

ECZEMA SOCIETY OF CANADA

ATOPIC DERMATITIS: PATIENT INSIGHTS REPORT

- MILD-TO-MODERATE DISEASE -



OVERVIEW OF SURVEY RESULTS

INTRODUCTION

PATIENT INSIGHTS BY THE NUMBERS:

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Adult Atopic Dermatitis (AD)

In the past two years, 29% of respondents have seen a doctor four or more times due to their AD, and 22% have seen three or more different doctors to manage their AD

One in four adults with AD report having lived a decade or longer without adequate treatment



Only 13% of respondents reported that their AD is well controlled

37% of respondents have treatment needs that are **not being met by current therapies**



82% of respondents report that their day-to-day life is negatively impacted by their condition

The three most important aspects of atopic dermatitis to control were rated as:

- 1) Interrupted or lost sleep
 2) Anxiety related to AD
- 3) Missed work or important events

Children's Atopic Dermatitis (AD)

In the past two years, 28% of respondents have seen a doctor four or more times related to their child's AD, and 17% have seen three or more different doctors

One in four reported having to wait six months or longer for their child to see a dermatologist



One in four children who miss school due to their AD miss **ten or more days each year**

20% of children find treatments **painful** to apply



Less than **1/3 of parents** surveyed indicated their child's AD was **well controlled**

The three biggest challenges of treatment were rated as:

- 1) Fears of medication safety
- 2) Pain and discomfort of treatments
 3) Complex routines that are difficult
- 3) Complex routines that are difficult to follow

ATOPIC DERMATITIS: MORE THAN JUST DRY, ITCHY SKIN

Atopic dermatitis (AD), a common form of eczema, is a chronic, inflammatory skin condition characterized by dry, itchy skin that goes through periods of flares and periods of clearing. During times of flare the skin can become very itchy and painful, and skin becomes red and inflamed. AD patients can have periods of remission; however, some patients never experience complete remission from these

life altering symptoms. AD can range from mild to severe, and all forms of the disease can have significant quality of life impact on patients, caregivers, and their loved ones. AD is often diagnosed and managed by primary care physicians and nurse practitioners. While Canadian data is not available, AD is estimated to affect 11% of children 2, and 7% of adults 3 in the United States.

INTRODUCTION: OUR PATIENT INSIGHTS REPORT

Eczema Society of Canada (ESC) is a registered Canadian charity dedicated to improving the lives of Canadians living with eczema, through our mission of education, support, awareness, advocacy, and research. In late 2016, ESC set out to better understand the burden of disease of Canadians living with AD, and the existing barriers to better care.

ESC conducted online surveys of Canadians living with AD and had a total of 1,035 respondents from all provinces across Canada. Of those respondents, 377 were adults living with AD and their caregivers, and 658 were children and their caregivers. Mild or moderate AD is often thought

of dismissively as simply dry, itchy skin; however, even mild disease can have significant impact on sufferers. The adult survey gathered data from 137 adults who live with moderate AD, and the children's survey gathered data on 384 children who live with mild or moderate AD. This report contains the data and insights gathered that are specific to mild and moderate patients.

The content of this report details the survey data collected from both the adult and children's survey, and reflects the insights gathered through survey responses from Canadians impacted by AD.

DEFINITIONS OF ATOPIC DERMATITIS SEVERITY







MILD

Areas of dry skin, infrequent itching, with or without small areas of redness.

MODERATE

Areas of dry skin, frequent itching, and redness with or without broken skin or localised skin thickening.

SEVERE

Widespread areas of dry skin, incessant itching, and redness with or without broken skin, extensive skin thickening, bleeding, oozing, cracking and alteration of pigmentation.

These definitions of atopic dermatitis were used within the surveys to define disease severity.

ADULT INSIGHTS

ADULT INSIGHTS

ADULT SURVEY INSIGHTS



Atopic dermatitis (AD) is often thought of as a childhood condition, however many children who suffer with AD continue to suffer into adulthood.⁴ Data presented in this section is based on responses from Canadian adult respondents (18 years of age and older) who suffer with moderate AD.

Survey respondents were asked to indicate all health care providers who diagnosed their disease, and respondents indicated that the family physician and dermatologist were most often the health care providers diagnosing their AD, with 62% of respondents having been diagnosed by a primary care physician, and 59% diagnosed by a dermatologist. The management of AD is similar, with just over half of respondents (55%) reporting that their AD is managed by the primary care physician, and a third (36%) reporting that their AD is managed by a dermatologist (again, respondents were asked to check all that apply).

Who manages your atopic dermatitis?*



In the past two years, 29% of respondents have seen a doctor four or more times due to their AD, and 22% of respondents report having seen three or more different doctors to manage their AD. Wait times for dermatologists

are long, with 62% waiting three months or longer and 21% waiting six months or longer. Access to primary care physicians is better, with 43% of respondents experiencing no wait time to see their family physician.

1 in 5 survey respondents have **waited six months** or longer **to see a dermatologist**

TREATMENTS

AD is a chronic condition for which there is no cure, and therefore patients are caught in a cycle of treating recurrent flares. Only 13% of respondents report that their AD is well controlled. Additionally, nearly three quarters (74%) of respondents have been suffering for

more than a year without adequate treatment, and a third (33%) report that they have lived six years or longer without adequate treatment. Sadly, nearly one in four (24%) report having lived a decade or longer without adequate treatment.

Only 13% of respondents report that their AD is well controlled

98% of respondents have used topical corticosteroids
44% of respondents have used topical calcineurin inhibitors
57% of respondents have used oral antihistamines
24% of respondents have used phototherapy

1/3 of survey respondents have tried **systemic medications**

Bathing and moisturizing techniques used in AD can reduce dryness and therefore reduce itching. 86% of respondents reported using bathing and moisturizing techniques to manage their disease. Although moisturizing skin is important for AD management, medications are typically required to manage the inflammation of AD.

Topical corticosteroids (TCS) are a first line therapy for AD and almost all (98%) of respondents report having used TCS. Patient fears about TCS (sometimes referred to as "topical corticosteroid phobia") is a common problem and a barrier to care as confirmed by recent medical literature.⁵ AD sufferers commonly cite fears related to side effects of the TCS, such as thinning of the skin, and this may contribute to the under-treatment of AD.

Topical calcineurin inhibitors (TCI) are a second line therapy for AD, and 44% of respondents have used TCI to manage their condition. In Canada, TCI medications have a black box warning from Health Canada due to a potential cancer risk. While recent studies have supported the safety of these medications,⁶ caregivers report concerns surrounding their safety and the cancer warning contained in the product monograph.

AD sufferers also cycle through many different medications. Four out of five (80%) report having used four or more different treatments to manage their AD, 31% having used 10 or more, and 22% having used 15 or more different treatments to manage their condition.

ADULT INSIGHTS

CHILDREN'S INSIGHTS

48% of respondents **find treatments uncomfortable**

47% of respondents report it is difficult to dress after applying treatments
22% of respondents find it physically painful to apply treatments

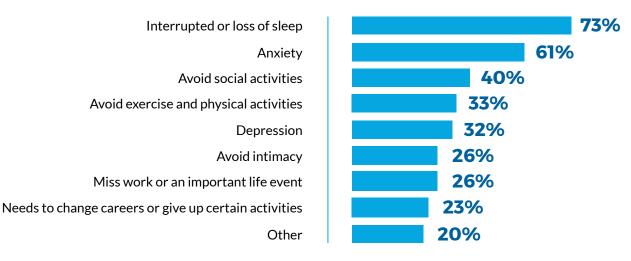
37% of respondents report treatment **needs** that are **not being met by current therapies**

QUALITY OF LIFE IMPACT

AD has a significant impact on quality of life with 82% of respondents indicating that their day-to-day life is negatively impacted by their condition. Sleep, anxiety, and avoidance of social activities were the three most common areas of life affected by AD. Nearly three quarters (73%)

of respondents experience loss of sleep related to their AD, and of those respondents, 72% report a loss of three or more nights each month, and 38% lose eight or more nights each month.

Has your atopic dermatitis contributed to any of the following in the past two years?



*Respondents were asked to check all that apply.

The three most important aspects of atopic dermatitis to control were rated as:

- (1) Interrupted or lost sleep
- (2) Anxiety related to AD
- (3) Missed work or important events

CHILDREN'S SURVEY INSIGHTS

91%

of responses pertain to children **12 years of age** and younger



25%

of responses pertain to **mild atopic dermatitis**

of responses pertain to **moderate atopic dermatitis**

75%





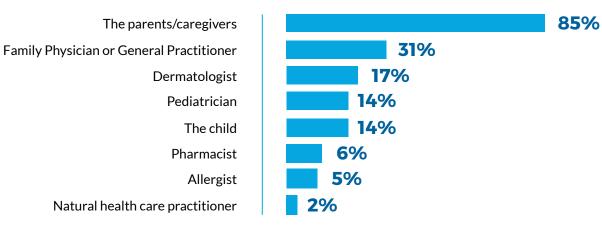
CARE OF ATOPIC DERMATITIS

Paediatric atopic dermatitis (AD) is primarily diagnosed by family physicians or primary care providers with 62% of children having been diagnosed by the primary care provider. Pediatricians and dermatologists are also important members of the medical team with 33% and 23%, respectively, making the diagnosis. The management of the AD is primarily done by parents and/or caregivers with 85% reporting that they manage their child's condition. Nearly a third (31%) reported that their family physicians or primary care provider manage their child's AD, and dermatologists and paediatricians were cited as managing the condition for 17% and 14% of respondents

respectively. This data indicates that parents are the most frequent manager of a child's AD.

Respondents indicated that in the past two years 28% have seen a doctor four or more times related to their child's AD, and 17% have seen three or more different doctors. In one-on-one interviews ESC learned that seeing multiples doctors is common as the chronicity of the disease often has parents seeking second opinions and new treatment options in hopes they can "cure" the disease.

Who manages your atopic dermatitis?*



*Respondents were asked to check all that apply.

CHILDREN'S INSIGHTS

CHILDREN'S INSIGHTS

WAIT TIMES

Wait times are a common concern within the Canadian health care system, and access to specialists and wait times were also a concern for survey respondents. While 62% report experiencing no wait time to see their family physician, and 54% of respondents experience no wait time

to see a paediatrician, wait times to see a dermatologist were longer. Nearly half of the children (46%) waited three months or longer to see a dermatologist, and one in four (24%) waited six months or longer.

CHALLENGES WITH TREATMENT

It is well documented that patients with AD have difficulty adhering to recommended treatment plans.⁷ Of caregivers surveyed, 39% indicated that their child finds the treatments uncomfortable, 35% reported difficulty

dressing after applying topical treatments, and 20% of respondents find the treatments physically painful. Patients interviewed indicated that pain from topical medications includes stinging and burning of the skin.

67% of caregivers experience **challenges** following their **child's treatment plan**

TREATMENT

8

65%

of respondents' have used **four or more different** treatments to manage their child's atopic dermatitis

The majority of parents surveyed are dissatisfied with the management of their child's AD with only 29% indicating their child's AD is well controlled. Families of children, including very young children, have tried multiple treatments to try and gain control of their child's disease, with more two thirds (65%) having used four or more different treatments, and 19% having used 10 or more different treatments.

Bathing and moisturizing techniques are a common method of AD management, used by 94% of respondents. Topical corticosteroids (TCS) are a first line therapy for AD to manage inflammation, and almost all (94%) of respondents report having used TCS. Caregivers cited fears related to side effects of the TCS and this may contribute to undertreating the AD. 14% of respondents indicated they don't follow the regimen as prescribed by the doctor.

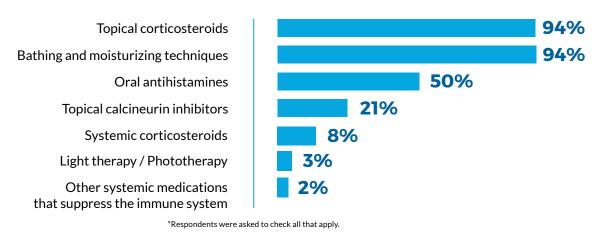
Fear of TCS is sometimes called "topical corticosteroid phobia" and is a common problem and a barrier to optimal care.⁵ Although TCS have been used for more than four decades, AD sufferers and caregivers commonly cite fears related to side effects, such as thinning of the skin, and this may contribute to under treating the AD.

One fifth (21%) of respondents have used topical calcineurin inhibitor (TCI)s. In Canada, TCI medications

have a black box warning from Health Canada for potential cancer risks. While recent studies have supported the safety of these medications, 6 caregivers have concerns surrounding their safety and the cancer warning contained in the product monograph.

Adherence is a challenge with TCI treatment as well, with 17% indicating that they don't follow the regimen as prescribed by the doctor. Children with AD who do not respond to topical therapy may be prescribed systemic therapies, even for moderate AD, with 2% of respondents reporting the use of off-label systemic medications.

Which treatments has your child used to manage their atopic dermatitis? *



The three biggest challenges of treatment were rated as:

- (1) Fears of medication safety
- (2) Pain and discomfort of treatments
- (3) Complex routines that are difficult to follow

QUALITY OF LIFE

Quality of life is negatively impacted by mild and moderate AD. A common concern among sufferers is that AD is not considered a serious medical concern, and it is reduced to simply "dry itchy skin". Just over a third (37%) of respondents indicated their child's daily life is negatively impacted by atopic dermatitis. More than half of children experience interrupted sleep, with 58% of respondents being impacted. More than half of children with mild to moderate AD experience loss of sleep related to their disease. Of those, 24% experience sleep loss 8 nights per month or more.

Caregiver sleep is also significantly impacted, with 44% experiencing sleep loss. Anxiety was also a significant concern, with 27% of caregivers experiencing anxiety specifically related to their child's AD, and 21% of children with AD experiencing anxiety related to their AD. Participations in sports and physical activity is also impacted, with 16% of children experiencing limitations related to their AD. AD can also lead to school absences, with 9% of children missing school specifically related to their AD, with 25% of them missing 10 or more days of school per year.

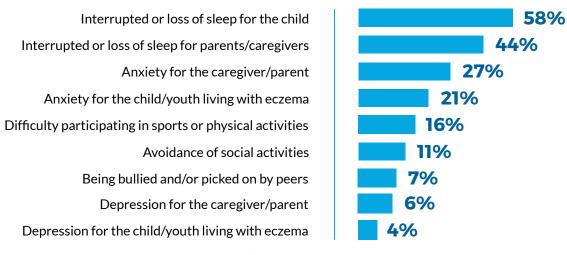
One in four children experience **sleep loss** 8 nights per month or more

CHILDREN'S INSIGHTS

REPORT SUMMARY

25% of children who miss school due to their AD **miss ten or more** days per year

Does your child's atopic dermatitis contribute to any of the following? *

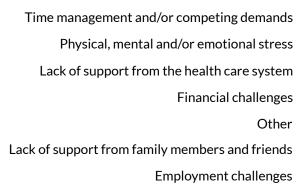


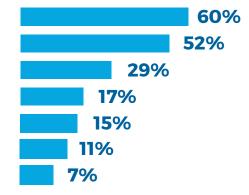
*Respondents were asked to check all that apply.

The three most important aspects of their child's atopic dermatitis to control are:

- (1) Pain and/or discomfort
- (2) Interrupted or loss of sleep
- (3) Anxiety related to AD

What challenges do you face in caring for your child with atopic dermatitis?*





*Respondents were asked to check all that apply.



SUMMARY

While some patients with mild or moderate atopic dermatitis (AD) are well managed with current therapies, for other patients current therapies are inadequate to manage their condition as indicated by survey results. The insights reflected in this report demonstrate a clear need for additional treatment solutions to help with the management of AD. The impact AD has on quality of life is significant, whether it is associated sleep loss, time away from work, school, or social activities, or frustration with finding help and control of the disease.

Mild or moderate AD is more than dry, itchy skin and Canadians deserve relief from the anxiety, pain and complexity associated with this condition. This report sheds light on the unique and often overlooked needs of these patients, and opportunities for change. As we sit on the cusp of a new era in care for AD patients, ESC hopes this report drives change by initiating a discussion among patients, caregivers, healthcare professionals, government decision-makers, scientists, researchers, and the general population.

REFERENCES

- 1. Stern RS, Nelson C. J Am Acad Deramtol. 1993;29 (5 pt 1):773-777.
- 2. Shaw TE et al. J Invest Dermatol. 2011; 131:67-73.
- 3. Silverberg JI et al. J Invest Dermatol. 2015; 135:56-66.
- 4. Margolis JS et al. JAMA Dermatol. 2014 Jun; 150(6):593-600.
- 5. Li AW et al. JAMA Dermatol. 2017 Jul 19; doi: 10.1001/jamadermatol.2017.2437. [Epub ahead of print]
- 6. Legendre L et al. J Am Acad Dermatol. 2015 Jun;72(6):992-1002.
- 7. Krejci-Manwaring J et al. J Am Acad Dermatol. 2007 Feb;56(2):211-6.

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