

Article Type: Original Article

Title page

Title: Caregivers of children with no food allergy – their experiences and perception of food allergy

Authors full names: Kiwako Yamamoto-Hanada, MD^{1,2}, Masaki Futamura, MD, PhD², Osamu Takahashi, MD, MPH, PhD³, Masami Narita, MD, PhD¹, Fumio Kobayashi, MD, PhD², Yukihiro Ohya, MD, PhD¹

1) Division of Allergy, Department of Medical Subspecialties, National Center for Child Health and Development, Tokyo, Japan.

2) Department of Health and Psychosocial Medicine, Aichi Medical University School of Medicine, Aichi, Japan.

3) Center for Clinical Epidemiology, St Luke's Life Science Institute, Tokyo, Japan.

Running title: Food Allergy Perception and Experience

Correspondence: Kiwako Yamamoto-Hanada, MD.

Division of Allergy, Department of Medical Subspecialties, National Center for Child Health and Development, Tokyo, Japan.

2-10-1 Okura, Setagaya-ku, Tokyo, 157-8535, Japan.

E-mail: yamamoto-k@ncchd.go.jp

Tel: +81-3-3416-0181

Abstract page

Yamamoto-Hanada, KYH; Futamura, MF; Takahashi, OT; Narita, MN; Kobayashi, FK; Ohya, YO.

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/pai.12442

This article is protected by copyright. All rights reserved.

Title: Caregivers of children with no food allergy – their experiences and perception of the condition

Abstract: Background: Food allergy (FA) is one of the most important health issues in school children. Although one of the most common places where paediatric anaphylaxis occurs is the home of a peer, the perception and experiences of caregivers who do not have a child with FA are unclear. Methods: An anonymous paper-based questionnaire was distributed to caregivers of FA children (FA caregivers) in the National Center for Child Health and Development and caregivers of non-FA children (non-FA caregivers) in public school in Tokyo. We examined the perception and experiences of FA among three groups: Group 1, non-FA caregiver who had not witnessed adverse reactions and near-miss events related to FA; Group 2, non-FA caregivers who had witnessed adverse reactions and near-miss events related to FA; and Group 3, caregivers who had a child with FA. Results: Epinephrine auto-injector was recognized by 43.6% non-FA caregivers. Only 2.8% of non-FA caregivers had experienced a child being bullied, harassed or refused by a school because of FA. There were more caregivers in Group 2 who thought they could take the appropriate action if they witnessed a child with adverse response to causal food than in Group 1 ($p<0.05$). All groups felt anxious over adverse events related to FA. Conclusion: The experiences and perception of FA were lacking among non-FA caregivers. Therefore, it is also important to provide FA education for non-FA caregivers to improve the quality of life of FA children.

Key words: anxiety, bully, caregivers, education, epinephrine auto-injector, experiences, food allergy, perception, public health, school

We would like you to send offprints to Kiwako Yamamoto-Hanada.

Address: 2-10-1 Okura, Setagaya-ku Tokyo, 157-8535, Japan.

Main text

Introduction

Food allergy (FA) is a serious concern in school children, with 1-2% of Japanese children shown to have FA (1). A systematic review has noted that there are many gaps in

This article is protected by copyright. All rights reserved.

Accepted Article

knowledge of anaphylaxis management among physicians, patients and the community (2). The European Academy of Allergy and Clinical Immunology (EAACI) guidelines have demonstrated that education for family, teachers and peers of individuals with FA can lower the risk of adverse reactions to food allergens (3). Notably, one of the most common places where paediatric anaphylaxis occurs is the home of a peer (4). Hence, caregivers who do not have a child with FA themselves can still encounter FA-related adverse events. However, it remains unclear what the experiences and perception of those caregivers are in relation of FA. The aims of our study were to examine those unknown factors and to investigate whether a past history of encountering FA-related adverse events influenced their perception.

Methods

Our study design was a cross-sectional study using a questionnaire. We created a questionnaire for caregivers, which was anonymous, paper-based, and written in the Japanese language. The questionnaire included questions on demographic variables, experiences of FA and perception of FA. Ordinal variables were administered with a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree).

We sent the questionnaire to two groups of caregivers. One group consisted of 150

Accepted Article

caregivers (FA caregivers) whose children visited the paediatric allergy outpatient care clinic at the National Center for Child Health and Development (NCCHD) in Tokyo, Japan. The other consisted of 933 caregivers (non-FA caregivers) whose children attended two public elementary schools in Tokyo where the allergists at NCCHD had educated school teachers for food allergy. The children ranged from first graders to sixth graders. As the Japanese elementary school system does not practice grade retention or grade skipping, all the children were between six and 12 years old. The participants returned the questionnaire by mail. Data collection was carried out between September 10, 2014, and December 31, 2014.

For data analysis, we excluded the caregivers who had a child with FA and were recruited through a public elementary school because it was unclear whether the children had a true FA because many caregivers misunderstand the condition. Then, we subdivided the caregivers into three groups: Group 1, non-FA caregiver who had not witnessed adverse reactions and near-miss events related to FA; Group 2, non-FA caregivers who had witnessed adverse reactions and near-miss events related to FA; and Group 3, caregivers who had a child with FA. Chi-square test was used to compare the three groups of baseline characteristics. Bonferroni correction for multiple testing was applied to examine the

Accepted Article

differences in experiences of FA between the three groups, and Tukey's test was used to examine the differences in perception of FA. A p-value of 0.05 was considered significant for chi-square test and Tukey's test. A p-value of 0.05/3 was considered for Bonferroni correction for multiple test. SPSS for Windows version 19.0 (SPSS Inc., Chicago, IL, USA) was used for all statistical analyses.

This study was conducted based on the Ethical Guidelines for Epidemiological Research proposed by the Japan's Ministry of Health and Welfare (currently the Ministry of Health, Labour and Welfare). The protocol was reviewed and approved by the Ethics Committees of the NCCHD. The purpose and the procedure of the questionnaire were explained to all participants, and informed consent was obtained.

Results

We received completed questionnaires from 117 FA caregivers (response rate, 78%) and 383 non-FA caregivers (response rate, 41.1%). A total of 413 subjects were eligible for analysis after excluding the caregivers according to our exclusion criteria.

Table 1 shows the characteristics of the participants included in this study. There were no significant differences in terms of caregiver's age and child's grade between the three groups.

Accepted Article

As for experiences of food allergy, 106 of the 296 (35.8%, 95% CI: 30.3-41.6%) non-FA caregivers in Group 1 and Group 2 who had witnessed adverse responses and/or adverse events related to causal food were assigned to Group 2. Three of the 296 (1%, 95% CI: 0.2-2.9%) of non-FA caregivers had seen a child experience bullying, harassment or school refusal because of FA. Epinephrine auto-injector was recognized by 129/296 (43.6%, 95% CI: 37.9-49.4%) non-FA caregivers, and the percentage of FA-caregivers who had heard of an epinephrine auto-injector before was statistically higher than that of non-FA caregivers (Group1 and Group 2) ($p<0.001$) (see Table 2). Based on the results from the multiple testing, we did not find significant differences between Group 1 and Group 2 relating to having heard of an epinephrine auto-injector and participation in a meeting or seminar for FA. However, the percentages in Group 2 of caregivers who had heard of an epinephrine-auto injector and those who had participated in a meeting or a seminar for FA were higher than those in Group 1. On the other hand, there was significant difference between Group 1 and Group 2 for reading a leaflet or book about FA. In terms of perception of food allergy, the results among the three groups are shown in details in Figure 1. There were no significant differences among the three groups in terms of anxiety when witnessing a child with adverse responses to causal food. The number of caregivers who thought they

could take appropriate actions when they witnessed a child with adverse responses to causal food was lower in Group 1 than in Group 2 ($p=0.028$). The number of Group 1 caregivers who thought non-FA caregivers should have the opportunity to learn about FA was statistically lower than that of Group 3 caregivers ($p<0.001$); however, there were no differences between Group 1 and Group 2.

Discussion

To the best of our knowledge, this report is the first to examine the perception and experiences of FA among non-FA caregivers and to investigate whether past experiences of adverse events related to FA had an influence on the perception of FA. We found that witnessing an adverse reaction of FA seemed to have an influence on the caregivers' perception of their ability to provide appropriate actions for FA but not on reducing the anxiety over adverse events related to FA. In fact, a study has found that an experience of anaphylaxis was associated with poorer quality of life of FA caregivers (5). Further studies are necessary to examine the factors that influence the perception of FA. To alleviate anxiety related to FA, effective interventions should be introduced, as shown by a study that education for parents with FA children was useful in increasing knowledge of FA and in turn decreasing the level of anxiety (6). Similarly, FA education for restaurant workers was

Accepted Article

found to have a positive impact in the management of FA (7). For non-FA caregivers, education can help improve understanding of the condition. Similarly, people who received CPR training performed better in bystander cardiopulmonary resuscitation than those who did not (8). We postulate that the higher the number of non-FA caregivers who received FA education, including training on how to use an epinephrine auto-injector, the lower the risk of near-miss adverse events and anaphylaxis will be in children with FA. In addition, the quality of life of such children may be improved. Notably, we found that more than half of the non-FA caregivers in our study had not heard of an epinephrine auto-injector. Hence, effort should be made in educating non-FA caregivers to enhance proactive management for FA children and their family.

Interestingly, we also found that many non-FA caregivers actually encountered FA-related incidents. According to a previous report, the frequency of FA-related adverse events that occurred at a peer's home is high (4). This suggests that we should be aware that a peer's home can be a major place for adverse events in a child and the respective response to FA.

Bullying is a serious yet common issue for children with FA (9, 10). However, a similar phenomenon has not been reported in Japan, probably due to a discrepancy in the

reporting of bullying between parents and their children (9). In our study, only a few non-FA caregivers recognized negative events such as bullying, harassment or school refusal due to FA. Hence, we should pay more attention to children with FA to avoid such negative events.

A limitation of this study is that we did not evaluate the caregivers' background in detail, such as allergy history. We assumed that the included caregivers did not impact our results because the prevalence of adults with FA is lower than those of children with FA. In spite of the limitation, this was the first original article to report the data for non-FA caregivers and the number of subjects was adequate to demonstrate the gap between caregivers who did not have a child with FA and those who did.

Conclusion

Despite some non-FA caregivers having experienced adverse events related to FA, their perception of FA was different from that of FA caregivers. We should encourage FA education for non-FA caregivers to improve the quality of life of FA children.

Acknowledgement

Our study was supported by the Japan Society for the Promotion of Science (JSPS) KAKENHI Grant Number 26870890. We deeply thank all participants for attending our study. We thank Dr. Julian Tang of the Department of Education for Clinical Research,

This article is protected by copyright. All rights reserved.

National Center for Child Health and Development, for proofreading, editing and rewriting part of this manuscript.

Figure legend

Figure 1: Perceptions of the caregivers for food allergy among the three groups calculated with the Tukey's test. * $P < .05$; *** $P < .001$.

References

1. Ebisawa M, Nishima S, Ohnishi H, Kondo N. Pediatric allergy and immunology in Japan. *Pediatric allergy and immunology : official publication of the European Society of Pediatric Allergy and Immunology*. 2013;24(7):704-14.
2. Kastner M, Harada L, Waserman S. Gaps in anaphylaxis management at the level of physicians, patients, and the community: a systematic review of the literature. *Allergy*. 2010;65(4):435-44.
3. Muraro A, Agache I, Clark A, Sheikh A, Roberts G, Akdis CA, et al. EAACI food allergy and anaphylaxis guidelines: managing patients with food allergy in the community. *Allergy*. 2014;69(8):1046-57. Epub 2014/06/07.
4. Versluis A, Knulst AC, Kruizinga AG, Michelsen A, Houben GF, Baumert JL, et al. Frequency, severity and causes of unexpected allergic reactions to food: a systematic literature review. *Clinical and experimental allergy : journal of the British Society for Allergy and Clinical Immunology*. 2015;45(2):347-67.
5. Ward CE, Greenhawt MJ. Treatment of allergic reactions and quality of life among caregivers of food-allergic children. *Annals of allergy, asthma & immunology : official publication of the American College of Allergy, Asthma, & Immunology*. 2015.
6. Vargas PA, Sicherer SH, Christie L, Keaveny M, Noone S, Watkins D, et al. Developing a food allergy curriculum for parents. *Pediatric allergy and*

immunology : official publication of the European Society of Pediatric Allergy and Immunology. 2011;22(6):575-82.

7. Bailey S, Billmeier Kindratt T, Smith H, Reading D. Food allergy training event for restaurant staff: a pilot evaluation. Clinical and translational allergy. 2014;4:26.

8. Tanigawa K, Iwami T, Nishiyama C, Nonogi H, Kawamura T. Are trained individuals more likely to perform bystander CPR? An observational study. Resuscitation. 2011;82(5):523-8.

9. Shemesh E, Annunziato RA, Ambrose MA, Ravid NL, Mullarkey C, Rubes M, et al. Child and Parental Reports of Bullying in a Consecutive Sample of Children With Food Allergy. Pediatrics. 2013;131(1):E10-E7.

10. Muraro A, Polloni L, Lazzarotto F, Toniolo A, Baldi I, Bonaguro R, et al. Comparison of bullying of food-allergic versus healthy schoolchildren in Italy. J Allergy Clin Immunol. 2014;134(3):749-51.

Table 1. Characteristic of Study Participants

	n ^a	Total n (%)	Group 1 n (%)	Group 2 n (%)	Group 3 n (%)	P-value
Number of caregivers	413	413 (100)	190 (46.0)	106 (25.7)	117 (28.3)	
Caregiver's age, years, mean±SD	407	41.58±4.46	41.92±4.53	41.67±4.46	40.89±4.31	p=0.579
Child's grade	407					
First		81 (19.9)	34 (18.2)	22 (21.2)	25 (21.6)	p=0.554
Second		80 (19.7)	36 (19.3)	18 (17.3)	26 (22.4)	
Third		80 (19.7)	43 (23.0)	21 (20.2)	16 (13.8)	
Fourth		72 (17.7)	30 (16.0)	21 (20.2)	21 (18.1)	
Fifth		50 (12.3)	27 (14.4)	12 (11.5)	11 (9.5)	
Sixth		44 (10.8)	17 (9.1)	10 (9.6)	17 (14.7)	
Relationship	410					
Mother, n (%)		392 (95.6)	178 (95.2)	103 (97.2)	111 (94.9)	p=0.835
Father, n (%)		15 (3.7)	7 (3.7)	3 (2.8)	5 (4.3)	
Another, n (%)		3 (0.7)	2 (1.1)	0 (0.0)	1 (0.9)	

SD, standard deviation; Group 1 included the caregivers who did not have a child with FA (food allergy) nor had experiences

seeing adverse reactions and near miss events to FA. Group 2 included the caregivers who did not have a child with FA and had

experiences about seeing adverse reactions and near miss events to FA. Group 3 included the caregivers who had a child with FA.

^aNumber of caregivers without missing value. P-value represents the difference among the three groups calculated with the chi-square test.

Table 2. Experiences of Study Participants

	n ^a	Total n (%)	Group 1 n (%)	Group 2 n (%)	Group 3 n (%)	P-value
Bully, harassment, or school refusal because of FA	413					p<0.001***
Yes		22 (5.3)	0 (0.0)	3 (2.8)	19 (16.2)	
No		369 (89.3)	180 (94.7)	97 (91.5)	92 (78.6)	
Not sure		22 (5.3)	10 (5.3)	6 (5.7)	6 (5.1)	
Perception of epinephrine auto-injector	413					p<0.001***
Yes		244 (59.1)	78 (41.1)	54 (50.9)	112 (95.7)	
No		160 (38.7)	106 (55.8)	49 (46.2)	5 (4.3)	
Not sure		9 (2.2)	6 (3.2)	3 (2.8)	0 (0.0)	
Participation in a meeting or a seminar for FA	413					p<0.001***
Yes		105 (25.4)	5 (2.6)	11 (10.4)	89 (76.1)	
No		307 (74.3)	185 (97.4)	94 (88.7)	28 (23.9)	
Not sure		1 (0.2)	0 (0.0)	1 (0.9)	0 (0.0)	
Reading a leaflet or a book about FA	412					p<0.001***
Yes		201 (48.8)	40 (21.1)	50 (47.6)	111 (94.9)	
No		198 (48.1)	139 (73.2)	53 (50.5)	6 (5.1)	
Not sure		13 (3.2)	11 (5.8)	2 (1.9)	0 (0.0)	

Group 1 included the caregivers who did not have a child with FA (food allergy) nor had experiences seeing adverse reactions and near miss events to FA. Group 2 included the caregivers who did not have a child with FA and had experiences about seeing adverse reactions and near miss events to FA. Group 3 included the caregivers who had a child with FA.

^aNumber of caregivers without missing value. P-value represents the difference among the three groups calculated with the chi-square test.

***P<0.001.

Figure 1

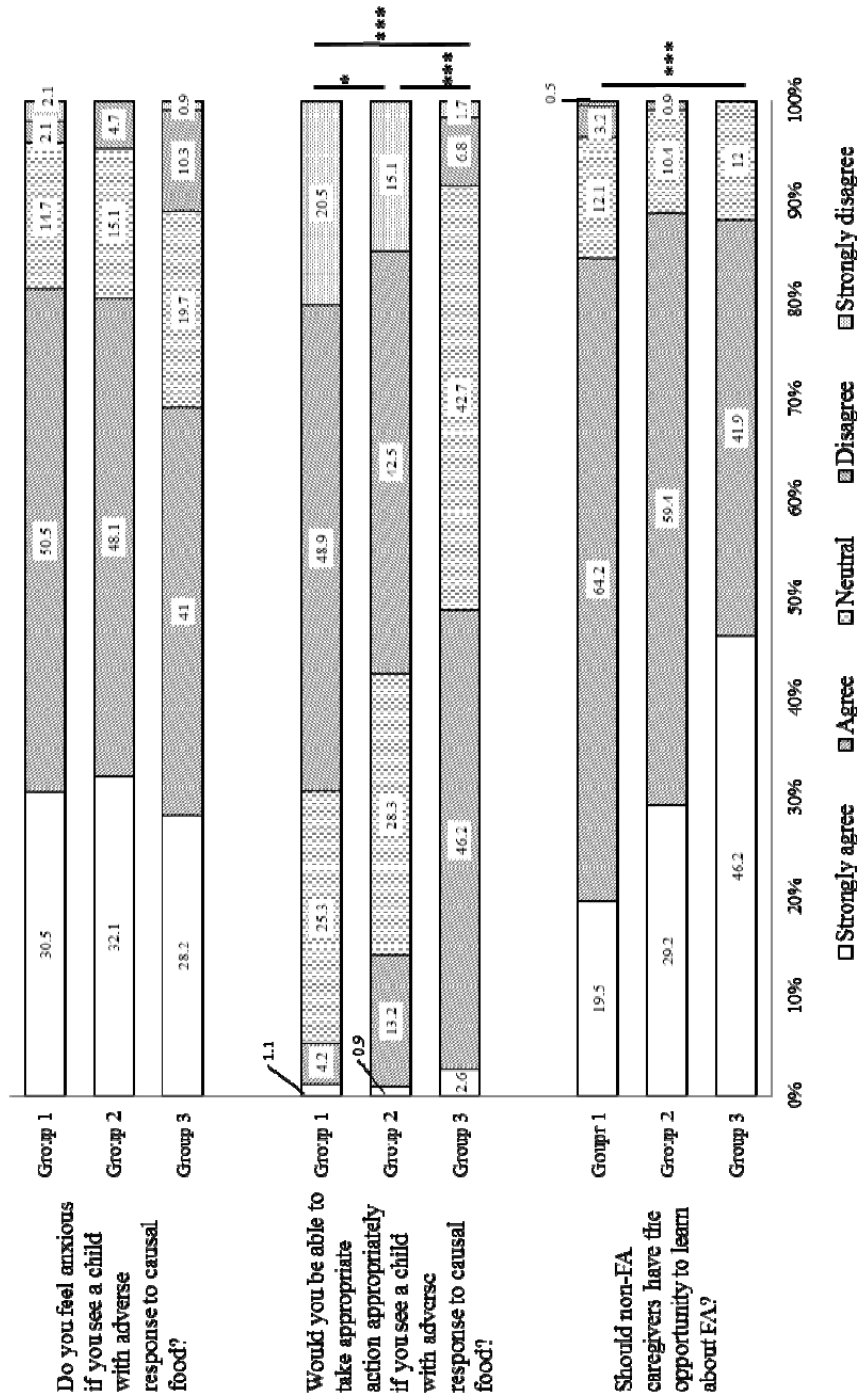


Figure 1. Perceptions of the caregivers for food allergy among the three groups calculated with the Tukey's test. * $P < 0.05$; *** $P < 0.001$.