

ORIGINAL ARTICLE

Food allergy knowledge of parents – is ignorance bliss?

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Abstract

Background: Food allergic children are at least partially dependent on their parents to care for their food allergy. In addition, parents are often responsible for the education of others regarding food allergy, including the family, school, neighbors, and friends. The aim of this study was to investigate food allergy knowledge, attitudes, and beliefs of parents with food allergic children in the Netherlands. In addition, a cross-cultural comparison was made between parents from the USA and parents from the Netherlands.

Methods: The original Chicago Food Allergy Research Survey for Parents of Children with Food Allergy (CFARS-PRNT) was translated into Dutch. Parents of children with at least one doctor-diagnosed food allergy were included. Knowledge scores and attitude/beliefs scores were determined and compared with the data from 2945 parents from the USA. Predictors of overall knowledge scores were investigated.

Results: Dutch parents of children completed the translated CFARS-PRNT (n = 299). The mean overall knowledge score in the Netherlands was 9.9 after adjusting for guessing, compared with 12.7 in the USA (p < 0.001). Attitudes and beliefs regarding food allergy among parents from the Netherlands were generally more optimistic. The overall knowledge scores could be predicted by country of origin, educational degree, being member of a patient organization, visiting an allergist, and a history of anaphylaxis.

Conclusions: Food allergy knowledge among parents of food allergic children from the Netherlands is suboptimal when compared with their counterparts from the USA, although these parents tend to be more optimistic toward food allergy than parents from the USA.

The prevalence of food allergy in children from Europe and the USA is considered to be 3–8% (1–4). Unfortunately, there is no curative treatment available for food allergic patients. The key treatment is avoidance of allergenic foods, education, and prescription of an epinephrine auto-injector (EAI) for emergency treatment in case of accidental ingestions (5–8). Food allergic children are at least partially dependent on their parents to seek medical care, to avoid culprit foods, and, in the event of accidental allergic reactions, to determine the severity

of the food allergic reaction and the need for emergency treatment. In addition, parents often carry the responsibility for educating the family, school, neighbors, and friends regarding their child's food allergy.

Previous studies have shown that having a child with a food allergy has a significant impact on quality of life (9, 10). Parental anxiety about avoiding and responding to allergic reactions may play a role, particularly among parents educated about the potentially life-threatening nature of anaphylactic

events (9). Nevertheless, food allergy education improves self-management skills involving food avoidance, identifying allergic reactions and implementing emergency treatment with an EAI (5–7).

Food allergy knowledge, attitude, and beliefs among parents have never been investigated in European countries before, although such studies have previously been conducted in the USA. The aim of this study was therefore to investigate food allergy knowledge, attitudes, and beliefs among parents of food allergic children in the Netherlands. In addition, a cross-cultural comparison of food allergy knowledge, attitudes, and beliefs was made between parents from the Netherlands and parents from the USA.

Methods

Participants and procedure

Parents of food allergic children (<18 of age, with at least one doctor-diagnosed food allergy) were recruited through an online advertisement on the website of the Dutch Food Allergy Foundation, using a newflash by e-mail to all members to increase awareness of the study. In addition, parents were recruited from the food allergy challenge units of two medical centers in Groningen, the Netherlands. After entering the website, the online survey started with an introduction and instructions. If parents had more than one food allergic child, they were asked to complete the survey with the child in mind who had the most severe food allergy.

Materials

The original Chicago Food Allergy Research Survey for Parents of Children with Food Allergy (CFARS-PRNT) (11, 12) was translated and back-translated as prescribed by the World Health Organization (13). An expert panel (an allergist, a psychologist, a food allergy questionnaire expert, a native English speaker, and a native Dutch speaker) judged the individual items on relevance for the Dutch parental population

and the quality of the translation. Subsequently, two parents and a food allergy challenge nurse tested the translated questionnaire in a small pilot study, during which participants were interviewed about the understanding and relevance of the individual items. The translated CFARS-PRNT was modified slightly based on these comments (Table 1). The final version was converted into an online survey. The translated CFARS-PRNT consisted of 21 knowledge items, 24 attitude and beliefs items, and 13 demographic items. All knowledge, attitudes, and beliefs items corresponded to one of the eight identified food allergy content domains (11, 12).

Knowledge

Knowledge items were completed using response options consisting of both multiple choice scaling systems (true/false/do not know) and items with multiple responses. The mean number and percentages of correctly answered knowledge items (overall knowledge score; ranging from 0–21) were determined. The overall knowledge score and individual item scores were adjusted for guessing using established methods (14).

Attitude and beliefs

All attitudes and beliefs items were answered using a 5-level Likert scale, ranging from 1 ('totally disagree') to 5 ('totally agree'). Most items had a 'does not apply' option. Mean attitude and beliefs scores were determined for all individual items.

Participant characteristics

Three types of participant characteristic items were included in the CFARS-PRNT: items about the participant him/herself; items about his/her food allergic child; and items about the use of food allergy health care services.

Cross-cultural comparison

The overall knowledge scores, individual knowledge items, and attitude and beliefs items were compared with answers of

Table 1 Adjustments of the original CFARS-PRNT for the translated CFARS PRNT

Original version (USA)	Translated version (NL)
<i>EpiPen or Twinject</i>	<i>Epipen or Anapen</i>
<i>Nurses offices</i>	<i>Teachers room</i>
<i>Which of the following resources have you used for food allergy education or support?</i>	Removed (resources were not applicable for the Netherlands)
<i>What is your race/ethnicity?</i>	Removed (inappropriate to ask in this context in the Netherlands)
<i>Which of the following categories best represents the combined income for all family members in your household for the past months before taxes?</i>	Removed (inappropriate to ask in this context in the Netherlands)
<i>Please tell us more about your children under the age of 18</i>	Removed (questionnaire was too long with these items included, according to parents from the Netherlands)
<i>Food additives are common allergens (false)</i>	Removed (sulfite is considered to be an allergen)
<i>Food ingredients can cause allergic reaction (Play-doh)</i>	Removed (no clear evidence in literature)
<i>Food ingredients can cause allergic reaction (medicines)</i>	Removed (no clear evidence in literature)
<i>Food ingredients can cause allergic reaction (toothpaste)</i>	Removed (no clear evidence in literature)
<i>Food ingredients can cause allergic reaction (lotions/crèmes)</i>	Removed (no clear evidence in literature)

parents from the original study in the USA (11). In addition, predictors of overall knowledge scores of parents with food allergic children were determined using data from both countries.

Statistical analyses

Statistical analyses were primarily descriptive. A cross-cultural comparison of the individual knowledge items (chi-square test), the overall knowledge scores (Mann–Whitney *U*-Test), and the attitude and beliefs scores (Mann–Whitney *U*-Test) were performed. Predictors of overall knowledge scores were determined by scatter plots and univariate linear regression analyses. Significantly contributing variables were included in a multivariate regression analysis in a stepwise manner. Only statistically significant variables in the final analyses were incorporated in the multivariate regression model. *P*-values of <0.05 were considered to be statistically significant in all analyses. Statistical analyses were performed with SPSS 19.0 (SPSS inc. Chicago, IL, USA).

Ethical approval

No ethical approval of a medical ethics commission was required for this study. Participants were asked to participate voluntarily in this study and were able to enter the online survey only after reading the information and instructions page. Completing the online questionnaire after reading this information was taken as an informed consent.

Results

Participants

Between May 2011 and March 2012, 447 parents with food allergic children completed the online CFARS-PRNT in the Netherlands. Thirty parents were excluded from this study because they did not indicate whether the food allergy of their child was diagnosed by a doctor or not. One-hundred and eighteen parents did not fill out the CFARS-PRNT completely and were excluded (they stopped during the knowledge items and therefore surveymonkey.com only reported their intention to participate). After exclusions, data were analyzed for a total of 299 parents of food allergic children. Participants were able to complete the online CFARS-PRNT in a median time of 9 minutes (IQR: 7–11 min). Participant characteristics, characteristics of the food allergic child, and the frequency of using food allergy health care services are shown in Tables 2 and 3. No data were obtained about participant characteristics of the parents who did not fill out the CFARS-PRNT completely.

Knowledge, attitudes, and beliefs

The mean overall knowledge score was 9.9 of 21 (SD 4.3), which means that 47% of the knowledge items were answered correctly, after adjusting for guessing (Table 4). The parent with the best score answered 90% correctly,

Table 2 Participant characteristics and characteristics of food allergic child*

	N = 299
Gender, n (%)	
Male	11 (3.7)
Female	288 (96.3)
Marital status, n (%)	
Married	278 (93.0)
Divorced	9 (3.0)
Single	12 (4.0)
Highest degree, n (%)	
Primary school	2 (0.7)
High school	20 (6.7)
Community college	97 (32.4)
4 yr (university) college	132 (44.1)
Graduate degree	48 (16.1)
Total number of children <18, n (%)	
1	78 (26.1)
2	159 (53.2)
3	49 (16.4)
4	9 (3.0)
5 or more	4 (1.3)
Lives together with food allergic child, n (%)	
Yes	295 (98.7)
No	4 (1.3)
Experienced anaphylaxis, n (%)	
Yes	107 (35.8)
No	192 (64.2)
Number of doctor-diagnosed food allergies, n (%)	
1	76 (25.4)
2	65 (21.8)
3	51 (17.1)
4	38 (12.7)
>4	69 (23.0)
Type of doctor-diagnosed food allergy, n (%)	
Peanut	169 (56.5)
Nut	136 (45.5)
Milk	169 (56.5)
Egg	144 (48.2)
Wheat	45 (15.1)
Soy	74 (24.7)
Sesame	41 (13.7)
Fish	22 (7.4)
Shell fish	28 (9.4)
Fruit	74 (24.7)
Vegetable	35 (11.7)

*Parents with multiple food allergic children were instructed to complete the survey considering their child with the most severe food allergy.

whereas the seven parents with the lowest score answered 0% correctly. Scores were highest in domains '*Definition and Diagnosis*' and '*Symptoms and Severity*'. Scores were lowest (<15% correct) on the items '*asthma is a risk factor for anaphylaxis*' (true) and '*teenagers at higher risk for fatal anaphylaxis*' (true). Attitude and beliefs scores are shown in Table 5.

Table 3 Use of food allergy healthcare services

	N = 299
Member of patient organization, n (%)	
Yes	111 (37.1)
No	188 (62.9)
Visited pediatrician in last 12 months, n (%)	
No	77 (25.8)
1–2 times	93 (31.1)
3–5 times	9 (3.0)
6–9 times	84 (28.1)
10–12 times	21 (7.0)
More than 12 times	15 (5.0)
Visited allergist in last 12 months, n (%)	
No	138 (46.2)
1–2 times	102 (34.1)
3–5 times	5 (1.7)
6–9 times	39 (13.0)
10–12 times	13 (4.3)
More than 12 times	2 (0.7)
Visited emergency department/emergency visit GP for food allergy, n (%)	
Yes	91 (30.4)
No	208 (69.6)

Cross-cultural comparison

The overall knowledge score and individual item scores of participants from the Netherlands and their counterparts from the original study in the USA (11) are shown in Table 4. Difference in overall knowledge score between participants from the USA and the Netherlands was adjusted for all other reported variables, as shown in the prediction model for overall food allergy knowledge scores (Table 6).

Predicting food allergy knowledge

The overall knowledge scores could be predicted by the following: country of origin (USA–more knowledge); highest educational degree (better education–more knowledge); membership of a patient organization (members–more knowledge); visit/contact allergist (visit/contact–more knowledge); visit/contact pediatrician (visit/contact–less knowledge); and the experience of anaphylaxis in the child (history of anaphylaxis–more knowledge) (Table 6). The variables number of food allergies, type of food allergy, visit to an emergency department, and gender were not significantly related to the overall knowledge in the multivariate model. All included variables contributed significantly to the prediction of overall knowledge scores ($\alpha < 0.05$). The prediction model was able to explain 20% of the variance in the overall knowledge scores.

Attitudes and beliefs

Significant variation in attitude and beliefs was observed between parents from the Netherlands and the USA (Table 5). However, there was a cross-cultural agreement on several statements. On average, both parents from the Netherlands and parents from the USA agreed with the

Table 4 Food allergy knowledge

	NL	USA	P
Number of participants	299	2945	
Overall knowledge score*, mean (SD)	9.9 (4.3)	12.7 (4.8)	<0.001
Definition and diagnosis†			
FA involves immune system	82%	80%	0.42
Medical test only way to know child has FA	59%	34%	<0.001
Symptoms and severity†			
Eczema may be first sign of FA	87%	77%	<0.001
Sign of milk allergy reaction (hives)	65%	90%	<0.001
Sign of milk allergy reaction (tongue swelling and trouble breathing)	55%	89%	<0.001
Triggers and environmental risk†			
Asthma is risk factor for anaphylaxis	2%	71%	<0.001
Food can pass from mother to child by breastfeeding	76%	89%	<0.001
Three most common childhood food allergens (egg)	38%	42%	0.02
Three most common childhood food allergens (milk)	93%	75%	<0.001
Three most common childhood food allergens (peanut)	46%	75%	<0.001
Perceptions of susceptibility and prevalence†			
Teenagers at higher risk for fatal FA than children	0%	20%	<0.001
Age group most likely to have FA	80%	74%	0.03
Percentage of children with milk allergy who develop tolerance	26%	12%	<0.001
Percentage of children with peanut allergy who develop tolerance	16%	51%	<0.001
Treatment and utilization of health care†			
Daily antihistamine can prevent FA reaction	22%	53%	<0.001
Best place to use an EAI	59%	82%	<0.001

*Overall knowledge score: mean number of correctly answered items (ranging 0–21).

†Percentage of participants who answered the individual item correctly, adjusted for guessing. **Bold** values are significant ($\alpha < 0.05$) p-values.

statements: ‘Frustrated because doctors say different things about child’s food allergy’ and ‘How I deal with food allergy affects how child deals with food allergy’. On average, parents from both the Netherlands and the USA disagreed with the statements: ‘Child’s food allergy causes strain on marriage/relationship’; ‘Partner and I do not agree on how to care for child’s food allergy’; ‘Partner thinks I exaggerate seriousness of child’s food allergy’ and ‘My career has suffered because of child’s food allergy’. On average, both parents from the Netherlands and the USA were neutral about the statement: ‘Food labeling laws decreased choice of foods my child can eat’.

Table 5 Food allergy attitudes and beliefs

Item	NL	USA	P
Treatment and utilization of health care, mean* (SD)			
Frustrated because doctors say different things about child's FA	3.2 (1.4)	3.3 (1.4)	0.37
Stigma and acceptability, mean* (SD)			
Some relatives do not accommodate child's FA	2.9 (1.3)	3.1 (1.4)	<0.001
Child's friends treat him/her differently because of FA	2.3 (0.9)	2.6 (1.1)	<0.001
Experienced hostility from other parents in accommodating child's FA	2.7 (1.1)	3.0 (1.3)	<0.001
How I deal with FA affects how child deals with food allergy	4.0 (1.0)	4.1 (1.0)	0.02
Most people know symptoms of FA	2.0 (0.9)	1.8 (1.0)	<0.001
Most people take FA seriously	2.8 (1.1)	2.2 (1.2)	<0.001
Perceptions of quality of life, mean* (SD)			
Child's food allergy causes strain on marriage/relationship	2.5 (1.3)	2.5 (1.3)	.99
Partner and I do not agree on how to care for child's FA	1.9 (1.0)	2.0 (1.1)	0.94
Pay more attention than partner to keep child from allergenic food(s)	2.7 (1.3)	3.0 (1.5)	<0.001
Worry more than my partner about child's FA	2.8 (1.3)	3.3 (1.5)	<0.001
Partner thinks I exaggerate seriousness of child's FA	1.9 (0.9)	2.2 (1.3)	0.06
Child with FA affects other children's daily lives	3.5 (1.2)	3.7 (1.2)	0.008
My career has suffered because of child's FA	2.3 (1.1)	2.4 (1.3)	0.20
Career of partner has suffered because of child's FA	1.8 (1.0)	1.7 (1.0)	0.02
FA of child causes financial problems for my family	2.4 (1.0)	2.7 (1.3)	<0.001
Policy issues, mean* (SD)			
Comfortable that school/daycare staff can manage FA emergency	2.9 (1.0)	3.3 (1.0)	<0.001
Children with FA should have EAI with them at school	3.8 (0.9)	4.4 (0.9)	<0.001
EAI should be kept only in teacher's office at school	3.0 (1.2)	2.1 (1.2)	<0.001
Schools should ban all products with nuts	2.7 (1.0)	3.4 (1.3)	<0.001
Trained adults should be at school lunch, parties, and field trips	3.7 (1.0)	4.5 (0.8)	<0.001
Food labeling laws decreased choice of foods my child can eat	3.0 (1.1)	3.0 (1.3)	0.85
More government money should go toward FA research	4.0 (0.8)	4.4 (0.9)	<0.001
Which of the following is most important to help food allergic patients, %			
Developing a cure	32.1	42.4	<0.001
Improving treatment	13.0	20.6	<0.001
Identifying the cause	28.4	20.4	<0.001
Promoting public awareness	19.7	8.9	<0.001
Promoting school education programs	6.7	7.7	<0.001

*Mean response score (range 1–5, scores above and below 3 indicate general agreement and disagreement, respectively); **Bold** values are significant p-values ($\alpha < 0.05$).

On average, both parents from the Netherlands and the USA found '*Developing a cure*' most important and '*Promoting school education programs*' least important to help children with food allergy.

Discussion

This is the first European study to investigate food allergy knowledge, attitudes, and beliefs among parents with food allergic children. Furthermore, this is the first cross-cultural comparison of knowledge, attitudes, and beliefs among parents from two different continents. The most remarkable finding in this study is that parents of food allergic children in the USA are more knowledgeable about their child's disease than their counterparts from the Netherlands (also after adjusting for guessing and after adjusting for all other reported variables: Table 6). On the other hand, parents from the Netherlands tend to be more optimistic regarding food allergy than parents from the USA.

Knowledge

There may be several possible reasons for the difference in overall knowledge scores between parents from the USA and the Netherlands. Healthcare professionals in the Netherlands may spend less time on patient education or emphasize other aspects of care. This might explain why parents from the Netherlands were generally more optimistic toward food allergy as well.

Two specific knowledge items were answered remarkably poorly: None of the participants from the Netherlands knew that teenagers are at higher risk of a fatal food allergic reaction, and only 2% knew that asthma is considered to be a risk factor for anaphylaxis. As asthma is a prevalent disease in children from Western countries and parents will be responsible for ensuring proper care as their younger children become teenagers, it is important to make sure that parents are aware of these facts.

Also troubling, only 59% of the participants from the Netherlands knew that the outer thigh is considered to be the

Table 6 Determinants of food allergy knowledge

	N	B	SE	p
Constant		7.736	0.441	<0.001
Variable, B				
Country of origin	3244			
The Netherlands (reference)	299	–	–	–
USA	2945	1.236	0.338	<0.001
Highest educational degree	3244			
High school or less (reference)	307	–	–	–
Associate	604	0.603	0.307	0.049
Bachelor	1364	1.921	0.277	<0.001
Graduate	969	2.241	0.281	<0.001
Member patient organization	3244			
No (reference)	1383	–	–	–
Yes	1861	2.937	0.164	<0.001
Visited allergist in past 12 months	3129			
No (reference)	435	–	–	–
Yes	2694	1.324	0.235	<0.001
Visited pediatrician in past 12 months	3129			
No (reference)	477	–	–	–
Yes	2652	–1.325	0.215	<0.001
Child experienced anaphylaxis	3229			
No (reference)	1690	–	–	–
Yes	1539	0.709	0.155	<0.001

Only variables that significantly contributed to the regression model are shown. R square = 0.202 (SE of the estimate: 4.270). Food allergy overall knowledge scores ranged from 0 to 21 and were corrected for guessing (adjusted for guessing). For the regression algorithm, the reference group was always 0 and the other groups were counted as 1 (times the B coefficient) when applicable.

best place to use an EAI. Seven parents who did not answer this item correctly have a child with a history of anaphylaxis, illustrating the importance of correcting this misconception. Not surprisingly, confusion about the EAI use is not limited to the Netherlands: Previous studies in the USA have demonstrated that many parents of food allergic children are not familiar with proper EAI use (6, 11).

Predicting food allergy knowledge

Food allergy knowledge of parents with food allergic children is predictable to a certain extent (20%), as shown in Table 6. The model shows that knowledge of food allergy was likely to be higher in parents from the USA, parents with a higher educational degree, parents who were a member of a patient organization, parents visiting an allergist, and parents whose child had a history of anaphylaxis.

An important finding is that visiting an allergist is associated with higher overall knowledge scores. Although not tested longitudinally, visiting an allergist for food allergy care is most likely preferable to visiting a physician without specialty training in allergy. A previous study in the USA found that pediatricians have several misconceptions regarding food allergy, are often not comfortable interpreting food allergy test results, and express concern in their training regarding their ability to care for food allergic patients (15).

Parents whose child had a history of anaphylaxis had a higher overall knowledge score than parents without such an experience. These parents may be more motivated to learn

about food allergy to keep their child safe. In addition, physicians may also be more punctilious with regard to providing parents with correct food allergy information.

Members of a food allergy patient organization had a higher overall food allergy knowledge score than non-members. This was previously shown in the USA (6). Although not confirmed longitudinally, healthcare professionals should encourage parents to become a member of a patient organization to promote reliable education in addition to fostering personal commitment.

Attitudes and beliefs

Attitudes and beliefs regarding food allergy were generally optimistic in participants from the Netherlands. However, parents express concern regarding food allergy knowledge of the general public and felt that the general public often underappreciates the seriousness of food allergy. This suggests that investigation of the food allergy knowledge, attitudes, and beliefs of the general public in the Netherlands may be warranted to identify areas best suited for public educational initiatives.

Another remarkable finding is that parents expressed discomfort with the ability of school/daycare staff to manage a food allergy emergency. Most parents agreed that trained adults should be present during school lunches, at parties, and field trips to keep affected children safe. As no data are available about actual arrangements concerning food allergy of schools in the Netherlands, it might be worthwhile to investigate

whether these concerns are legitimate and guide policy changes as needed.

A positive finding in this study is that parents do not perceive financial problems in their families because of their child's food allergy. This is in line with previous studies where lower household costs were found in families with food allergic children (16, 17).

Parents from the Netherlands were generally more optimistic about food allergy when compared to parents from the USA. Whether this is related to their suboptimal knowledge warrants further research. One might suggest that more food allergy knowledge could contribute to more anxiety and frustration among parents in the effort to keep their child safe. The challenge is to manage patients in such a way that pessimism is great enough to foster appropriate vigilance while optimizing HRQL.

Limitations

A limitation of this study is a relatively high number of participants who did not fill out the CFARS-PRNT completely (26% in NL, 19% in USA). The results of these participants were not included in the analyses, and no further information about these participants was available. These parents may have less knowledge than the participants who did complete the CFARS-PRNT. Food allergy knowledge of parents in the Netherlands might therefore be poorer than ascertained in this study. Although a greater number of participants were not needed for statistical significance to be achieved, more robust

generalizability would have been achieved with a greater number of Dutch participants.

Conclusion

In conclusion, food allergy knowledge among parents of food allergic children in the Netherlands is suboptimal when compared with their counterparts from the USA. Moreover, a higher educational degree, being member of a patient organization, visiting an allergist, and a history of anaphylaxis are independent predictors for better food allergy knowledge. Attitudes and beliefs regarding food allergy are more optimistic in parents from the Netherlands compared with parents from the USA. Thus, although ignorance may be bliss, it can also be dangerous. Clinicians should be aware of this paradox when developing education programs for their patients aimed at improving knowledge and safety while minimizing potential detrimental aspects on quality of life.

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