

A Canadian Adult Cross-Sectional Survey of the Burden of Moderate to Severe Atopic Dermatitis

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Keywords

dermatitis, eczema, atopic dermatitis, quality of life

Atopic dermatitis (AD) has a substantial disease burden due to its high prevalence, chronicity, and impact on quality of life (QoL).¹ Despite the recognition of the widespread impact of AD, Canadian literature on the subject matter is sparse.

In November and December 2016, the Eczema Society of Canada (ESC) conducted an online national cross-sectional survey to assess the burden of self-reported moderate to severe atopic dermatitis for adult patients living in Canada. Participants were recruited through direct email invitation, an electronic newsletter, and social media. The survey specifically assessed QoL, treatments used, and access to care in Canada. Results of this survey were originally published in a lay report by the ESC, and here we present some of the notable results for a medical audience.² Data tables and figures are provided in the online supplement.

We had 377 initial respondents to our survey, the majority from Ontario (147/377, 39%) and Quebec (84/377, 22%), 246 of whom met inclusion criteria by living in Canada and having or caring for someone with moderate or severe atopic dermatitis.

Atopic dermatitis had a substantial impact on the QoL: 87% (187/216) of respondents reported their daily life was negatively affected by their disease. The most common negative experiences reported were dysfunctional sleep (148/187, 79%), anxiety (120/187, 64%), avoidance of social activities (90/187, 48%), avoidance of physical activity (88/187, 47%), and avoidance of intimacy (75/187, 40%).

Many respondents also reported difficulty accessing specialty care and appropriate treatments. Nearly one-third (62/193, 32%) reported having difficulty in accessing treatment, and 41% (80/193) felt their treatment needs were unmet. While AD is typically managed by primary care physicians, patients with moderate to severe disease often require dermatological consultation. Among respondents reporting moderate to severe AD, only 42% were managed by a dermatologist. Survey participants shared challenges and frustration with accessing a dermatologist in their local area, accessing a dermatologist in a timely manner, and, for some, accessing a dermatologist at all. For patients seeing a dermatologist, wait times are long, with 69% (111/160) having to wait more than

3 months for an initial consultation. This suggests that access to specialists may be a barrier to optimal care.

Treatment of AD can at best achieve disease remission and not cure, so improving QoL is a major therapeutic goal.³ Many respondents noted difficulty in managing AD. Only 9% (19/202) reported their disease was well controlled, and over three-fourths (158/202, 78%) of respondents reported they had lived more than 1 year without adequate treatment for their disease.

Our survey results are limited by self-report of AD diagnosis and disease severity and selection bias in a convenience sample. Future studies should be conducted over longer periods of time in a more representative sample.

Nevertheless, our findings provide insight into the burden of this chronic and sometimes debilitating skin disease in Canada. Consistent with previous studies, AD can affect social, academic, and occupational functioning, and patients are at increased risk for mental health problems.^{4,5} Improving access to care for these patients may improve outcomes.

Declaration of Conflicting Interests

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Supplementary Materials

The use of online-only supplementary files is available and encouraged for use by *JCMS* authors. These files may include more detailed methods, extended data sets/data analysis, surveys, forms, tables or additional figures, and other supporting material that is not essential for inclusion in the full text of the manuscript but would nevertheless benefit the reader. In addition, other material, including video clips and podcasts, that enhance or extend the context of the paper beyond that which can appear in print are welcome. Supplementary files are peer reviewed. Complete guidelines for Supplementary Files are available on the journal website.