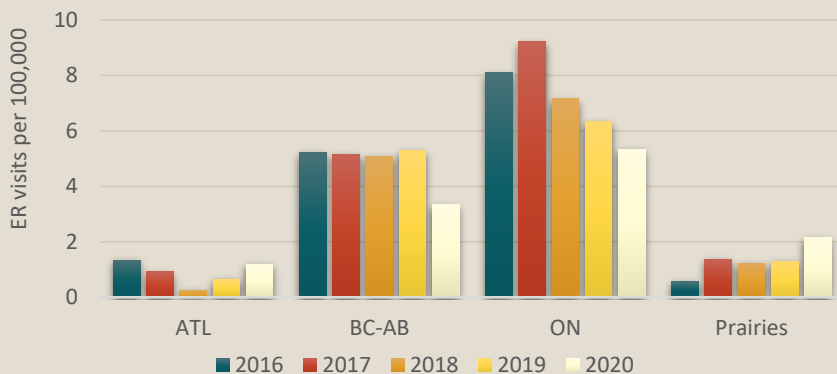
ER visit numbers increased nearly 30-fold when dermatitis and eczema were recorded as the main problem. This likely demonstrates that clinicians were not using the AD-specific code and were either purposely choosing the broader dermatitis and eczema code for an AD patient instead, or misdiagnosing. AD appears to cause much higher healthcare resource use than the specific code implies.

In comparison, the numbers for the comparator diagnoses were even higher. Across each of the graphs, numbers were highest in Ontario, and lowest in Atlantic and Prairie provinces.

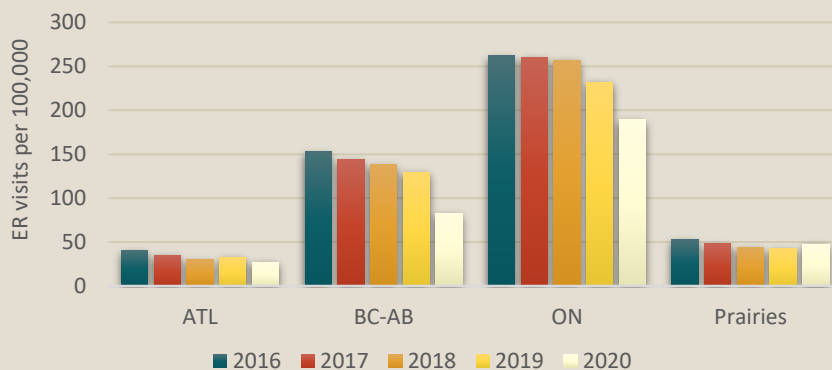
A decline in most numbers was observed in 2020, likely due to COVID-related reasons. It is possible that the same burden of disease existed during that year, but individuals chose not to seek care for fear of exposure to COVID in healthcare settings.

Alternatively, there may have been a lower incidence of ER visits and hospitalizations in 2020 due to lockdowns preventing patients from environmental exposures that typically triggers flares.

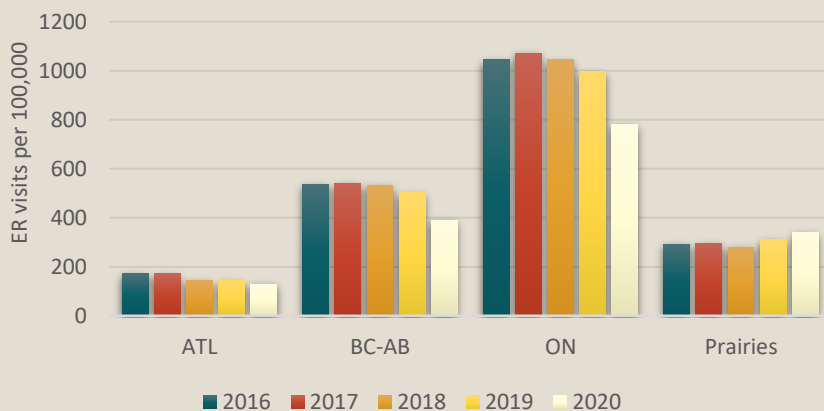
**ER Visits per 100,000 with AD as main problem**



**ER Visits per 100,000 with Dermatitis and Eczema as main problem**



**ER Visits per 100,000 with Comparator Diagnoses\* as main problem**



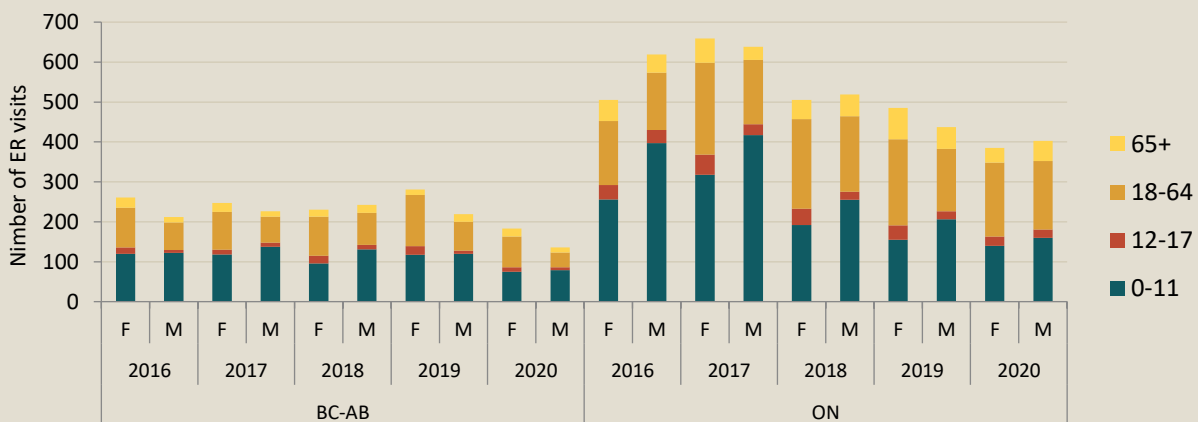
\*cellulitis, other local skin infections, rash and non-specific skin eruptions, impetigo

When we observed ER visits per age group and sex, with AD as main problem, cases in Ontario and British Columbia/Alberta were predominantly from the 0-11 and 18-64 age groups, which was consistent with the two spikes in AD typically seen in childhood and adulthood. Individuals 12-17 years contributed a much smaller proportion to total cases, likely attributed to smaller populations in this small age range, combined with a lesser burden of disease compared to those younger and older, at least in terms of disease not addressed/controlled. There also appeared to have been a decline in cases in both males and females in recent years, although it is unclear whether this was attributed to changing epidemiology of AD or improved control of the condition.

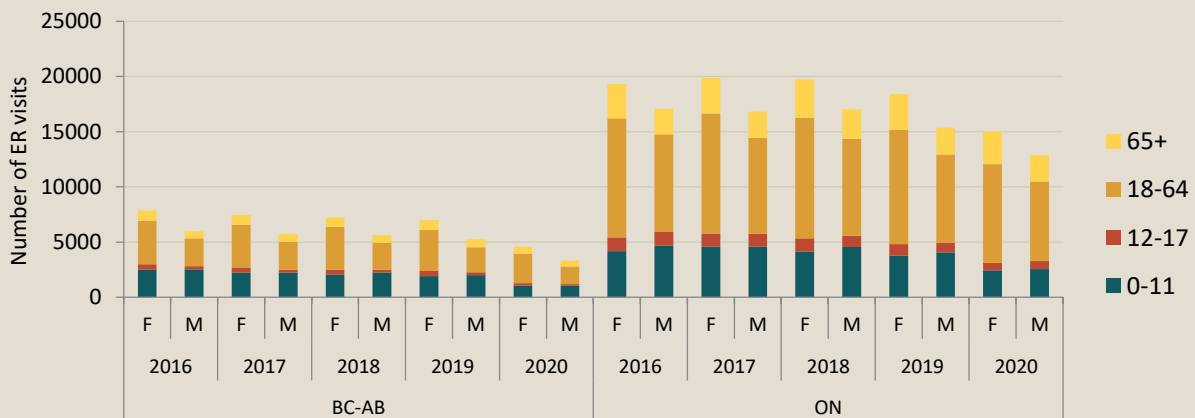
ER visits with dermatitis and eczema as the main problem came mainly from the 18-64 year age group, pointing to misdiagnosis in these adults, with AD being coded as dermatitis and eczema, potentially due to less awareness by ER physicians of the manifestations of AD beyond childhood. Adult ER visits may have been driven by those without a primary care practitioner that was helping them manage their condition.

We have not presented data for Atlantic and Prairie provinces, given the very low numbers in these regions.

**ER Visits per Age Group and Sex, with AD as *main problem***



**ER visits per Age group and Sex, with Dermatitis and Eczema as *main problem***

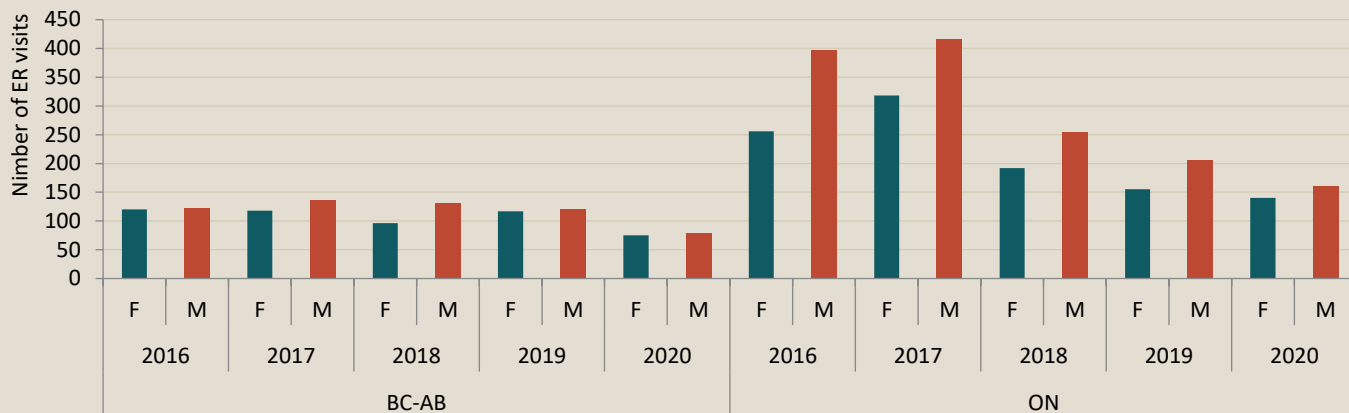


We present the number of ER visits with AD as main problem, across three age groups. Numbers may have been higher for those 0-11 years than the older groups because AD is a common childhood condition that physicians are used to seeing, meaning diagnosis is fairly straightforward and accurate.

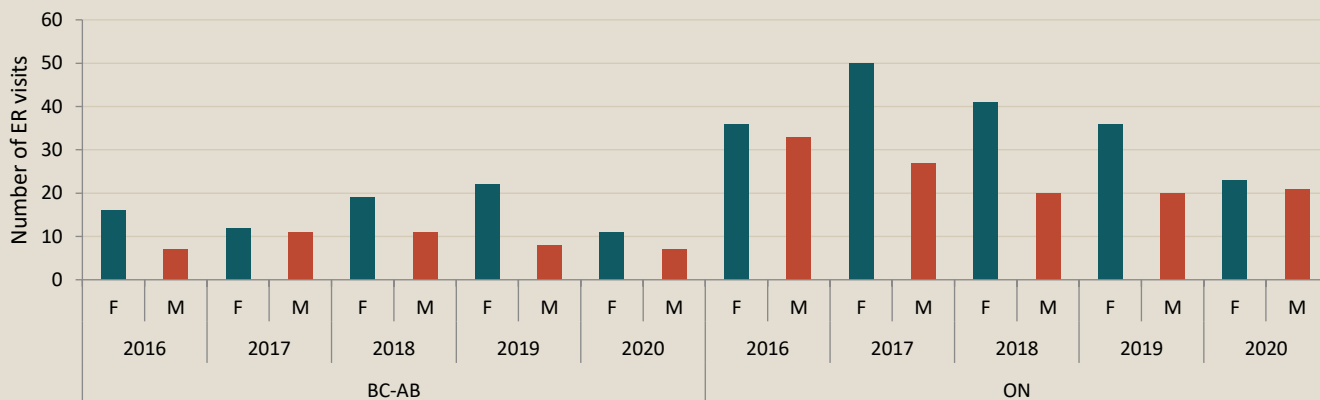
However, in the older age groups, physicians were less likely to consider AD as the cause of the skin condition, so there was more room for delays and misdiagnoses.

There appeared to be a male predominance of AD in children, although this trend reversed with age.

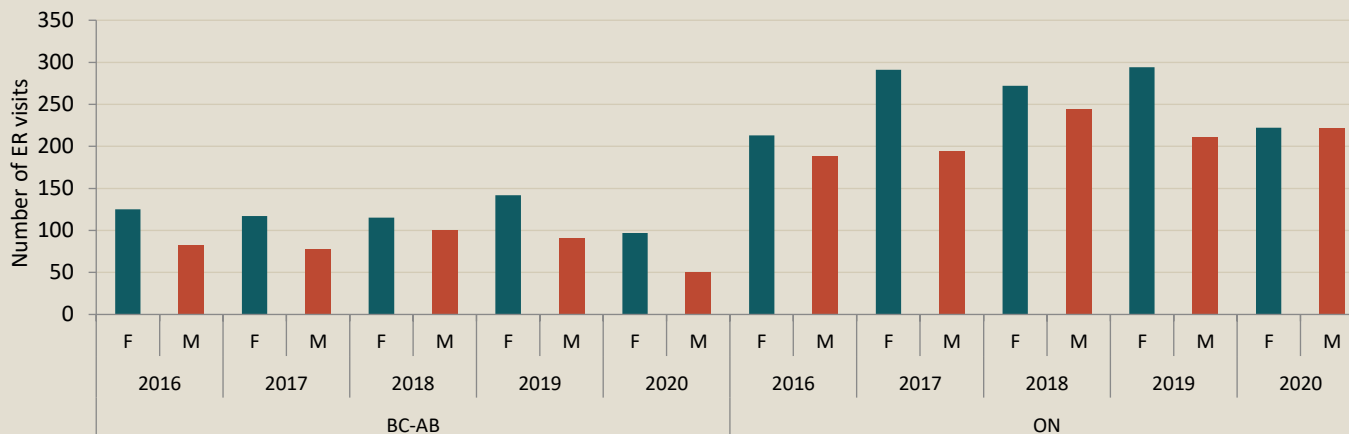
**ER Visits with AD as *main problem* (0-11 years)**



**ER Visits with AD as *main problem* (12-17 years)**



**ER visits with AD as *main problem* (18+)**





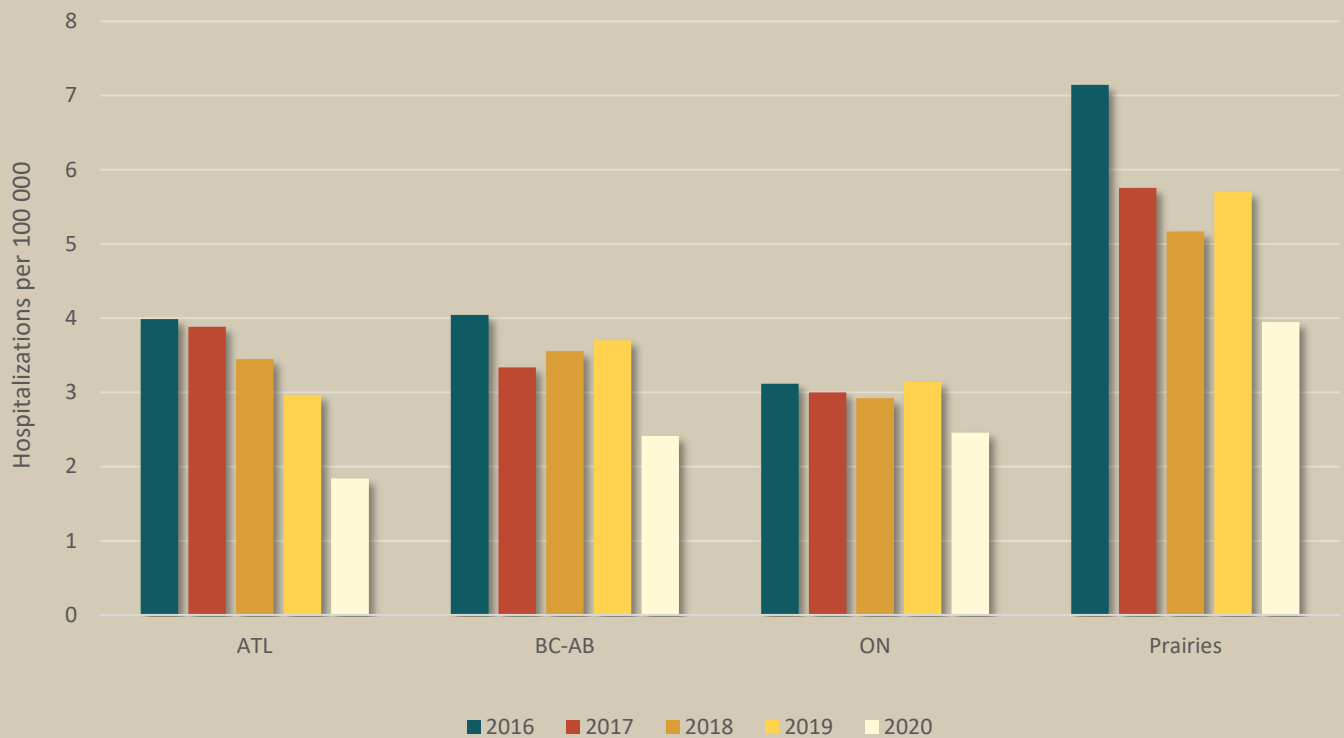
## ii. Hospitalizations

While we intended to present hospitalization data specifically for a code of AD as the main reason for hospitalization, the numbers were mainly suppressed and therefore we estimated that – as observed with data on ER visits – AD was not being used as the primary code. However, we found substantially higher numbers of hospitalizations coded as dermatitis and eczema. Given that of all of the conditions captured with these codes (L20-30), AD is the most likely to lead to hospitalization, and we believe it to be the driving diagnosis in hospitalization for dermatitis and eczema. Data for the 12-17 age group was not presented due to suppression.

While ER visits across all age groups were fairly low, hospitalizations in Prairie provinces were surprisingly

higher than observed in other larger provinces. There could be various reasons for this, including significant variation in healthcare access between provinces. The lower number of dermatologists in Prairie provinces (15 in Manitoba and 12 in Saskatchewan) compared to larger provinces (215 in Ontario and 228 in Quebec)<sup>32</sup> may mean that individuals with AD and related skin conditions do not have regular access to care by a dermatologist (or possibly a primary care provider), and only seek care when their condition is so severe that it requires hospitalization. This may be particularly true of those living in the rural regions of these provinces, and for whom primary healthcare or even an ER visit may be too far to readily access before the condition becomes severe enough for hospitalization.

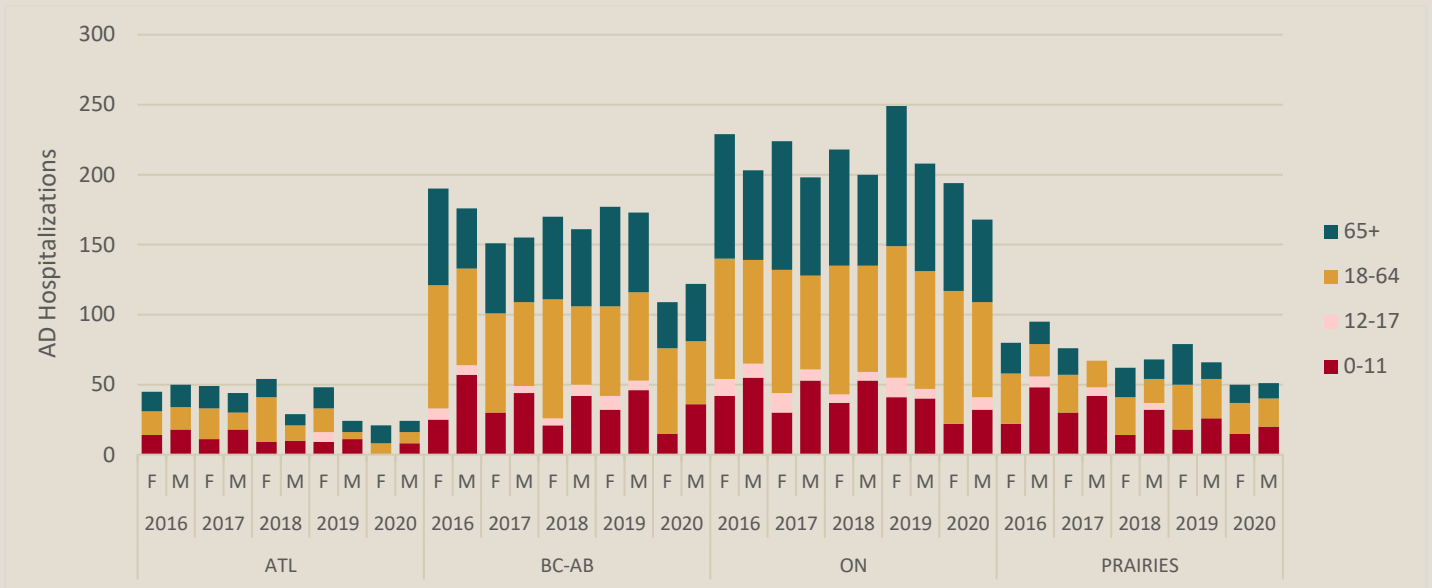
**Hospitalizations per 100,000 with dermatitis and eczema as *main problem***



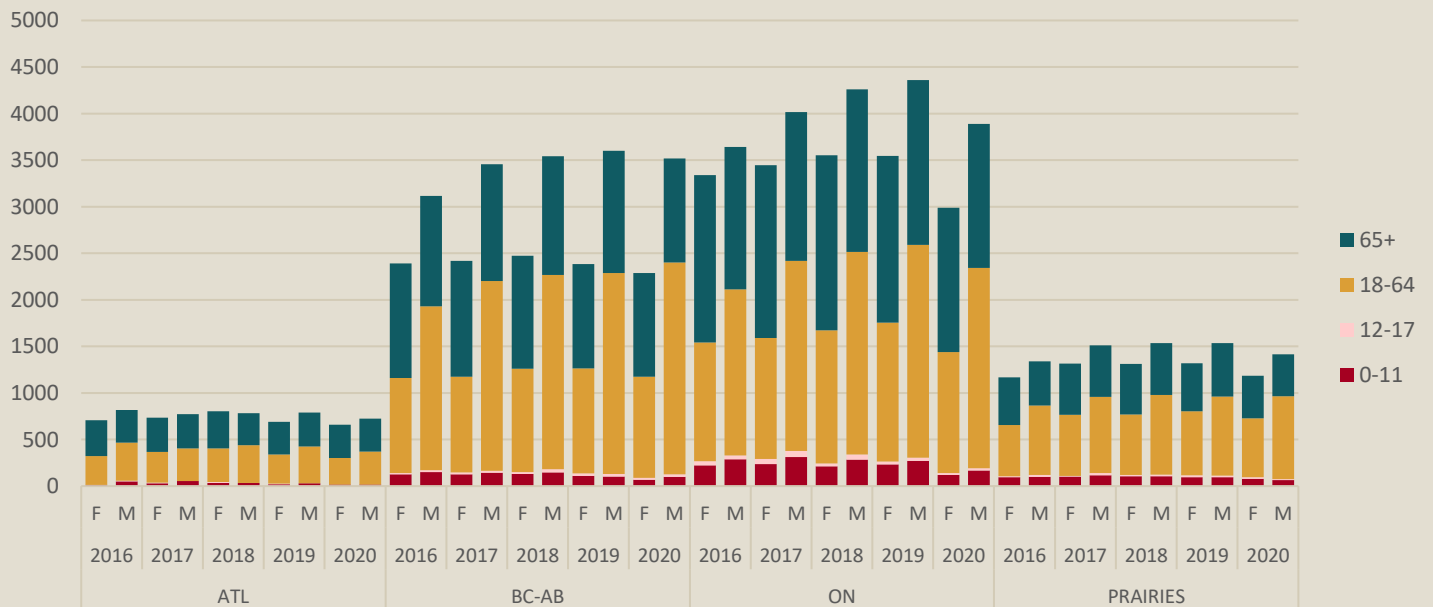
It is notable that hospitalizations happened mainly in adults compared to children, demonstrating that AD often bears a lifelong burden (even in the 65+ age group which is not typically considered affected by this skin condition) despite being considered a childhood disease. This may be attributed to AD not being as controlled in adults as it is in children. Additionally,

females were being hospitalized more than males for eczema and dermatitis. This may have been due to the natural prevalence of these conditions more commonly afflicting females, particularly during hormonal milestones. It could also be attributed to males being more likely to ignore the burden of their condition and more reticent about seeking treatment.

**Hospitalizations by gender and age with dermatitis and eczema as *main diagnosis***



**Hospitalizations by gender and age, with comparator diagnosis\* as *main diagnosis***

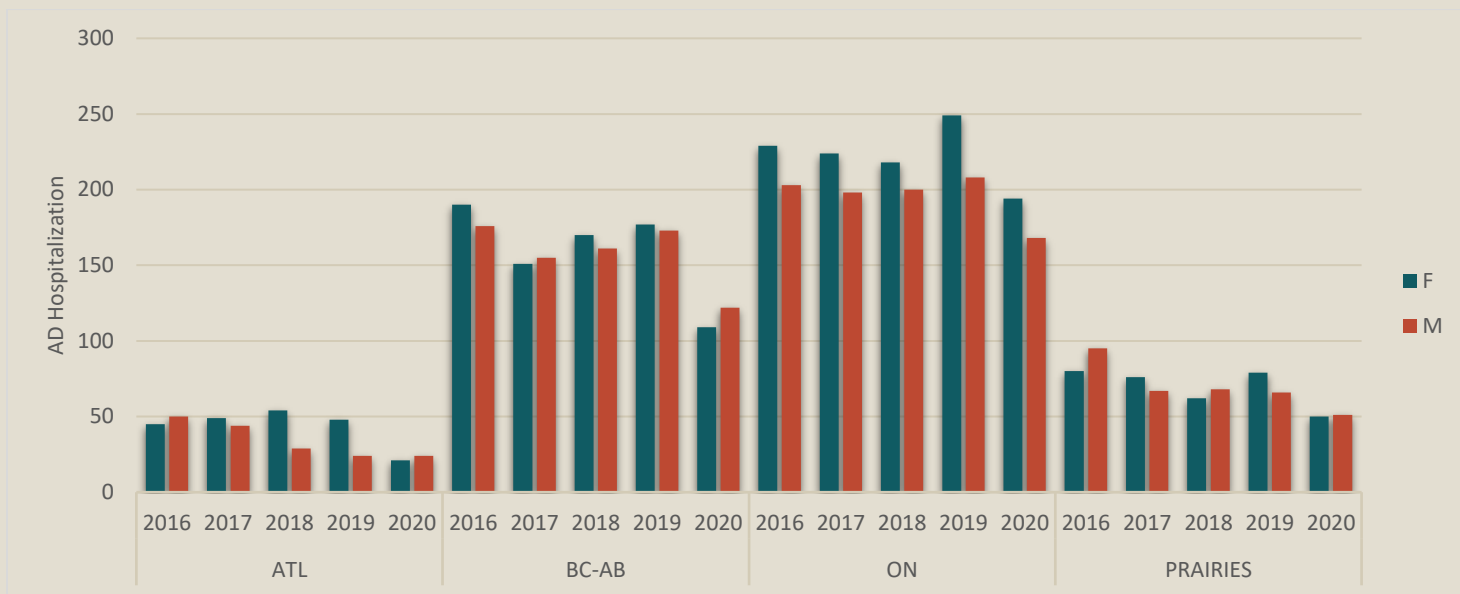


\*Cellulitis, other local skin infections, rash and non-specific skin eruptions, impetigo

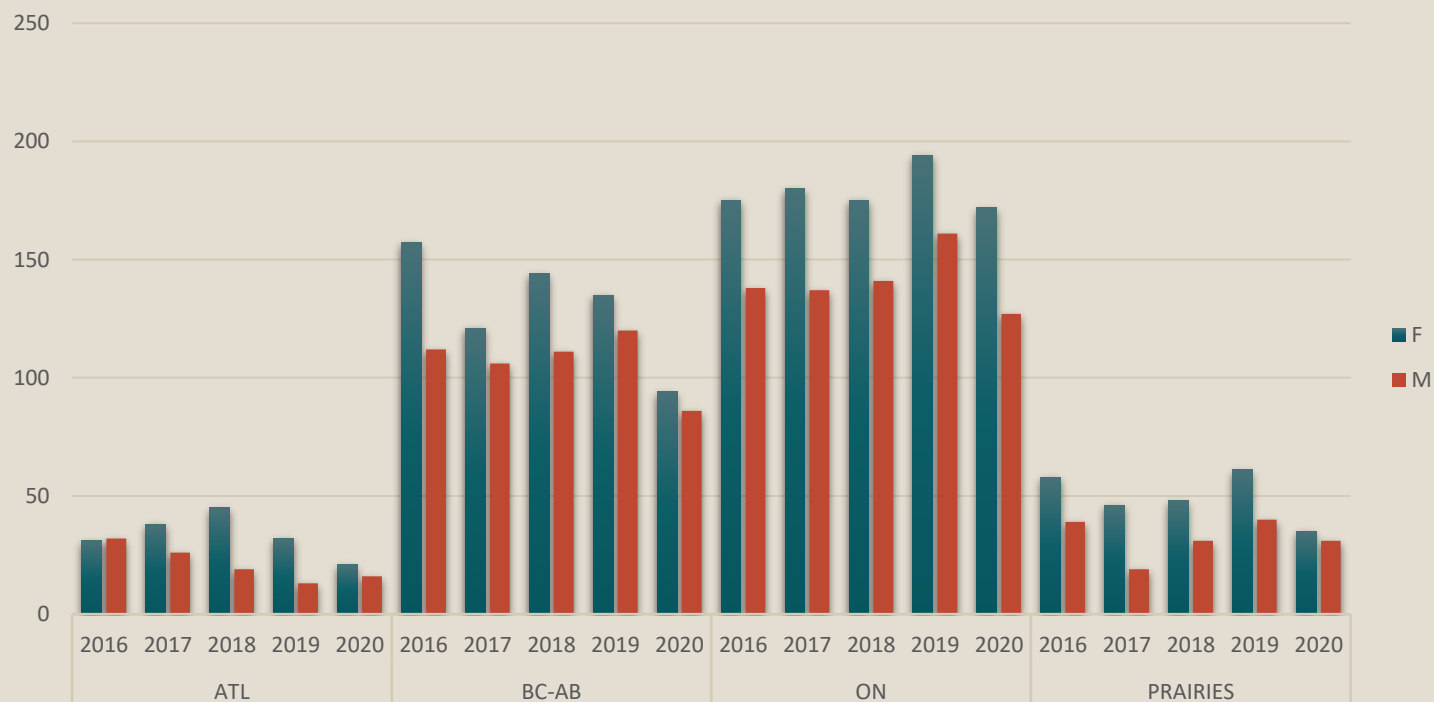
Hospitalization for dermatitis and eczema in those 0-11 years was higher in females than males in BC/AB and Ontario, in contrast to the data for ER visits

in this same age group. It is unclear whether this reflects less control of the disease/a more severe condition in females.

### Hospitalizations with dermatitis and eczema as main diagnosis (0-11 years)



### Hospitalizations with dermatitis and eczema as main diagnosis (18+)



We calculated length of stay per hospitalization to range from two to eight days (data not shown), and noted that duration of stay was longer for the 65+ population, as expected, due to increased likelihood of comorbidities.

While we also collected data on number of cases where AD was reported as the “other problem” – that is, an existing comorbidity but not the main reason for which the patient visited the ER or hospital – the

numbers were very low, and often suppressed due to CIHI data restrictions. Given the prevalence of AD, we believe that such data was likely incomplete, and represented the physician coding only the main reason for which the patient sought healthcare (or being limited in their ability to code for all of the patient’s comorbidities). Until there are more uniform coding practices across Canada to reduce the inter-provincial variation that currently exists, it will be impossible to truly measure epidemiological parameters including disease burden.

---

*“I wish I was taken seriously and for people to realize that it's more than ‘just a skin disease’.”*

# REFERENCES

---

1. Langan SM, Irvine AD, Weidinger S. Atopic dermatitis. *Lancet* 2020;396(10247):345-60.
2. Kaufman BP, Guttman-Yassky E, Alexis AF. Atopic dermatitis in diverse racial and ethnic groups – variations in epidemiology, genetics, clinical presentations and treatment. *Experimental Dermatology* 2018;27(4):340-57.
3. Eczema. Canadian Dermatology Association. 2018. Available from: <https://dermatology.ca/public-patients/skin/eczema>. Accessed 2022-01-23.
4. de Bruin-Weller M, Gadkari A, Auziere S, et al. The patient-reported disease burden in adults with atopic dermatitis: a cross-sectional study in Europe and Canada. *Journal of the European Academy of Dermatology and Venereology* 2020;34(5):1026-36.
5. Adesanya EI, Schonmann Y, Hayes JF, et al. Risk factors for mental illness in adults with atopic eczema or psoriasis: protocol for a systematic review. *BMJ Open* 2020;10(12):e038324.
6. Xie QW, Dai X, Tang X, Chan CHY, Chan CLW. Risk of mental disorders in children and adolescents with atopic dermatitis: a systematic review and meta-analysis. *Front Psychol* 2019;10:1773.
7. Bantz SK, Zhu Z, Zheng T. The atopic march: progression from atopic dermatitis to allergic rhinitis and asthma. *J Clin Cell Immunol* 2014;5(2):202.
8. Ghazal S, Ridha Z, D'Aguanno K, et al. Treatment guidelines for atopic dermatitis since the approval of dupilumab: a systematic review and quality appraisal using AGREE-II. *Front Med (Lausanne)*. 2022;9:821871.
9. Rapaport MJ, Lebwohl M. Corticosteroid addiction and withdrawal in the atopic: the red burning skin syndrome. *Clin Dermatol* 2003;21(3):201-14.
10. Hajar T, Leshem YA, Hanifin JM, et al. A systematic review of topical corticosteroid withdrawal (“steroid addiction”) in patients with atopic dermatitis and other dermatoses. *Journal of the American Academy of Dermatology* 2015;72(3):541-9.
11. Sheary B, Harris MF. Cessation of long-term topical steroids in adult atopic dermatitis: a prospective cohort study. *Dermatitis* 2020;31(5):316-20.
12. Misery L. Why is there poor adherence to topical corticosteroid therapy in atopic dermatitis? *Expert Review of Dermatology* 2012;7:5-7.
13. [https://www.abbvie.ca/content/dam/abbvie-dotcom/ca/en/documents/press-releases/RINVOQ\\_AD\\_NOC\\_Press\\_Release\\_EN.pdf](https://www.abbvie.ca/content/dam/abbvie-dotcom/ca/en/documents/press-releases/RINVOQ_AD_NOC_Press_Release_EN.pdf) Accessed 2022-01-23.
14. <http://sanoficanada.mediaroom.com/2021-02-23-Health-Canada-approves-DUPIXENT-R-dupilumab-injection-as-the-first-biologic-for-the-treatment-of-moderate-to-severe-atopic-dermatitis-in-children-aged-6-to-11-years> Accessed 2022-01-23.
15. [https://www.leo-pharma.ca/Media-Centre/News/Health-Canada-approves-ADTRALZA%C2%AE-\(tralokinumab\)-as-a-treatment-for-adults-with-moderate-to-severe-atopic-dermatitis.aspx](https://www.leo-pharma.ca/Media-Centre/News/Health-Canada-approves-ADTRALZA%C2%AE-(tralokinumab)-as-a-treatment-for-adults-with-moderate-to-severe-atopic-dermatitis.aspx) Accessed 2022-01-23.
16. Long Q, Jin H, You X, et al. Eczema is a shared risk factor for anxiety and depression: A meta-analysis and systematic review. *PLoS ONE* 2022;17(2):e0263334.
17. Rønnstad ATM, Halling-Overgaard AS, Hamann CR, Skov L, Egeberg A, Thyssen JP. Association of atopic dermatitis with depression, anxiety, and suicidal ideation in children and adults: a systematic review and meta-analysis. *J Am Acad Dermatol* 2018;79(3):448-56.
18. Pompili M, Bonanni L, Gualtieri F, Trovini G, Persechino S, Baldessarini RJ. Suicidal risks with psoriasis and atopic dermatitis: Systematic review and meta-analysis. *J Psychosom Res* 2021;141:110347.

19. Chuang YC, Wang CY, Huang WL, et al. Two meta-analyses of the association between atopic diseases and core symptoms of attention deficit hyperactivity disorder. *Sci Rep* 2022;12:3377.
20. Jeon C, Yan D, Nakamura M, et al. Frequency and management of sleep disturbance in adults with atopic dermatitis: a systematic review. *Dermatol Ther (Heidelb)* 2017;7(3):349-64.
21. Bender BG, Ballard R, Canono B, Murphy JR, Leung DY. Disease severity, scratching, and sleep quality in patients with atopic dermatitis. *Journal of the American Academy of Dermatology*. 2008;58(3):415-20.
22. Nørreslet LB, Ebbenhøj NE, Ellekilde Bonde JP, et al. The impact of atopic dermatitis on work life—a systematic review. *Journal of the European Academy of Dermatology and Venereology* 2018;32(1):23-38.
23. Canadian Skin Patient Alliance. Atopic dermatitis report. [http://canadianskin.ca/images/Documents/Atopic\\_report/CSPA\\_Atopic\\_Dermatitis\\_report\\_Feb\\_2\\_2018\\_FINAL\\_.pdf](http://canadianskin.ca/images/Documents/Atopic_report/CSPA_Atopic_Dermatitis_report_Feb_2_2018_FINAL_.pdf) Accessed 2022-01-23.
24. Charman CR, Venn AJ, Ravenscroft JC, Williams HC. Translating Patient-Oriented Eczema Measure (POEM) scores into clinical practice by suggesting severity strata derived using anchor-based methods. *British Journal of Dermatology* 2013;169(6):1326-32.
25. Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI)--a simple practical measure for routine clinical use. *Clin Exp Dermatol* 1994;19(3):210-6.
26. Bertakis KD, Azari R, Helms LJ, et al. Gender differences in the utilization of health care services. *Journal of Family Practice* 2000;49(2):147.
27. Thompson AE, Anisimowicz Y, Miedema B, et al. The influence of gender and other patient characteristics on health care-seeking behaviour: a QUALICOPC study. *BMC Family Practice* 2016;17(1):1-7.
28. 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). Accessed 2022-01-23.
29. Barbeau M, Lalonde H. Burden of atopic dermatitis in Canada. *International Journal of Dermatology* 2006;45(1):31-6.
30. Ameen M, Meller S, Pinter A, Shear NH, Soria A; (the BADEL Study Group). Perception and experience of biologic therapy in atopic dermatitis: a qualitative focus group study of physicians and patients in Europe and Canada. *Dermatol Ther* 2021;11(6):2159-77.
31. Silverberg JI, Garg NK, Paller AS, et al. Sleep disturbances in adults with eczema are associated with impaired overall health: a US population-based study. *Journal of Investigative Dermatology* 2015;135(1):56-66.
32. Canadian Medical Association. Dermatology Profile. <https://www.cma.ca/sites/default/files/2019-01/dermatology-e-v2.pdf>. Accessed 2022-05-30.