Chapter 4

The compliance and burden of treatment with the epinephrine auto-injector in food-allergic adolescents

J. Saleh-Langenberg
B.M.J. Flokstra-de Blok
N.J. Goossens
J.C. Kemna
J.L. van der Velde
A.E.J. Dubois

**ABSTRACT**

**Background:** Food-allergic patients at high risk for (fatal) anaphylaxis should carry an epinephrine auto-injector (EAI) at all times. This treatment may be perceived as burdensome and this may affect compliance. The aims of the study were (1) to determine the burden of treatment (BoT) of an EAI, (2) to examine the relationship between this burden and compliance, and (3) to analyze which factors contribute to the BoT of the EAI as perceived by food-allergic adolescents and their parents.

**Methods:** Dutch food-allergic patients prescribed an EAI and their parents completed a questionnaire-package (n=55). Relationships between BoT and health-related quality-of-life (HRQL), illness severity and perception, and anxiety measures were investigated.

**Results:** Food-allergic adolescents and their parents were (extremely) positive about the EAI (54.5%;72.7% respectively)(=low BoT). The BoT-measure showed a significantly greater burden in food-allergic adolescents prescribed an EAI who reported not carrying the EAI at all times than adolescents who reported they did. The BoT-scores of both adolescents and their parents were not associated with HRQL, illness severity and perception, or trait anxiety.

**Conclusions:** The majority of food-allergic adolescents and their parents were positive about the EAI (=low BoT). However, the BoT was significantly associated with self-reported compliance with carrying the EAI. The BoT was higher in food-allergic adolescents prescribed an EAI who reported not carrying the EAI at all times. The BoT-measure seems to be a useful tool to study compliance with carrying an EAI. The BoT of an EAI is not associated with HRQL. The BoT measures a distinct concept related to compliance behavior.
INTRODUCTION

Currently the only treatment for food allergy is avoidance of the culprit food. Despite taking precautions, accidental food-allergic reactions may occur, and for some food-allergic patients such reactions may be fatal. Therefore, food-allergic patients at high risk for anaphylaxis should always have an epinephrine auto-injector (EAI) available.\textsuperscript{1-3}

A number of studies show that food-allergic patients, adolescents in particular, are often poorly compliant and do not always carry their EAI.\textsuperscript{1,4,5} The reluctance to carry an EAI may be the result of the perception of patients that such treatment is burdensome. It has been previously shown that the burden of treatment (BoT) with an EAI in vespid allergic patients is high.\textsuperscript{6} However, it is currently unknown whether food-allergic adolescents and their parents find always having to carry an EAI burdensome. Allen et al. showed that a prescription of an EAI did not increase the parental burden of food-allergic children.

A previous study using parent-proxy-reports found a more impaired health-related quality of life (HRQL) in children being prescribed an EAI compared to those who were not prescribed an EAI.\textsuperscript{7} It is of interest whether HRQL contributes to the burden of treatment (BoT) of the EAI as perceived by food-allergic adolescents and their parents.

Adolescents are the age-group with the highest risk for food allergy fatalities.\textsuperscript{2,8} This may be caused by problems occurring at the time of the transfer of responsibility for managing their food allergy from their parents to themselves.\textsuperscript{4,9} The fact that they often engage in risk-taking behaviors\textsuperscript{1,8-10} resulting in reduced vigilance about food consumption or reluctance to carry their EAI may contribute to this outcome.\textsuperscript{9-13}

The aims of the study were (1) to determine the burden of treatment (BoT) of an EAI, (2) to examine the relationship between this burden and compliance, and (3) to analyze which factors contribute to the BoT of the EAI as perceived by food-allergic adolescents and their parents.
METHODS

Participants and procedure

Food-allergic patients (13-17 years old) and parents were recruited through our pediatric allergy clinic or Dutch food allergy support organizations between October 2010 and May 2011. Food-allergic patients and parents were analyzed separately.

The participants (adolescents and parents) were asked to complete a questionnaire-package including: BoT-measure, Food Allergy Quality of Life Questionnaire-Teenager Form (FAQLQ-TF) or Food Allergy Quality of Life Questionnaire-Parent Form Teenager (FAQLQ-PFT), Food Allergy Independent Measure (FAIM), Illness Perception Questionnaire (IPQ), State Trait Anxiety Inventory (STAI), statements about the EAI, and descriptive questions.

The participants recruited from the clinic were asked to complete the questionnaire-package while attending our clinic. The other participants were sent the questionnaire-package by mail to be completed at home.

Adolescent-parent pairs were requested not to discuss questions and responses with each other. Parents were asked to explain a question to their child when needed but to do so without telling the child which answer to give.

Adolescents with at least one physician-diagnosed food allergy and who had been prescribed an EAI were included. Adolescent-parent pairs were excluded if the BoT-measure was not completed. Participation in the study was completely voluntary. This study was assessed by the local medical ethics review committee (METc 2010/318) who deemed that formal approval from the committee was not required.

Questionnaire-package

The BoT-measure was completed by the food-allergic patients and parents of food-allergic adolescents both from their own perspective. The BoT-measure contains a single item which is scored on a scale ranging from 1 (extremely positive) to 7 (extremely negative). The BoT-measure objectifies the overall effect of the treatment from the patient’s perspective and attempts to capture negative aspects of treatment with the EAI and weigh them against the positive aspects of such treatment. The BoT-measure was previously validated in venom allergic patients,\textsuperscript{6,14} and was adapted for food allergic patients in this study.

The FAQLQ-TF was completed by the adolescent and is a self-report instrument for measuring the impact of food allergy on the adolescent’s HRQL.\textsuperscript{15}

The FAQLQ-PFT is a parent-proxy-report instrument for measuring the impact of food allergy on the adolescent’s HRQL.\textsuperscript{16,17} The FAQLQ-TF and the FAQLQ-PFT may be downloaded from www.FAQLQ.com.
The FAIM-TF was completed by the adolescent and is a self-reported measure for patients’ perceived disease severity. The FAIM-PFT was completed by the parent and is proxy-reported.

The brief-IPQ was completed by the adolescent and parent both from their own perspective. The brief-IPQ contains five items reflecting cognitive illness representations, two items reflecting emotional illness representations and two items reflecting coherence (illness comprehension) and causal illness representation. The New Zealand brief-IPQ was previously validated in the Netherlands.

The STAI was completed by the adolescent and parent both from their own perspective. The STAI measures anxiety in a specific situation (state) or anxiety as a disposition (trait). In this study only trait anxiety was measured.

A total of 11 statements about the EAI were included in the questionnaire to examine possible negative and positive aspects of carrying the EAI (Table 3). The statements about the EAI were completed by the adolescent and parent both from their own perspective.

**Statistical analyses**

Statistical analyses were conducted using SPSS version 20.0 (SPSS Inc. Chicago, IL, USA.). Spearman’s correlations and Fisher’s exact test were used to investigate associations between the BoT-measure and other outcome measures. The Mann-Whitney U-test was used to investigate differences in total scores for BoT, HRQL, perceived disease severity, illness perception, and anxiety between participants who reported carrying an EAI at all times and participants who reported they did not.

To investigate associations between the BoT-measure and the statements about the EAI, the BoT-score was divided into a dichotomous variable in which an (extremely) positive opinion of the EAI was the opposite of a slightly positive to slightly negative opinion. The statement scores were also divided into a dichotomous variable in which agree was the opposite of disagree. The self-reported compliance scores were also divided into a dichotomous variable in which carrying an EAI by the adolescent and/or parent was the opposite of not carrying an EAI by the adolescent and/or parent. For the characteristics of the adolescents-parent pairs descriptive methods and statistics were used.
RESULTS

Participants
In total seventy adolescent-parent pairs were asked to complete the questionnaire-package. In total 63 adolescent-parent pairs (response rate 89%) completed the questionnaire-package. Eight adolescent-parent pairs were excluded because they did not complete the BoT-measure. Therefore, a total of 55 adolescent-parent pairs were eligible for analysis. Forty-one of these adolescent-parent pairs were recruited through our clinic and fourteen recruited by Dutch food allergy support organizations. There were no significant differences in the descriptive characteristics between adolescents depending on their manner of recruitment. The allergenic foods reported most frequently were tree nuts, followed by peanut. The majority of the food-allergic adolescents (78%) had multiple food allergies. There were slightly fewer girls than boys, and significantly more mothers than fathers who filled out the questionnaire-packages. Descriptive characteristics of adolescents and parents are shown in Table 1.

EAI issues
Compliance
Most food-allergic adolescents had initially been prescribed an EAI more than 2 years before the study and replaced these since then on expiry. The majority of the food-allergic adolescents reported they carried the EAI themselves. However, despite medical advice, the EAI was not carried at all times by eighteen (33%) of these adolescents and/or parents. Whether they carried the EAI or not depended on the perceived need to do so under various circumstances.

Accidental exposure and EAI use
After being prescribed an EAI, twenty-eight (51%) adolescents had a food-allergic accident for which they had been instructed to use the EAI (Figure 1). The majority of these patients had reactions to tree nuts or peanuts. Four of these twenty-eight adolescents (14%) did not have the EAI available at the time of the accidental food-allergic reaction. Eighteen adolescents and/or parents (75%) who had the EAI in their possession at the time of the accidental food-allergic reaction did not use the EAI even though it was available. Six adolescents and/or parents (25%) used their EAI as instructed. None of these six adolescents received a second dose of epinephrine. Three of them were admitted to hospital.
# Table 1. Descriptive characteristics adolescent-parent pairs

<table>
<thead>
<tr>
<th></th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number adolescent-parent pairs</strong>, n</td>
<td>55</td>
</tr>
<tr>
<td><strong>Sex adolescent</strong>, boys/girls</td>
<td>29/26</td>
</tr>
<tr>
<td><strong>Mean age adolescent</strong>, years (SD)</td>
<td>15.9 (1.29)</td>
</tr>
<tr>
<td><strong>Sex parent</strong>, male/female</td>
<td>6/49</td>
</tr>
<tr>
<td><strong>Mean age parent</strong>, years (SD)</td>
<td>48.3 (3.9)</td>
</tr>
</tbody>
</table>

## Type of food allergies*, n (%)

- Tree nut: 45 (81.8)
- Peanut: 38 (69.1)
- Fruit: 13 (23.6)
- Soy: 10 (18.2)
- Milk: 8 (14.5)
- Vegetables: 7 (12.7)
- Shell fish: 5 (9.1)
- Sesame: 5 (9.1)
- Wheat: 3 (5.5)
- Fish: 1 (1.8)
- Celery: 0

## Number of food allergies, n (%)

- 1 food: 11 (20.0)
- 2 foods: 18 (32.7)
- 3 foods: 13 (23.6)
- > 3 foods: 12 (21.7)

## Most severe symptoms**, n (%)

- Cardiovascular: 24 (43.6)
- Respiratory: 40 (72.7)
- Gastro-intestinal: 32 (58.1)
- Skin: 38 (69.9)
- Other***: 52 (94.5)

## Epinephrine auto-injector, n (%)

- Epipen®/Anapen®, yes/no: 52/3 (94.5/5.5)
- Always carrying EAI, yes/no: 37/18 (67.3/32.7)

## Person carrying EAI, n (%)

- Adolescent: 34 (61.8)
- Parent: 3 (5.5)
- Both: 9 (16.4)
- None: 9 (16.4)

## Time since prescription, n (%)

- < 6 months: 1 (1.8)
- 6 months – 2 years: 13 (23.6)
- > 2 years: 41 (74.5)

## EAI prescription by, n (%)

- General practitioner: 4 (7.3)
- Pediatrician: 12 (21.8)
- Allergist: 31 (56.4)
- Other: 8 (14.5)

## Anaphylaxis, n (%)

- EAI carriage at time of reaction, yes/no: 24/4 (86.0/14.0)
- EAI used at time of reaction, yes/no: 6/18 (25.0/75.0)

## Last experience of anaphylaxis, years (SD)

- 5.2 (4.5)

## Atopic co-morbidities****, n (%)

- Asthma: 27 (49.1)
- Allergic rhinitis: 23 (41.8)
- Eczema: 16 (29.1)

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* Some adolescents reported having more than one food allergy; ** Some adolescents reported having more than one severe symptom; *** Oral allergy symptoms, nose and eye symptoms; **** Some adolescents reported having more than one atopic co-morbidity.
Figure 1. Flowchart accidental food-allergic reaction and EAI use

- Adolescents: n=55
  - Accident: n=28 (51%)
    - EAI used: n=6 (25%)
    - EAI not used: n=18 (75%)
  - No accident: n=27 (49%)
    - No EAI: n=4 (14%)
Questionnaires

**Burden of Treatment**

Of the 55 adolescents, 54.5% were positive to extremely positive about the EAI, and 3.6% were slightly negative (Figure 2). None of the adolescents were negative or extremely negative about the EAI. Parents were even more positive about the EAI than the adolescents: 72.7% of the parents were positive to extremely positive. Thus, parents perceived a lower burden of treatment associated with the EAI than did adolescents themselves. Adolescents who reported not to carry the EAI at all times (n=18) had a significantly higher burden than adolescents who reported they did carry the EAI at all times (n=37) (z=-3.35; p=0.001; mean rank 22.64, 37.22 respectively). This was not the case for parents.

**Figure 2.** The Burden of Treatment in adolescents and their parents (n=55)

n=number of participants; *The BoT-measure contains a single item which is scored on a scale ranging from 1 (extremely positive) to 7 (extremely negative); none of the adolescent and their parents were negative or extremely negative about the EAI
Adolescents who reported only carrying their EAI when going on holidays reported also a significantly higher burden of treatment ($p=0.01$).

There was no significant association between the burden of treatment and the number of food allergies ($p=0.52$), co-morbidities (asthma ($p=0.12$), eczema ($p=0.98$), hay fever ($p=0.54$)), time since EAI prescription ($p=0.20$) or the type of specialist who had prescribed the EAI ($p=0.62$).

**FAQLQ, IPQ and STAI**

There were no significant correlations between the burden of treatment and the other outcome measures: FAQLQ-TF and FAQLQ-PFT total scores; brief-IPQ total score of adolescents and parents, and STAI total score of adolescents and parents (Table 2). In addition, there were no significant differences in total scores for these outcome measures for either adolescents or parents between self-reported compliance and non-compliance with carrying an EAI at all times.

**FAIM**

There was no significant correlation between the BoT-measurement and FAIM-TF total score ($p=0.17$), nor between the BoT-measurement and FAIM-PFT total score ($p=0.43$) (Table 2). However, there was a significant correlation between the BoT-measurement and one individual FAIM-TF item “chance of not dealing with a reaction” ($p=0.02$). Those reporting a greater burden of treatment were more concerned that they would not be able to deal with a reaction successfully. There was no significant difference in the FAIM-TF total score or FAIM-PFT total score between self-reported compliance and non-compliance with carrying an EAI at all times ($\rho=0.105$, $p=0.54$; $\rho=0.117$, $p=0.60$, respectively).
The compliance and burden of treatment with the EAI in food-allergic adolescents

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Mean (SD) Adolescent-report</th>
<th>Mean (SD) Parent-report</th>
<th>Corr Coef (adolescent/parent)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FAQLQ score</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>FAQLQ domains scores</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allergen avoidance &amp; Dietary Restrictions*</td>
<td>4.03 (1.35)</td>
<td>3.42 (0.97)</td>
<td>0.175/0.009</td>
<td>0.20/0.95</td>
</tr>
<tr>
<td>Risk of accidental exposure*</td>
<td>3.92 (1.46)</td>
<td>3.27 (1.24)</td>
<td>0.220/0.179</td>
<td>0.14/0.19</td>
</tr>
<tr>
<td>Emotional impact*</td>
<td>3.99 (1.51)</td>
<td>3.27 (1.24)</td>
<td>0.065/-0.215</td>
<td>0.64/0.19</td>
</tr>
<tr>
<td><strong>FAIM score±</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total score</td>
<td>3.57 (0.96)</td>
<td>3.58 (0.81)</td>
<td>0.17/0.60</td>
<td></td>
</tr>
<tr>
<td>Chance of accidental exposure</td>
<td>3.51 (1.14)</td>
<td>3.27 (1.24)</td>
<td>0.065/-0.215</td>
<td>0.64/0.19</td>
</tr>
<tr>
<td>Chance of severe reaction</td>
<td>4.60 (1.69)</td>
<td>4.36 (1.89)</td>
<td>0.221/-0.101</td>
<td>0.10/0.47</td>
</tr>
<tr>
<td>Chance of dying following exposure</td>
<td>2.91 (1.57)</td>
<td>2.87 (1.52)</td>
<td>-0.068/-0.105</td>
<td>0.62/0.46</td>
</tr>
<tr>
<td>Chance of not dealing with a reaction</td>
<td>3.00 (1.37)</td>
<td>3.09 (1.27)</td>
<td>0.311/0.110</td>
<td>0.02/0.43</td>
</tr>
<tr>
<td>Number of products to avoid</td>
<td>4.29 (1.32)</td>
<td>4.13 (1.35)</td>
<td>0.023/-0.166</td>
<td>0.87/0.23</td>
</tr>
<tr>
<td>Impact on social life</td>
<td>2.95 (1.42)</td>
<td>2.93 (1.35)</td>
<td>0.238/-0.004</td>
<td>0.08/0.98</td>
</tr>
<tr>
<td><strong>IPQ score#</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IPQ items scores:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consequences</td>
<td>6.02 (2.65)</td>
<td>5.69 (2.38)</td>
<td>0.065/-0.215</td>
<td>0.64/0.19</td>
</tr>
<tr>
<td>Timeline</td>
<td>10.3 (1.41)</td>
<td>10.1 (1.89)</td>
<td>-0.160/-0.222</td>
<td>0.24/0.88</td>
</tr>
<tr>
<td>Personal control</td>
<td>8.45 (2.28)</td>
<td>8.75 (2.42)</td>
<td>-0.178/-0.290</td>
<td>0.19/0.03</td>
</tr>
<tr>
<td>Treatment control</td>
<td>6.01 (2.57)</td>
<td>6.49 (3.04)</td>
<td>-0.124/-0.242</td>
<td>0.37/0.08</td>
</tr>
<tr>
<td>Identity</td>
<td>4.86 (3.23)</td>
<td>4.78 (2.92)</td>
<td>0.076/0.187</td>
<td>0.58/0.18</td>
</tr>
<tr>
<td>Illness concern</td>
<td>4.86 (3.23)</td>
<td>5.19 (2.75)</td>
<td>0.105/-0.144</td>
<td>0.45/0.29</td>
</tr>
<tr>
<td>Coherence (illness comprehension)</td>
<td>9.41 (1.74)</td>
<td>9.76 (1.97)</td>
<td>-0.152/0.041</td>
<td>0.26/0.77</td>
</tr>
<tr>
<td>Emotional representations</td>
<td>3.62 (2.62)</td>
<td>4.14 (2.58)</td>
<td>0.214/0.174</td>
<td>0.12/0.21</td>
</tr>
</tbody>
</table>

**STAI scores^**

<table>
<thead>
<tr>
<th>STAI scores</th>
<th>Mean (SD) Adolescent-report</th>
<th>Mean (SD) Parent-report</th>
<th>Corr Coef (adolescent/parent)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>23.54 (17.50)</td>
<td>19.20 (12.21)</td>
<td>0.113/0.094</td>
<td>0.41/0.51</td>
<td></td>
</tr>
</tbody>
</table>

¶ Corr Coef = Correlation coefficient; * Not a domain in FAQLQ-TF; ** Not a domain score in FAQLQ-PFT.
§ FAQLQ scores: 1 (minimal impairment in HRQL) to 7 (maximal impairment in HRQL); ±FAIM score 1 (minimal perceived disease severity) to 7 (maximal perceived disease severity); #IPQ score 1 (benign view of illness) to 11 (threatening view of illness); ^STAI score 1 (no anxiety) to 80 (severe anxiety).
**Statements about EAI**

A low burden of treatment as reported by adolescents was associated with statements that the EAI has an agreeable shape (p=0.04) and size (p=0.007), and gives a feeling of safety (p=0.01) (Table 3). A high burden of treatment was associated with the statement that it is inconvenient to have to carry an EAI (p=0.01). These associations were not found in adolescents who reported not carrying the EAI at all times. A low burden of treatment as perceived by parents was associated with statements that the EAI has an agreeable size (p=0.009), and it reassuring to carry an EAI (p=0.019). A high burden of treatment was associated with the statement that it is inconvenient to have to carry an EAI (p=0.04).

**Table 3. Statements about EAI for food-allergic adolescents**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree n (%)</th>
<th>Disagree n (%)</th>
<th>No opinion n (%)</th>
<th>Correlation with BoT* p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Carrying an EAI makes you feel safe. (n=53)</td>
<td>37 (69.1)</td>
<td>4 (7.3)</td>
<td>12 (21.8)</td>
<td>0.01</td>
</tr>
<tr>
<td>2. One EAI is sufficient for the treatment of an allergic reaction. (n=54)</td>
<td>26 (47.3)</td>
<td>15 (27.3)</td>
<td>13 (23.6)</td>
<td>1.00</td>
</tr>
<tr>
<td>3. I am afraid of the side-effects of an EAI. (n=54)</td>
<td>6 (10.9)</td>
<td>39 (70.9)</td>
<td>9 (16.4)</td>
<td>0.38</td>
</tr>
<tr>
<td>4. I am concerned that a single EAI might be insufficient for the treatment of an allergic reaction. (n=53)</td>
<td>7 (14.5)</td>
<td>30 (54.4)</td>
<td>16 (29.1)</td>
<td>1.00</td>
</tr>
<tr>
<td>5. The EAI can cure your allergy. (n=55)</td>
<td>1 (1.8)</td>
<td>51 (92.7)</td>
<td>2 (3.6)</td>
<td>0.46</td>
</tr>
<tr>
<td>6. The EAI is patient-friendly because of its shape. (n=54)</td>
<td>24 (43.6)</td>
<td>15 (27.3)</td>
<td>15 (27.3)</td>
<td>0.05</td>
</tr>
<tr>
<td>7. It is inconvenient to have to carry an EAI. (n=54)</td>
<td>28 (50.9)</td>
<td>22 (40.0)</td>
<td>4 (7.3)</td>
<td>0.02</td>
</tr>
<tr>
<td>8. It is reassuring having an EAI. (n=54)</td>
<td>35 (63.6)</td>
<td>5 (9.1)</td>
<td>14 (25.5)</td>
<td>0.06</td>
</tr>
<tr>
<td>9. The EAI is patient-friendly because of its size. (n=54)</td>
<td>22 (40.0)</td>
<td>23 (41.8)</td>
<td>9 (16.4)</td>
<td>0.007</td>
</tr>
<tr>
<td>10. I think I would not dare to use the EAI if this were necessary. (n=54)</td>
<td>9 (16.4)</td>
<td>40 (72.7)</td>
<td>5 (9.1)</td>
<td>0.27</td>
</tr>
<tr>
<td>11. I know how to use the EAI because of instructions given. (n=54)</td>
<td>43 (78.2)</td>
<td>6 (10.9)</td>
<td>(9.1)</td>
<td>0.01</td>
</tr>
</tbody>
</table>

*Associations with the BoT-measurement were measured with Fisher exact test*
DISCUSSION

This is the first study examining the relationship between self-reported compliance with carrying the EAI and the burden of treatment as perceived by food-allergic adolescents and their parents. We found that the majority of food-allergic adolescents and their parents were positive about the EAI: the burden of treatment was low. Moreover, the BoT score was not associated with HRQL, perceived disease severity, illness perception, or trait anxiety. However, the BoT was significantly associated with self-reported compliance with carrying the EAI. The burden of treatment was higher in food-allergic adolescents prescribed an EAI who reported not carrying the EAI at all times. Thus, although adolescents perceive a limited burden of having to carry an EAI, this burden does seem to influence the decision many adolescents make to do so on a daily basis.

In contrast to the low burden of treatment we found in food-allergic patients, it was previously shown that patients with vespid allergy carrying an EAI reported a high burden of treatment. These differences in BoT-scores are likely to be context dependent. An EAI is much more likely to be perceived as burdensome in vespid allergy, where it is a temporary measure until curative treatment makes the EAI superfluous. In food allergy it is the only meaningful measure offering protection when accidental food-allergic reactions occur. Also, vespid exposure is usually limited to certain seasons while food allergen exposure may occur throughout the year.

Food-allergic adolescents take risks pertaining to their food allergy, including not carrying their EAI at all times. In our study considerably more food-allergic adolescents (14%) carried the EAI at the time of an accidental food-allergic accident compared to other studies, whereas 38-50% did not have the EAI available when needed. As in previous studies, we found that compliance is often selective, where individuals report having the EAI with them in restaurants and during holidays more often than at other times. The inconvenience, shape and size of the EAI were not associated with self-reported non-compliance with carrying the device.

Previous studies have reported that 57-78% food-allergic adolescents and adolescents prescribed an EAI reported to have had a food-allergic reaction within a 2-5 year period. The high percentage of accidental food-allergic reactions for which an EAI was needed in our study is thus in keeping with previous reports.

Eighteen adolescents (75% of those who had an EAI available) did not use the EAI during the accidental food-allergic reaction, which is greater than in previous studies reporting 11% to 33% of adolescents not using available epinephrine. Many of the reactions in our study often included respiratory and/or cardiovascular symptoms, and many adolescents had asthma and were reacting to accidental ingestion of peanuts or tree nuts. Reasons given for non-use of the EAI were “other medication used”, “unsure if it was necessary”, “didn’t seem severe enough”, “unsure they ingested the food” and one
patient did not dare to use the EAI. These explanations for the non-use of the EAI are similar to those found in a previous study.\textsuperscript{29} Our data show that individuals not using available epinephrine perceived their disease as being less severe than those who did. This suggests that perceived disease severity is a motivating factor for use of the EAI during an allergic reaction to foods.

In our study there were no significant differences in the descriptive characteristics between adolescents depending on their manner of recruitment. However, it is possible that compliance in the general population is not as good as in individuals participating in studies such as ours. Conclusions in the present study should be confirmed in a “real life” setting to clarify this.

A limitation of this study may be that the parental questionnaires were mainly completed by mothers. The burden of treatment of an EAI as perceived by fathers may differ from mothers. A previous study showed that there is a sex difference in parental coping with food allergy.\textsuperscript{30} Therefore, parental gender is important to take into account in future research. Another limitation of this study may be recall bias, to which self-reported data are prone. However, investigation using self-reported data has been accepted within the food allergy literature despite such limitations.\textsuperscript{31}

A further possible limitation is that the size of the study may have been inadequate to find correlations between the BoT and the other outcome measures (FAQLO, FAIM, IPQ and STAI). However, the percentage of the response variable variation ($R^2$) is low, and it is thus unlikely that a larger study population would have shown these correlations to be significant.

In summary, for food-allergic adolescents prescribed an EAI, a higher burden of treatment is associated with self-reported non-compliance with carrying an EAI at all times. The BoT-measure thus seems to be a useful tool to study compliance with carrying an EAI. Remarkably, the BoT-scores of both adolescents and their parents are not associated with HRQL, perceived disease severity, illness perception, or trait anxiety. Thus, the BoT-measure measures a distinct concept related to compliance behaviour. Further studies on factors influencing the BoT of food-allergic adolescents may be helpful in order to improve compliance.
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