

# Patient Burden of Atopic Dermatitis

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## KEYWORDS

• Eczema • Atopic dermatitis • Burden • Quality of life • Atopy • Itch • Sleep • Outcome measures

## KEY POINTS

- Patient burden in atopic dermatitis (AD) is significant and is comparable to other dermatoses without systemic involvement.
- Itch and pain are the most common symptoms in AD, and can have pronounced detrimental effects on quality of life (QoL) and sleep in patients with AD.
- Disease impacts include work and leisure limitations, difficulties in interpersonal relationships, and time lost to management of the disease.
- Most studies demonstrate a significant association between increasing disease severity and worsening impact on QoL.
- Both pharmacologic and educational interventions that improve disease severity appear to simultaneously improve QoL.

## INTRODUCTION

Patients with atopic dermatitis (AD) experience symptoms and changes in skin appearance that can have significant impacts on physical and psychosocial health. The resulting negative effects on quality of life (QoL), relationships, and work or school performance can be overwhelming.

Although most cases will resolve before adulthood, AD is often persistent into and can begin in adulthood, resulting in a lifetime patient burden that is one of the largest among diseases worldwide.<sup>1,2</sup> In the 2010 Global Burden of Disease report, 267 diseases were assessed using years lived with disability (YLD). This summary measure is calculated using the prevalence of disease-associated health sequelae multiplied by disability weights to incorporate the extent and duration of the impacts of a disease. Eczema had the 25th

highest YLD of all diseases, and the highest among all skin diseases (note: we use the less-specific term “eczema” here, as that is what is used in the primary sources).<sup>3,4</sup>

To address the significant patient burden of AD, clinicians need to understand the main contributors to impaired QoL, possible predictors of more severe impacts, and the effects of different interventions.

## MEASUREMENT OF PATIENT BURDEN IN ATOPIC DERMATITIS

Assessment of QoL is important in the management of AD as well as in clinical trials. Although QoL generally correlates with disease severity, they are not always closely related.<sup>5</sup> This suggests that severity as assessed by clinicians does not fully capture the impact on patients. Therefore,

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when making therapeutic decisions, clinicians should take the QoL impact of a patient's AD into account and not only rely on assessments of symptoms and signs. For example, a patient with mild disease based on physical examination may have significant impacts on QoL, necessitating more aggressive therapy than their clinical signs would suggest. QoL can be assessed informally with open-ended questions or questions targeting domains known to be affected by AD, such as those detailed in this review. It may be preferable, though, to include a formal assessment of QoL or patient burden in clinical encounters.

A variety of different measures have been used to assess QoL in patients with AD, including generic health, dermatology-specific, and AD-specific scales (**Table 1**). These scales vary widely in target populations, domains assessed, and scoring algorithms. A recent systematic review of instruments used in AD trials identified 28 different QoL scales used in 45 trials.<sup>6</sup> The heterogeneity of these tools makes it challenging to compare or pool findings of impaired QoL or treatment effects on QoL across different studies. The most commonly used scales include the Dermatology Life Quality Index (DLQI) and the Childhood DLQI (CDLQI), used in more than 40 studies of patients with AD.<sup>7,8</sup> These scales include only 10 items, but cover a large breadth of variables, including symptoms and feelings, daily activities, leisure, work and school, personal relationships, and treatment. Although they target patients with skin disease, a concern is the lack of specificity for AD. An alternative patient-reported outcome measure is the 7-item Patient Oriented Eczema Measure (POEM), which is specific for signs and symptoms of AD, but does not assess impact on activities or psychosocial well-being.<sup>9</sup> Taking only a few minutes to complete, this is an attractive standardized option for assessing and monitoring symptoms in clinical practice.

## PREVALENCE OF SYMPTOMS AND IMPAIRED QUALITY OF LIFE IN PATIENTS WITH ATOPIC DERMATITIS

### *Itch and Pain*

Itch perpetuates the dermatitis cycle and is a major component of the diagnostic criteria for AD.<sup>10</sup> In an electronic questionnaire-based study of 304 patients with AD, 91% reported daily itch and 68% experienced itch more than 4 times each day.<sup>11</sup> Most patients who experience itch find it difficult to live with. The National Family Opinion survey in 2001 included 559 respondents with a self-reported history of AD symptoms or diagnosis.<sup>12</sup> In this population, 63.2% of respondents rated their itching (if present) as “very

bothersome” or “extremely bothersome” in the past 12 months.<sup>12</sup> In a pediatric cohort of 120 girls with AD, 95% were troubled by itching and scratching on the DLQI Questionnaire.<sup>13</sup>

The impact of itch on QoL can be pronounced. In addition to correlations between itch and measures of QoL, itch has been correlated with psychological distress, fatigue, and feelings of helplessness.<sup>14</sup> One of the most commonly reported consequences of itch is sleep disturbance.<sup>15–19</sup> In a multi-center cross-sectional survey of 151 children and 172 adults with AD, 87.1% had difficulty falling asleep either frequently or nearly always, and 73.5% stated that itching frequently or nearly always woke them up from sleep.<sup>18</sup>

Many patients with AD experience both pain and itch, and they can be difficult to separate. Some patients may perceive itch as painful, especially as itch intensity increases.<sup>11</sup> In a survey of 1111 patients with AD and parents from 34 countries, more than 80% identified pain/soreness as being “quite important” or “very important” when asked about what factors influence their decision about what treatments are working.<sup>20</sup>

### *Self-Esteem*

Patients with AD may feel self-conscious or embarrassed about the appearance of their skin, with resulting fear and avoidance of going out in public. Classmates or coworkers who tease or bully patients may reinforce these fears.

A study of 336 university students in California explored self-perceived stigma due to skin diseases with an online survey.<sup>21</sup> In 55 participants with a history of eczema, 21.8% reported being bullied or teased, 29.1% perceived being stared at by others, 21.8% had difficulty finding a romantic partner, and 25.5% reported that their eczema affected their social life. The strongest indicator of experiencing stigma was a feeling of awkwardness at being touched or seen by other people, reported in more than half of patients with eczema (58.2%). Fortunately, only a small percentage (3.6%) perceived discrimination at work or school.

In a telephone survey of 2002 patients and caregivers in 8 countries, 27% of adults reported a history of bullying; in children aged 8 to 17 it was even more prevalent at 39%.<sup>22</sup> In the same population, 44% of adults were embarrassed about their appearance, and 53% were concerned about being seen in public.<sup>22</sup>

### *Sleep Disturbance*

Patients with AD may experience a variety of negative effects on sleep, including difficulty falling

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