

## ORIGINAL ARTICLE

# Atopic dermatitis burden scale: creation of a specific burden questionnaire for families

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## Abstract

**Background** The notion of individual burden, associated with a disease, has been introduced to determine the 'disability' in the broadest sense (psychological, social, economic and physical). Atopic dermatitis (AD) is one of the most common chronic inflammatory skin diseases with an estimated prevalence of 5%–30% in children.

**Objective** To develop and validate a specific questionnaire which assess the burden of families of children with AD: the Atopic dermatitis Burden Scale (ABS).

**Methods** Items for inclusion in ABS were initially generated from a literature review and a verbatim report from parents whose child had AD. ABS was refined via item reduction according to interquestion correlations, consensus among experts and exploratory factor analysis. Internal consistency was determined by calculating the Cronbach's  $\alpha$ , concurrent validity by calculating the correlation between ABS and the Short-Form 12 items. Discriminant validity was analysed according to the severity degrees of AD assessed by Patient-Oriented SCORing index of Atopic Dermatitis (PO-SCORAD).

**Results** From an initial list of 29 items, ABS was reduced to a 14-item questionnaire, grouped into four dimensions based on the exploratory factor analysis. Construct validity was demonstrated and ABS showed good internal coherence (Cronbach's  $\alpha$ : 0.78). ABS was significantly correlated to the mental dimension of Short-Form 12 ( $r = -0.49$ ), but it was not correlated to the physical dimension ( $r = 0.04$ ). ABS scores were significantly different according to the severity degrees of AD, with higher ABS score in parents whose child had severe AD.

**Conclusion** The ABS questionnaire is a validated tool for assessing the burden of families of children with AD. An implementation of a prospective study is planned to estimate sensitivity to change and to confirm its domain structure in larger samples.

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## Conflict of interest

CT and SB are employed by Pierre Fabre Laboratories. SM is a consultant for the Foundation for Atopic Dermatitis, Pierre Fabre Laboratory. NPC is employed by Eau Thermale Avène. CM, CB and AT declare no conflict of interest.

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## Introduction

Atopic dermatitis (AD) is a chronic relapsing skin condition and one of the most common skin diseases worldwide.<sup>1</sup> Nowadays, the prevalence of AD is estimated to be between 5% and 30% in children, and between 2% and 10% in adults.<sup>1,2</sup> Therapeutic treatments include topical corticosteroids and long-term emollients as first-line therapy, followed by topical calcineurin inhibitors.<sup>3–5</sup> Many systemic treatments (including systemic

immunosuppression and phototherapy) have proven effective and can be used successfully for severe stages of the disease.<sup>4,6</sup> Hydrotherapy could also be an associated strategy.<sup>7</sup>

The disease alters not only physical well-being but also the affected child's emotional and social functioning and his or her family's.<sup>8–10</sup> AD symptoms, notably pruritus, can be intractable and lead to significant emotional distress and sleep loss,<sup>10–12</sup> affecting children's behaviour and productivity,<sup>13</sup> as well as their

parents'.<sup>14</sup> Numerous studies have assessed health-related quality of life (HRQoL),<sup>9,11,13,15</sup> and several specific quality-of-life instruments have been developed to assess the impact of AD on children and, in some cases, on their parents.<sup>9–11,15–17</sup>

Recently, the notion of 'burden' has been introduced by the World Health Organization to quantify the health of a population and to determine the priorities of action in public health domain.<sup>18</sup> The concept of 'burden of disease' now distinguishes between (1) the overall burden, by measuring the economic impact on society, and (2) the individual burden, which measures patients' disability in the broadest sense (psychological, social, economic and physical).<sup>19,20</sup>

AD is a major individual burden on patients and their families.<sup>21–24</sup> The cost of topical treatments, the difficulty to apply them daily, particularly for children, and time missed from work are problems expressed by families, which lead to a low therapeutic compliance. These difficulties have to be taken into consideration in the individual burden.<sup>21,24</sup> To the best of our knowledge, there is no tool available for assessing the individual burden of the families of children affected by AD and its evolution during the various strategies of AD care.

To assess the burden of AD, a self-administered questionnaire is the most relevant way to collect data. However, burden questionnaires are still poorly developed, and there is no methodological consensus for developing this type of tool yet. The design of HRQoL questionnaires follows a rigorous methodology that could be used to develop 'burden' questionnaires.<sup>15,25</sup> Indeed, two recent published burden questionnaires were inspired by this method.<sup>19,26</sup>

The aim of this study was to develop and validate a self-administered specific burden questionnaire for families of children affected by AD, the Atopic dermatitis Burden Scale (ABS) questionnaire.

## Materials and methods

To ensure clinical and scientific rigour throughout the entire methodological process, the questionnaire was developed by a working group. This multidisciplinary team was composed of individuals with expertise in the design and development of questionnaires, healthcare professionals (e.g. dermatologists, paediatric-dermatologists) with expertise in the management and care of patients with AD, representative of patients' association and patient-reported outcomes experts. The questionnaire was designed following standardized HRQoL questionnaire development and validation methodology.<sup>27</sup>

### Questionnaire development phase

**Stage 1: Generation of the items** During the first stage, a list of items was generated based on a verbatim report. Wording and concerns from parents (and from children with AD when possible) were collected from different sources of information:

literature review; parents of children monitored at the Avène Hydrotherapy Centre (educational workshop, discussion groups); feedback from specialized healthcare professionals and from an association of parents of children with AD (Association française de l'eczéma).

**Stage 2: Items analysis** Based on this feedback, the working group designed the ABS questionnaire. Items were converted into questions. A first assessment to simplify the questionnaire and to avoid redundancies was done by the working group. The questionnaire was created in a question and answer format. Response modalities were also determined at this point by consensus among the experts. Four types of answer were fixed: 'no without hesitation', 'I don't know', 'maybe' and 'yes without hesitation'; answers numbered from 0 to 3. An additional response 'Not concerned' was included to limit missing data.

**Stage 3: Cognitive debriefing interview** The cognitive debriefing interview was managed by a specialized institution (Lionbridge, Ireland). The aim was to guarantee the comprehension of the original French questionnaire in terms of use of words and use of vocabulary<sup>28</sup> to allow a good understanding by everyone (i.e. different socioprofessional groups, duration of the disease). A French native with a strong background in cognitive interviewing techniques conducted each interview. The questionnaire had to be discussed and modified if necessary. The samples had to be sufficient representative of the population for which the instrument was designed and the questionnaire was written in their mother language. A preliminary version of the questionnaire (ABS version 1.0; Pierre Fabre Laboratories, Castres, France) was consequently available.

### Questionnaire validation process

In this next stage, a study aiming to validate the pilot questionnaire and to reduce the number of questions was implemented. To ensure the participation of patients with diverse profiles, it was planned to include 55 parents whose child was followed at the department of Dermatology of Necker – Enfants Malades Hospital (50%), at the Avène Hydrotherapy Centre (30%) or from association of parents of children with AD (20%).

To be included in the study, parents should fulfil the following inclusion criteria: parents of a child with AD (age <18 years old), fluent in French and with an oral consent for participation.

Parents filled out the ABS version 1.0, and a validated non-specific self-administered questionnaire, the Short-Form 12 items v2 (SF-12).<sup>29</sup> The SF-12, a multipurpose short-form, results in the estimation of two health scores: Physical Component Summary and Mental Component Summary. Parents were also asked to complete the Patient-Oriented SCORing index of Atopic Dermatitis (PO-SCORAD) which results in an assessment of the severity degree of the disease,<sup>30,31</sup> and to answer a few additional questions to provide demographic and clinical information.

These questionnaires were filled out by one of the patient's parents at their home place and sent to the logistic centre using a prepaid envelope. As the questionnaires were strictly anonymous, approval by an ethics committee was not considered necessary by the administrative authorities.

### Statistical methods for psychometric validation

Psychometric properties were evaluated by assessing the construct validity, the internal consistency reliability, the concurrent validity and the discriminant validity of ABS.

**Construct validity** With regard to construct validity (domain structure), an exploratory factor analysis (principal factor analysis) was performed with the number of factors left free to highlight the underlying constructs. This analysis aimed also to categorize each item into its respective domain. An oblique promax rotation after an orthogonal varimax rotation was performed because the hypothetical constructs that constitute the burden were believed to be interrelated with each other. Items were considered for deletion if they loaded on two or more factors (standardized regression coefficients,  $SRC \geq 0.4$ ) or did not load on any of the factors ( $SRC < 0.4$ ). After this analysis, ABS version 2.0 was designed.

Subsequently, dimension scores were calculated by adding up each individual item score and transformed onto a 0–25 scale. A global score, the sum of all dimensions scores, was calculated. Higher scores indicated more severe burden of the AD for families.

**Internal consistency reliability** For reliability, the homogeneity of the items was evaluated using Cronbach's  $\alpha$  coefficient. Coefficient scores  $>0.7$  generally indicate good internal reliability.<sup>32</sup>

**Concurrent validity** Concurrent validity of the questionnaire was determined by calculating the Spearman's rank correlation

coefficient ( $r$ ) between the ABS questionnaire and each dimension of the SF-12.

**Discriminant validity** Discriminant validity (known-group validity) was analysed according to the severity of AD assessed by the PO-SCORAD. Kruskal–Wallis and post hoc multiple comparisons with a corrected  $\alpha$  tests were used as the parameters studied did not show a normal distribution.

Data were analysed using SAS<sup>®</sup> software version 9.3 (SAS Institute Inc., Cary, USA) for Windows. A significance level of 0.05 was fixed for all tests unless stated otherwise.

### Translation and cross-cultural validation

For each language, linguistic and cross-cultural validation following a rigorous process is required.<sup>28</sup> This process aims to refine the translation taking into account the nuances of the original. Several changes can be implemented throughout the validation process, without modifying the content. The aim is to allow an improvement on the first idiomatic rendering. In addition, the scales can be changed afterwards based on the debriefing cognitive to be consistent with the wording of same question in the other available languages.

The different stages of the linguistic and cross-cultural validation are summarized in Table 1.

## Results

### Questionnaire development phase

From an initial verbatim report drawn by 25 families, a list of 29 items was generated. Items which broach the same concept, but in different items were identified by the working group. The most relevant item was retained in the questionnaire. For example, 'Our child's atopic dermatitis creates tension in the relationship between me and my partner' was

**Table 1** Stages of the linguistic and cross-cultural validation

Stage	Details
1. Preparation	Evaluation of the source text from a linguistic and cultural point of view including definition of concepts
2. Forward translations	Forward translation into the required target language by two independent translators
3. Reconciliation	Comparison of the two forward translations to provide the best adaptation and produce a draft version of the text
4. Back translation	Translation of the draft forward translation back into the targeted language without reference to the original language
5. Back-translation review	Comparison of the original text and the back translation to verify that the meaning of the draft translation is equivalent to source
6. Analysis and implementation of back-translation review report	Analysis of the back-translation review report to verify if there are changes required to the draft forward
7. Pilot testing	Clinical review and cognitive debriefing
8. Review of cognitive debriefing or clinical review results	Review of the results from the cognitive debriefing or clinical review to identify translation modifications necessary for improvement.
9. Proofreading and finalization	Last stage, which aims to a cross-cultural and validated translation of the questionnaire

privileged to 'Our child's atopic dermatitis is a source of contention with my partner'.

As a result of the cognitive debriefing interview, few modifications were done to the questions. To be clearer or easier to understand, some questions were reformulated. Item 'Our home life is organized around our child's atopic dermatitis' was changed into 'Our family life is organized around our child's atopic dermatitis', and 'Our child's atopic dermatitis disrupts my daily life' into 'Our child's atopic dermatitis completely disrupts my daily life'.

At this stage, the questionnaire (ABS version 1.0) consisted of 25 questions.

### Questionnaire validation process

**Study population** Among the 110 parents recruited, 68.2% of them sent their questionnaire back. The study population ( $n = 75$ ) comprised 39 girls (52.0%) and 36 boys (48.0%). Patients demographic and clinical characteristic are reported in Table 2. Most of the parents who filled out the questionnaire were mothers (93.0%;  $n = 66$ ).

Based on the PO-SCORAD questionnaire, 13.3%, 45.4% and 41.3% of the children had mild, moderate and severe AD respectively.

**Psychometric validation.** Item analysis of the 75 questionnaires identified items that might disrupt the overall architecture of the questionnaire. Questions about work were highly corre-

lated with each other ( $r > 0.7$ ) and by consensus 2 of them were removed ('In the morning, I am late because of the care that I must provide to our', 'I often talk about our child's atopic dermatitis with my work colleagues'). Moreover, most parents (81.3%;  $n = 61$ ) replied 'yes, without hesitation' to the question about clothing choice. Assuming this question will not be discriminant, it was removed from the questionnaire. Similar observations were done for three other questions. At this stage, 6 of the 25 questions of the ABS version 1.0 were removed.

**Construct validity and internal consistency reliability** On the original 19 questions analysed by exploratory factor analysis, four questions were deleted due to cross-loadings on factors, and one question because it did not load on any of the factors. The 4-group model was the most parsimonious. This final version of the questionnaire (ABS version 2.0) was composed of 14 questions. The SRC were all higher than 0.4 on their factor except for the items 'I have had to take time off from work due to our child's AD' and 'The daily care I must provide to our child exhausts me' (SCR = 0.38 and 0.39, respectively) (Table 3). However, it was decided to retain these items because they were close to the a priori threshold of 0.4, and also due to their relevance.

According to the SRC, each group of questions was assigned a dimension. Consequently, the ABS version 2.0 consisted of four dimensions: 'Family life' (4 questions), 'Budget & Work' (4), 'Daily life' (3) and 'Treatment' (3). Interdimension correlations ranked from 0.19 (between dimensions 'Budget & Work' and 'Treatment') to 0.39 (between dimensions 'Family life' and 'Treatment'). Moreover, all dimensions correlated well to the overall ABS score (range: 0.65–0.71).

With regard to reliability, Cronbach's  $\alpha$  was 0.78. This indicated good internal coherence.

**Concurrent validity** The analysis of the SF-12 highlighted an alteration in the mental HRQoL dimension ( $40.6 \pm 10.1$ ), but not in the physical dimension ( $53.9 \pm 6.9$ ). The ABS score showed a significant inverse correlation with the mental dimension of the SF-12 ( $r = -0.49$ ;  $P < 0.001$ ), but it was not correlated with the physical dimension ( $r = 0.04$ ). Similar observations were done for the correlations between all the domains of the ABS version 2.0 and the SF-12 (Table 4).

**Discriminant validity** Based on the PO-SCORAD, the ABS score differed significantly according to the severity of AD (Fig. 1). Indeed, parents whose child had severe AD had higher ABS scores than those with a moderate AD ( $60.5 \pm 17.2$  vs.  $39.7 \pm 16.9$ , respectively;  $P < 0.0001$ ). The difference between mild ( $24.6 \pm 14.4$ ) and severe AD was also significant, but no significant difference was demonstrated between parents whose child had mild vs. moderate AD ( $P = 0.0561$ ). According to

**Table 2** Patients demographics and clinical characteristics ( $n = 75$ )

Characteristic	
Gender, n (%)	
Girl	39 (52.0)
Boy	36 (48.0)
Age, months (mean $\pm$ SD) [range]	60.1 $\pm$ 37.2 [1–206]
Age at diagnosis, months (mean $\pm$ SD) [range]	8.0 $\pm$ 10.5 [0;48]
Child with associated asthma, n* (%)	
Yes	17 (23.0)
No	57 (77.0)
Parent who filled out the questionnaire, n† (%)	
Mother	66 (93.0)
Father	5 (7.0)
Mother with atopic dermatitis history, n* (%)	
Yes	16 (21.6)
No	58 (78.4)
Father with atopic dermatitis history, n* (%)	
Yes	17 (23.0)
No	57 (77.0)

\*For each of these questions, they were one missing data.

†Four parents did not fill out this item, they were counted as missing data.

**Table 3** Standardized regression coefficients from the final rotated factor pattern.

	<b>Factor 1: Family life</b>	<b>Factor 2: Budget &amp; work</b>	<b>Factor 3: Daily life</b>	<b>Factor 4: Treatment</b>
Our child's atopic dermatitis completely disrupts my daily life	<b>0.63433</b>	0.03084	-0.03002	0.14331
Our child's atopic dermatitis affects my plans	<b>0.81850</b>	-0.10546	-0.03687	0.02238
Our child's atopic dermatitis complicates our family life	<b>0.68706</b>	-0.07782	0.26302	0.01922
Our child's atopic dermatitis creates tension in the relationship between me and my partner	<b>0.62638</b>	0.10971	-0.04462	-0.20778
I hesitate to buy certain medications because they are not reimbursed	-0.16221	<b>0.44967</b>	0.01284	0.08423
At work I am always thinking about our child's atopic dermatitis	0.13685	<b>0.60974</b>	0.01948	-0.28698
I often miss work to take our child to the doctor	0.09027	<b>0.53520</b>	0.04930	0.09441
I have had to take time off from work due to our child's atopic dermatitis	-0.05783	<b>0.38116</b>	0.34959	0.13634
The food we eat is chosen based on the atopic dermatitis	-0.08443	0.11153	<b>0.51754</b>	-0.01676
We prevent our child from participating in certain sports because of his/her atopic dermatitis	-0.01444	0.11781	<b>0.42148</b>	0.22514
Our child's atopic dermatitis affects my sleep	0.31780	-0.08647	<b>0.56591</b>	-0.01959
It seems like our child's atopic dermatitis is costing us more and more	-0.14315	-0.08811	0.18194	<b>0.46208</b>
I'm growing tired of our child's daily care	0.30239	0.05877	-0.17024	<b>0.53972</b>
The daily care I must provide to our child exhausts me	0.35028	0.10454	0.00126	<b>0.39913</b>

Regression coefficients shown in bold represent the individual items that were included in each dimension

**Table 4** Correlation coefficients for the concurrent validation of the ABS tool vs. the SF-12 questionnaires

	<b>Family life</b>	<b>Daily life</b>	<b>Budget &amp; work</b>	<b>Treatment</b>	<b>ABS score</b>
SF-12 - MCS	-0.43*	-0.27†	-0.28†	-0.37†	-0.49*
SF-12 - PCS	0.01	-0.06	0.19	-0.08	0.04

\* $P < 0.001$ .

† $P < 0.05$ .

children's gender, no significant difference in ABS score was noticed ( $P = 0.0577$ ).

### Translation and cross-cultural validation

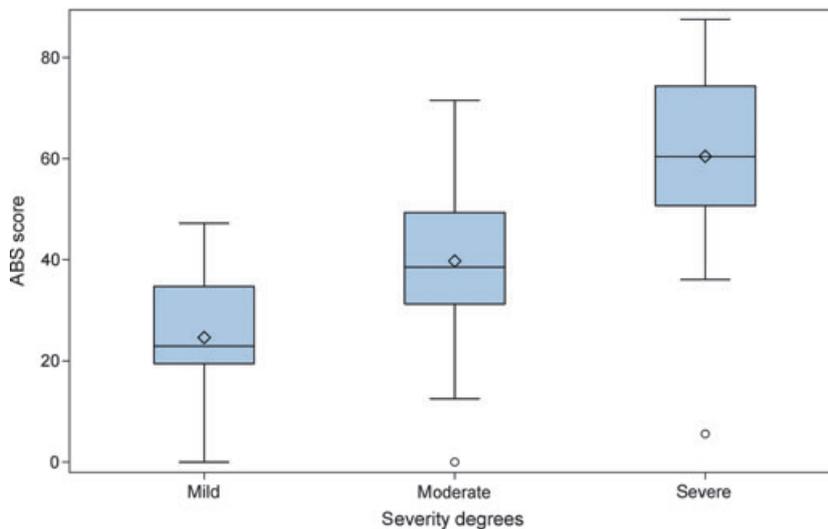
The ABS was translated and culturally adapted into English US and six others European languages (German, Italian, Spanish, Danish, Romanian and Georgian).

### Discussion

Individual burden covers the disability in the broadest sense (psychological, physical, social and economic). It simultaneously takes into account the quality of life, integration within the community, organization of everyday life and medical resources consumed. This burden can be evaluated directly among the patients with a particular disease. However, in paediatrics, it is also interesting to evaluate the possible impact of a disease on families. Several studies have reported a negative impact on the quality of life of children with AD, physiological and psychological, affecting the patient's sleep, behaviour and emotions, among other things.<sup>9,13,22</sup> This impact is also felt by parents, the disease can also affect their physical, social and emotional

well-being.<sup>21,24</sup> This is why not only the child's experience but also the entire family's experience should be taken into consideration. Additional factors to the burden of caring for a child with AD are the financial costs of treatment, time missed from work for physician appointments and lack of understanding and social support from friends and family members.<sup>21,24</sup> Moreover, treatment can be a very time-consuming and stressing process for the parents or caregivers. Several studies of the direct and in some cases indirect costs (out-of-pocket expenses and productivity loss) of the treatment of children with atopic dermatitis have shown that the economic impact can be extremely high.<sup>21,23,24,33-35</sup> These results highlight the importance of understanding and measuring the burden of the disease on the entire family.

The ABS questionnaire has been developed to address this point. Based on this study, preliminary validations of the ABS have been assessed. Indeed, the internal consistency reliability of the questionnaire was good ( $\alpha = 0.78$ ) and the ABS was correlated with the mental HRQoL dimension of the SF-12, confirming its concurrent validity. As ABS was designed for parents and not for children, the non-correlation between ABS and SF-12 Physical Component Summary seems to be natural. These results are consistent with those from previous studies evaluating the quality of life of parents of children with dermatological diseases.<sup>7</sup> Furthermore, known-group validity has been evaluated according to PO-SCORAD. A significant difference was highlighted between parents whose child had severe AD and those with a moderate AD. Due to a relatively small sample size, no significant difference was demonstrated between parents whose child had mild vs. moderate AD, but the p-value was close to the threshold of 0.05.



**Figure 1** Box and whisker plot of parents' ABS score according to the severity degrees of AD.

Limitations associated with this study include the fact that the psychometric analysis was conducted in a relatively small sample of parents. Even though the way of recruiting parents led to a sample of children with diverse profiles, it may not have been sufficient to highlight differences in ABS scores between degrees of severity of AD (less than 15% of children had mild AD). Moreover, further validation should be done. To assess the interpretability of ABS, it would be necessary to evaluate the questionnaire's sensitivity to clinically meaningful change or minimal-important difference in a prospective cohort study. Also, a confirmatory factorial analysis on another sample may be necessary to confirm the factorial structure of ABS. At this stage, item response theory has not been conducted yet. Item response theory examines items and test performance and how performance relates to the abilities that are measured by the items in the test.<sup>36</sup> According to Hambleton and Jones,<sup>36</sup> using this technique implies recruiting larger samples than for Classical Test Theory. Moreover, some of these techniques as the Rasch model were originally considered as a confirmatory tool.<sup>37</sup> Finally, no handling of missing data was done in this study. Indeed, they represented less than 5% of the data. Missing data is a problem in multi-item instruments and numerous methods are currently available for handling them.<sup>38</sup> It is planned that the design of future studies to confirm the utility of ABS will incorporate appropriate methodology for handling missing data.

To conclude, with a specific tool such as the ABS, an evaluation of the disability in the broadest sense caused by the disease is feasible, contrary to a HRQoL questionnaire. The interest of this instrument is that it also evaluates treatments. Accurate management of the disease and suitable treatment of flare-ups should help reduce the burden. Therapeutic educational programmes are currently in development and reveal their importance.<sup>39,40</sup> Beyond the improvement of the knowledge and the severity degree (PO-SCORAD), the assessment of the burden

of AD for families supplements the evaluation of such programmes.<sup>41</sup> Based on the availability of the ABS questionnaire, assessment of the AD therapeutic education is planned in USA.

The ABS questionnaire is available on request from Mapi Research Trust.

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