

ORIGINAL ARTICLE

Factors impacting parental burden in food-allergic children

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Aim: This study aims to determine factors impacting the parental burden in immunoglobulin E (IgE)-mediated food-allergic children (FAC), focusing on attitudes towards adrenaline autoinjectors (AAIs).

Methods: Questionnaires were sent to parents of diagnosed IgE-mediated FAC attending follow-up allergy clinic appointments at two Sydney hospitals in May–September 2013. The questionnaires ascertained parental attitudes, confidence and knowledge regarding AAIs and included the validated, Food Allergy Quality of Life-Parental Burden (FAQL-PB) questionnaire.

Results: The response rate was 68%. Of FAC, 62% were male aged 1–17 years (median 6.0). There was a high proportion of children with multiple food allergies (52% allergic to >2 foods), coexistent eczema (85%) and asthma (54%). Sixty-three per cent reported a past history of anaphylaxis and 42% reported reactions in the last 6 months. AAI had been prescribed for 84%. FAC with a history of anaphylaxis were more likely to have had an AAI prescribed ($P < 0.0001$). There was no difference in FAQL-PB mean scores with age or AAI prescription status. The PB score was greater if the parent had administered the AAI ($P = 0.02$) and where the child was allergic to >2 foods ($P < 0.0001$). The Ninety per cent of parents reported that the AAI increased or did not change the child's quality of life, the family or FACs freedom. Three per cent of parents whose FAC children were prescribed an AAI reported increased stress related to AAI prescription.

Conclusion: Severity of food allergy, number of food allergens and past anaphylaxis rather than prescription of an AAI appear to be major influences on parental burden.

Key words: adrenaline auto injector; food allergy; parental burden; quality of life.

What is already known on this topic

- 1 The impact on quality of life is significant in children and families with food allergy.
- 2 Adrenaline autoinjectors (AAIs) are the current out of hospital treatment for emergency treatment of anaphylaxis.
- 3 There are mixed reports regarding the impact of AAI prescription on the anxiety of parents and quality of life of children with food allergy.

What this paper adds

- 1 The major influences on parental burden in FAC were previous administration of AAI and number of food allergies.
- 2 Prescription of AAI did not increase parental burden.
- 3 Prescription of an AAI improved or did not change the family's perceived quality of life and the child and family's freedom.

Immunoglobulin E (IgE)-mediated food allergy (FA) affects a significant number of children with an estimated prevalence of 3–9%. Anaphylaxis rates have significantly increased over the last two decades, particularly in young children.^{1,2} The cornerstone of current FA management is avoidance of the offending allergen and an action plan for treatment in the event of accidental ingestion. In selected cases this emergency plan will include provision of a patient-prescribed adrenaline autoinjector (AAI). To maintain a diet strictly avoiding food allergens is a formidable task. Caregivers of food-allergic children (FAC) may

experience increased burden and over-protectiveness given the potential for severe reactions and their lack of control of accidental allergen exposures. Risk of anaphylaxis is not easily quantifiable and the prescription of an AAI is not without cost and social implications. Anxiety and stress has been reported as being increased in mothers of FAC.³ Although there is published data regarding impact of FA and AAI ownership on individuals with FA, there is little reported on the overall impact on families with FAC. We sought to determine what factors impact on the parental burden in FAC, with a focus on attitudes towards AAIs.

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Methods

We assessed parental burden and attitudes using a questionnaire-based study of parents whose IgE-mediated FAC (aged 0–17 years) attended the allergy clinics at Children's Hospital at Westmead and Royal North Shore Hospital between May and

Table 1 Characteristics of food-allergic children

	All <i>n</i> = 167	AAI prescribed <i>n</i> = 140	No AAI prescribed <i>n</i> = 27	<i>P</i> value
Gender	Male	60.7%	59.3%	0.89
Median age (range)	6.0 years (1–17)	7.0 (0.8–17.8)	3.4 (0.7–14.0)	0.01
Distance from closest hospital	<5 km	50.3%	70.0%	0.23
	>5 km	49.6%	30.0%	
Time since last reaction	<12 months	62.7%	70.0%	0.99
	>12 months	37.3%	30.0%	
Food allergies†	Peanuts	72.1%	40.7%	0.001
	Other nuts	61.4%	48.1%	0.20
	Milk	37.1%	29.6%	0.46
	Egg	62.9%	59.2%	0.72
	Soy	0.7%	11.0%	0.58
	Wheat	1.2%	7.4%	0.48
	Seafood	20.7%	7.4%	0.10
Allergic disease	Atopic dermatitis	85.7%	81.5%	0.57
	Asthma	57.9%	26.0%	0.002
	Eosinophilic esophagitis	0.03%	0.0%	0.44
Worst allergic reaction	Mild-moderate	30.7%	74.1%	<0.001
	Severe (anaphylaxis)	60.3%	25.9%	
Previous supervised oral food challenge in hospital	Yes	45.0%	25.6%	0.07

†>50% of children were allergic to >2 foods.

September 2013. The questionnaires consisted of the Food Allergy Quality of Life-Parental Burden (FAQL-PB)⁴ questionnaire and a questionnaire developed specifically to determine the parental attitudes, knowledge and confidence regarding AAIs with responses graded by Likert scale (Supporting Information Appendix S1). Mean Parental Burden Score was calculated from the FAQL-PB. The severity of reported allergic reactions (by parents) were divided in two categories: mild-moderate reactions (localised or generalised urticarial and/or oedema and/or gastrointestinal symptoms) and severe reactions (persistent coughing and/or wheeze and/or stridor and/or hoarse voice and/or difficulty breathing and/or pallor and/or cyanosis and/or collapse) consistent with anaphylaxis. Data were analysed with χ^2 , non-parametric tests, and linear regression analyses (SPSS, Social Science Statistics, Armonk, NY, USA). Informed consent was obtained from all participants. The project was approved by the Northern Sydney Local Health District Human Research Ethic Committee. (HREC no 1212-426M).

Results

The questionnaire return rate was 68.4% (167/244). Characteristics of the FAC are shown in Table 1. Those prescribed an AAI were significantly older and were more likely to have current asthma, previous anaphylaxis and peanut allergy ($P < 0.05$). This is in line with current Australasian Society of Clinical Immunology and Allergy guidelines for AAI prescription.

The mean MPB score was 2.0 (standard deviation 1.3), similar to a mean score of 2.8 in FAC used to validate the questionnaire (compared with families of atopic children without FA who scored 0).⁴ We found no significant difference

in parent FAQL-PB mean scores related to the age of the food allergic child, or their AAI ownership status. The FAQL-PB score was significantly greater where the parent reported that the child had required AAI administration ($P = 0.02$, 95% confidence interval (CI) 0.15–1.41) and when their FAC had two or more food allergies ($P < 0.0001$, 95% CI 0.60–1.40). These results were independent of other risk factors including severity of previous reactions. The number of foods the child was allergic to directly impacted the PB score with the addition of each additional allergen from 1 vs. 2 vs. 3 vs. >3 increasing the PB score by 0.5 for each additional allergen ($P < 0.001$).

Analysing specific responses within the FAQL-PB, half of the parents reported their child's food allergy limited them or caused trouble in everyday life; 43% reporting moderate/severe limitation in planning social activities, 71% reporting moderate/severe limitation in planning to eat in a restaurant and 56% reporting moderate/severe anxiety when leaving the child in the care of others because of FA.

Ninety per cent of parents reported AAI ownership increased or did not change the family's quality of life and the family or FAC's freedom. Only 3% of parents whose FAC children were prescribed an AAI reported an increase in stress related to allergy management they directly attributed to AAI ownership. The majority of parents reported that having an AAI reduced stress (70.6%) and anxiety (64.7%) (Table 2).

The 96.8% of parents reported it would be appropriate to administer an AAI for symptoms of a severe allergic reaction (anaphylaxis) but 55% also selected mild-moderate symptoms as a trigger for AAI administration. Eighty-three per cent reported taking the AAI wherever the child went.

Table 2 The impact of AAI prescription on stress and quality of life

	Increases %	Decreases %	Does not change %
Parental stress regarding allergy management	2.9	70.6	26.5
Anxiety about child's allergy	5.1	64.7	30.2
Family's quality of life	38.9	3.7	57.4
Family's freedom	42.7	5.8	51.5
Child's freedom	47.8	10.3	41.9
Anxiety of others regarding care of child	39.6	31.3	29.1
Anxiety about others taking care of child	19.4	48.5	32.1

Previous studies have reported AAI ownership can impair quality of life.⁵ This study cohort had high rates of AAI instruction that may explain the difference in our results compared with previous studies. It is possible that parents of children prescribed an AAI without sufficient education, training and support may have increased parental burden with having to carry and potentially administer this injectable rescue-therapy to their children.

Consistent with previous literature reporting that AAI prescription may improve maternal and FAC anxiety⁶ and the notion that children with more severe atopic disease were more likely to have parents reporting impaired quality of life and increased stress,⁷ we also report increased burden for parents with FAC who were allergic to more than two types of food and who had used an AAI in the past. Increased burden was not attributable to AAI prescription.

These FAC represent a highly atopic group from tertiary centres, thus a study limitation is that the cohort contains a relatively small proportion of FAC without an AAI. Hence our population may not reflect the general allergic population not requiring tertiary care. Moreover, burden attributed purely to having to carry an AAI in all circumstances cannot be easily or readily separated from parental burden related to the allergy itself.

In conclusion, this study provides supportive data that there is a significant (self-reported) burden on parents of FAC and that past administration of an AAI and number of food allergens were major influences on this burden. In our population of highly atopic children, AAI ownership was associated with reduced stress and anxiety with no change or improvement in the family's quality of life or feelings of freedom. There was no evidence from our cohort that AAI ownership increases parental anxiety. In particular, AAI ownership was associated with a decrease in reported parental anxiety in regard to others taking care of their food allergic child.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Appendix S1. Assessing the impact of adrenaline autoinjector prescription and ownership for families of children with food and/or insect allergy

Appendix S2. Multiple-choice questions

Assessing the impact of Adrenaline autoinjector prescription and ownership for families of children with food and/or insect allergy.

QUESTIONNAIRE

Part A - Demographics

1. Child's date of birth - ____/____/____

2. Suburb of Residence and Postcode _____

3. Gender - Male Female

4. Approximately how many kilometers do you have to drive to get to the nearest hospital?

<1km

1-5km

>6km

Part B- Allergy History

5. What food allergies have been diagnosed by your child's allergy Doctor?

Egg

Seafood

Milk/diary

Kiwi fruit

Soy

Sesame

Wheat

Other (please list)

Peanut

.....

Other nuts

.....

.....

6. Which (if any) insect allergies have been diagnosed by your child's allergy Doctor?

Bee

Ant

Wasp

Tick

7. When was your child's last allergic reaction ?

< 6 months ago

7-12 months ago

>13 months ago

8. Has your child been diagnosed as having asthma by a doctor/physician?

Yes

No

9. Has your child ever had wheeze or whistling in the chest at any time in the past when he/she did not have a cold or flu?

Yes

No

10. Has your child had asthma symptoms in the last 12 months?

Yes

No

11. If your answer was **YES** to either of the above questions (8, 9, 10) - How regularly has your child taken a reliever puffer in the last year (e.g. Ventolin, Asmol)?

Daily

1-3 times per month

Weekly

<6 times per year

12. Does your child regularly take a preventer puffer or tablet for asthma e.g. Flixotide, Seretide, Singulair?

Yes

No

13. Has a doctor ever told you that your child has eczema or atopic dermatitis?

Yes

No

14. Has a doctor ever told you that your child has Eosinophilic Esophagitis?

Yes

No

Part C - Allergic reactions

15. Please tick all of the symptoms or signs that your child has had within the first 2 hours of exposure to a food or insect or drug that they are allergic to.

Never experienced a reaction	Vomiting
Only ever had positive skin prick tests or blood test	Diarrhoea
Rash around the mouth	Change of skin colour - eg going pale
Facial rash , hives or welts	Floppy, lethargic
Rash, hives or welts all over the body	Coughing
Swelling of the eyes or face	Wheezing
Swelling of the tongue	Noisy breathing/difficulty breathing
Swelling of other parts of the body	Hoarse voice/change in voice
	Other (please describe below)

16. Has your child ever had a supervised oral food challenge (in hospital or in a doctors consulting rooms)?

Yes	No
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17. If yes, to which foods has your child had a food challenge? (please list)

Part D - Adrenaline Autoinjector (Epipen or Anapen) device history

18. Do you think an AA is really necessary in the management of your child?

Yes

No

19. Has your child ever been prescribed an AA?

Yes

No

20. If you answered "**No**" to question 19, please describe your response to the following statements:

1-strongly agree, 2-agree, 3-neutral, 4-disagree, 5-strongly disagree

I do not feel an AA is needed in my child's situation and am satisfied with current management	1	2	3	4	5
I would feel more comfortable managing my child's allergy if I had an AA	1	2	3	4	5
I do not know enough about AA's to have an opinion	1	2	3	4	5

Thankyou, please go to "Part E" on page 6.

21. If you answered "**Yes**" to question 19

How many years have you had an AA?

<1 year

1-5 years

>5 years

22. How many times has you child had their AA administered (ie- used)?

Never

2-5

1

>5

23. Has your child been given Adrenaline by an ambulance officer or hospital doctor since you have had an AA?

Yes

No

24. If you have administered (given) the adrenaline autoinjector, was it easier or harder than you had imagined?

Easier

Harder

25. If you have previously administered the AA - does that experience give you confidence to use it again in the future?

Yes

No

26. Do you feel you have had adequate instruction on how and when to use it?

Yes

No

27. Have you been shown how to use the AA with a trainer device?

Yes

No

28. Do you and/ or your child take an AA wherever your child goes?

Yes

No

29. Do you think your child needs to have an AA available at all times?

Yes

No

30. Please circle whether "increases", "decreases" or "does not change" fits best with your response to these statements .

Having an AA increases/decreases/does not change my stress about allergy management for my child

Having an AA increases/decreases/does not change my anxiety about my child's allergy

Having an AA increases/decreases/does not change our family's quality of life
--

Having an AA increases/decreases/does not change our family's freedom
--

Having an AA increases/decreases/does not change my child's freedom
--

Having an AA increases/decreases/does not change the anxiety others feel regarding care of my child
--

Having an AA increases/decreases/does not change my anxiety about others taking care of my child

Part E – Administering/giving the AA

31. How do you feel about administering the AA if your child was to have anaphylaxis?

Please circle your response to the following statements:

I would be too scared to do it and would not give my child a needle	yes	no
If necessary I would administer the AA, but I feel anxious about giving it	yes	no
I am not concerned and would be confident to give it at any time it was needed	yes	no

32. If your child had an allergic reaction, which of the following signs would make you think the child needed to have the AA administered. (Tick all relevant signs)

- | | |
|---|---------------------------------------|
| Never experienced a reaction | Vomiting |
| Only ever had positive skin prick tests or blood test | Diarrhoea |
| Rash around the mouth | Change of skin colour - eg going pale |
| Facial rash , hives or welts | Floppy, lethargic |
| Rash, hives or welts all over the body | Coughing |
| Swelling of the eyes or face | Wheezing |
| Swelling of the tongue | Noisy breathing/difficulty breathing |
| Swelling of other parts of the body | Hoarse voice/change in voice |
| | Other (please describe below |

33. Have you ever practiced administering an expired AA on an object (eg orange or cushion) ?

Yes

No

33. If your child has an **Epipen**, from memory please list the following steps in Epipen Administration in order of 1 to 6 (i.e without looking up the instructions)

- ___ Pull the pen away from the thigh and discard
- ___ Hold for 10 seconds
- ___ Pull off blue safety release
- ___ Hold orange end against outer mid thigh and push firmly so it "clicks"
- ___ Take pen out of protective sheath
- ___ Hold pen in your hand with your thumb covering your fingers

34. If your child has an **Anapen**, from memory please list the following steps in Anapen Administration in order of 1 to 6 (i.e without looking up the instructions)

- ___ Pull the pen away from the thigh and discard
- ___ Press red button so it clicks
- ___ Hold for 10 seconds
- ___ Place needle firmly against the thigh at 90 degree angle
- ___ Pull off grey safety cap from red button
- ___ Pull off black needle shield

Please feel free to add any further comments you would like to make:

If your child has a food allergy, please ensure you also complete the additional "Food Allergy Quality of life: parental burden questionnaire".

Thank you for completing this questionnaire, your time and opinions are valuable and we appreciate your contribution. 😊

Multiple Choice Questions

1. Which of the following factor was not associated with AAI ownership?

- a) Peanut allergy
- b) History of anaphylaxis
- c) Age over 5 years
- d) Current asthma
- e) Eczema

Explanation: Answer E

Children with peanut allergy, a past history of anaphylaxis, older age and current asthma were more likely to have been prescribed an Adrenaline autoinjector. Children with eczema often have food allergies but this was not a factor in AAI prescription.

1. Which of the following factors significantly increased Parental Burden Score?

- a) Adrenaline Autoinjector ownership
- b) Allergy to 2 or more foods
- c) Age
- d) Distance from hospital
- e) Asthma

Explanation: Answer B

The mean parental burden score was significantly higher in parents with children having allergy to 2 or more foods and a past history of anaphylaxis. Asthma, the child's age, the distance from home to a hospital and autoinjector ownership did not impact the score.

3. What percentage of parents reported that having been prescribed an AAI reduced or did not change their level of stress related to managing their child's food allergy?

- a) 97%
- b) 90%
- c) 70%
- d) 50%
- e) 25%

Explanation : Answer A

Most parents (97%) reported that having an AAI decreased or did not change their stress regarding the management of their child's allergies.