The Skin I’m In

2022 UPDATE

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

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Canadian Skin Patient Alliance

Eczéma Québec

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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.

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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.

ORG HCP

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.

ORG HCP P/T

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.

HCP P/T

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.

ORG FED PRIV HCP P/T

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.

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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.

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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