Article

Child Care Anxiety for Parents of Children with Food Allergies

- From the Questionnaire Survey-

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I. Introduction

The prevalence of food allergy in children has increased over the years (Imai, 2016). Food allergies in children are characterized by the large number of foods that can cause them and the complexity of the symptoms depending on the severity of the condition. The basis of treatment is to wait for spontaneous remission while preventing the appearance of symptoms through the removal of the causative food and general management of life and a comprehensive treatment with a certain amount of evidence has not currently been established. However, with medical advances, treatment methods have changed and diversified. (Ito, 2016). The conventional method of removing all causative foods has mainly been replaced by the elimination of the minimum necessary through appropriate diagnosis based on food stress tests and recently, oral immunotherapies, which are cured by eating, have been widely used. However, oral immunotherapy does not always guarantee a cure and involves risks and burdens. Especially when oral immunotherapy treatment is conducted in an outpatient setting, families, especially mothers who are responsible for food management, feel a great deal of burden and anxiety because of the attention to care and the need to respond appropriately in emergencies, including the use of EpiPen® (an adrenaline auto-injector). In fact, the management of children's life and meals is mainly left to their mothers, and it is said that this burden is heavy (Tatematsu & Ichie, 2008). Also, parents of children with food allergies have been reported to be highly stressed and anxious (Birdi, Cooke & Knibb, 2016). Cohen, Noone, Munoz-Furlong & Sicherer's (2004) evaluation by FAQL-PB (Food Allergy Quality of Life-Parental Burden) showed that the quality of life of parents caring for children with food allergies is low.

Various national and international previous studies on parents of food allergic children have been conducted, and as mentioned above, there are numerous studies on the QOL and burden/anxiety of the parents. However, no study has been conducted to date that provides a broad and comprehensive look at the specific nature and extent of parents' concerns. Furthermore, the anxiety of such parents is presumably dependent on the severity of the allergy and its treatment, and varies according to the child's age and stage of life, such as starting preschool and starting school, but this has not been adequately discussed.

There are few opportunities for professional education, such as workshops and trainings for parents, and the needs of parents are not sufficiently clarified. They receive individualized instructions on diet at the medical institutions they consult,

but the content and amount of instruction varies from institution to institution. It has been reported that some mothers distrust medical care because their treatment may proceed without adequate explanation and guidance (Honma, Tsukahara, Tanabe, Tsubokawa & Wada, 2015). The infant period, when food allergies occur, overlaps with a period of anxiety and stress for many of these parents, and more support is needed to understand the situation and meet the needs of the child. However, support for parents has not yet been established, and it is assumed that many parents raising children with food allergies are worried about their children's well-being. In this study, we will clarify the anxiety felt by parents raising children with food allergies and examine the appropriate and effective support for them.

II. Methods of research

(1) Subjects and Survey Methodology

Using snowball sampling, questionnaires were distributed to 415 parents of children under 15 years of age with food allergies who visited outpatient hospitals and clinics (7 facilities in total) in cities A and B in Aichi and Shizuoka, respectively, and asked to complete the questionnaire through their physicians. Of these, 225 people responded (54.2% response rate). Except for cases where there were many unanswered questions, 214 respondents were analyzed.

(2) Period

February 2019 - December 2019

- (3) Details of data collection
- ① Subject characteristics and background of children with food allergies: 18 items ※If there were more than one child with food allergies, each was asked to respond, and if there were three or more children, responses were asked for the two children with the most severe symptoms.
- ② Status of support (family support, satisfaction and consultation with medical institutions): 4 items
- 3 Child care anxiety: 12 items
- *Respondents were asked to respond on a 5-point Likert scale ranging from "5. Very much" to "1. Not at all".
- ① Level of knowledge about food allergy and means of collecting expert knowledge and information: 8 items
- **Respondents were asked to respond to the extent of their knowledge on a 5-point Likert scale from "5. Very much" to "1. Not at all".
- ⑤ Confidence in raising a child with food allergies: 10 items
- **Respondents were asked to respond on a 5-point Likert scale from "5. Very confident" to "1. "Not at all confident".

6 Attendance at food allergy workshops and training sessions and needs: 9 items

The questionnaires were prepared with the advice of an allergist and several researchers to ensure validity and reliability. After conducting a preliminary survey and making a number of revisions, this survey was conducted.

(4) Analytical methods

Of the data obtained, simple tabulation was used for the selective questions and descriptive statistics were processed. The data obtained from the free descriptions were analyzed by semantic content and organized on the basis of similarity. An analysis of variance was also performed for two factors, the age of the child and whether or not the child had experienced anaphylaxis, as well as for each anxiety.

(5) Ethical considerations

After obtaining approval from the Research Ethics Committee of Toyohashi Sozo University (Approval number: H2018007). Physicians at the hospitals and clinics that requested the distribution of the questionnaire were explained the purpose of the study and ethical considerations (If approval from the institution's research ethics committee was required to conduct the study at the hospital, an application for research ethics review of the institution was submitted, and approval was obtained in advance). The subjects were informed in writing of the purpose of the study, free and voluntary participation in the study, protection from disadvantage, adherence to anonymity, etc., and that their consent was deemed to be obtained by responding and returning to the questionnaire.

III. Result

(1) Subject characteristics and background of children with food allergies

There were 208 mothers (97.2%) and 6 fathers (2.8%), with a median age of 37 years. 169 (79.3%) had a nuclear family and 44 (20.7%) had an extended family (Table 1). The highest number of children with food allergies was 192 (89.7%) with one child, 21 (9.8%) with two and 1 (0.5%) with three. Respondents were asked to respond to each of two children with food allergies, and to respond to two children with severe symptoms if there were three or more children. Table 2 shows the status of a total of 236 children with food allergies. The median age of the children was 4 years. The largest number of students were 67 (28.4%), followed by 57 (24.2%) who were not yet enrolled in school. The most common cause of food was eggs in 154 (65.3%), milk in 110 (46.6%), wheat in 43 (18.2%) and peanuts in 40 (16.9%), in that order. Regarding the previous history of anaphylaxis, 45 (19.1%) had a history of anaphylaxis only once and 52 (22.0%) had more than once. Sixty-nine respondents (29.2%) owned adrenaline self-injection. Eighty-eight parents (41.1%) had experienced anaphylaxis of their children.

Table 1. Characteristics of the subjects.

Age(n=155)	37 (Median value)		
	24-51 (Range)		
		number of persons	%
Relationship	Mother	208	97.2
	Father	6	2.8
Number of children with food allergies	1 child	192	89.7
(n=214)	2 children	21	9.8
	3children	1	0.5
Family composition (n=213)	Nuclear family	169	79.3
	Extended family	44	20.7
Previous experience with anaphylaxis	Experience.	88	41.1
(n=214)	No experience	126	58.9

(2) Family support, satisfaction with medical facilities and consultation

138 respondents (64.5%) said they would get "very much" support from their families. Fifty-five respondents (25.7%) said they would "get a little bit of support", and about 90% said they would get support. About 90% of respondents were satisfied with their medical institution, 134 (62.6%) who were "very satisfied" and 56 (26.2%) who were "a little satisfied". Regarding the status of consultation with medical institutions, 169 respondents (79%) said "they were able to consult sufficiently". And thirty-four respondents (15.9%) said "they were available for a little consultation", and more than 90% said they were available for consultation.

(3) Anxiety about raising children

Table 3 shows the average values for each item of anxiety. The mean values were 3.99 (SD=1.01) for anxiety about accidental feeding, 3.97 (SD=1.13) for anxiety about how to respond to the appearance of serious symptoms, 3.96 (SD=1.09) for anxiety about how to respond in case of disaster, and 3.94 (SD=1.06) for anxiety about the future progress, the mean were higher in order. On the other hand, the items with a mean value of less than 3.0 were anxiety about the child's interpersonal relations 2.92 (SD=1.35), anxiety about diagnosis and testing 2.71 (SD=1.13), and anxiety about the implementation of the indicated treatment 2.63 (SD=1.13).

Table 2. Background of children with food allergies

n=236

Age	4 (Median value) 0-15 (Range)		
		number of persons	%
Starting pre-school/starting school	Pre-school	57	24.2
	Nursery	45	19.0
	Kindergarten	36	15.2
	Children's kindergarten	14	6.0
	Elementary school	67	28.4
	Junior high school	13	5.5
	Others	4	1.7
Foods of cause	Egg	154	65.3
(Multiple answers)	Milk	110	46.6
	Wheat	43	18.2
	Peanuts	40	16.9
	Fruit	26	11.0
	Fish roe	20	8.5
	Buckwheat noodles	20	8.5
	Walnut	18	7.6
	Almond	7	3.0
	Cashew nuts	7	3.0
	Soya bean (sovbean)	7	3.0
	Crustaceans	7	3.0
	Others	25	10.6
History of anaphylaxis	Yes (once)	45	19.1
	Yes (More than once)	52	22.0
	None	139	58.9
EpiPen (adrenaline self-injection)	Yes	69	29.2
prescription	None	167	70.8

We also performed an analysis of variance for two factors, the age of the child and the experience of anaphylaxis or not, as well as for each anxiety (Table 4). The age of the children was classified into two categories: parents with infant children and parents with post-school-age children (parents with two or more children with food allergies were

classified as post-school-age if one of the children was school-age or older, and otherwise as infants and toddlers, given the parents' experience in caring for their children depending on the age of the children). The results showed that there was no interaction of the two factors for 11 items except for anxiety about cooperation and coordination with the preschool and school. A simple main effect test was performed on the 11 items that did not show an interaction. As a result, parents' anxiety due to the age of their children was about two items: anxiety about food preparation and management, and anxiety about future progress, and parents with children with food allergies in infancy had significantly higher average levels of anxiety.

Parents with previous experience of anaphylaxis tended to have significantly higher mean values of anxiety for a total of eight items: anxiety about accidental feeding, anxiety about how to respond to the emergence of serious symptoms, anxiety about how to respond to disasters, anxiety about the future progress of the disease, anxiety about the emergence of serious symptoms, anxiety when eating out, anxiety about the influence on the child's development, and anxiety about the child's interpersonal relationships.

An analysis of variance between the two factors of the child's age and whether or not the child had experienced anaphylaxis and anxiety about cooperation and coordination with the preschool and school showed a significant interaction (F (1, 20) = 4.31, p < 0.05). Since the interaction was significant, a simple main effect test was performed. As a result, simple main effect was significant depending on whether or not the child has an regarding anxiety about coordination and cooperation with pre-schools and schools,

Table 3. Child care anxiety

n=214

Item	Average value (SD)
Anxiety about accidental eating	3.99(1.01)
Anxiety of dealing with serious symptoms when they appear	3.97(1.13)
Anxiety about disaster response	3.96(1.09)
Anxiety about the future progress of the disease (whether it will be cured or not)	3.94(1.06)
Anxiety about the appearance of serious symptoms	3.84(1.11)
Anxiety when eating out	3.83(1.12)
Anxiety about coordination and cooperation with preschools and schools	3.63(1.12)
Anxiety about meal preparation and management	3.26(1.19)
Anxiety about the influence on children's development	3.05(1.29)
Anxiety about children's interpersonal relationships	2.92(1.35)
Anxiety about diagnosis and testing	2.71(1.13)
Anxiety about the implementation of the indicated treatments.	2.63(1.13)

Table 4. Results of analysis of variance between children's age and experience of anaphylaxis and each anxiety

	Experies anaph	nce with	No experience with anaphylaxis		Main Effect	_	
	Infants (n = 42)	After school age (n = 46)	Infants (n = 99)	After school age (n = 27)	Child's age	Experience with anaphylaxis	Interaction
Item	Average value (SD)	Average value (SD)	Average value (SD)	Average value (SD)	p value	p value	F value (degree of freedom) p value
Anxiety about accidental	4.36	4.33	3.75	3.67	n.s.	**	0.31(1,20)
eating	(0.79)	(0.82)	(1.09)	(1.07)			n.s.
Anxiety about dealing with serious symptoms when they appear	4.33 (0.95)	4.24 (0.90)	3.75 (1.24)	3.73 (1.15)	n.s.	**	0.05(1,20) n.s.
Anxiety about disaster	4.26	4.52	3.68	3.48	n.s.	**	1.96(1,20)
response	(0.86)	(0.78)	(1.17)	(1.05)			n.s.
Anxiety about the future progress of the disease (whether it will be cured or not)	4.31 (0.84)	3.93 (1.04)	3.93 (1.09)	3.42 (1.14)	*	*	0.17(1,20) n.s.
Anxiety about the appearance of serious symptoms	4.40 (0.83)	4.09 (1.03)	3.57 (1.15)	3.54 (1.14)	n.s.	**	0.79(1,20) n.s.
Anxiety when eating out	4.36 (0.69)	4.22 (0.87)	3.62 (1.17)	3.15 (1.29)	n.s.	**	1.06(1,20) n.s.
Anxiety about coordination and cooperation with preschools and schools	3.73 (1.00)	3.93 (1.00)	3.58 (1.17)	3.08 (1.16)	n.s.	**	4.31(1,20) **
Anxiety about meal preparation and management	3.55 (1.17)	3.15 (1.21)	3.33 (1.20)	2.74 (1.23)	*	n.s.	0.30(1,20) n.s.
Anxiety about the influence on children's development	3.17 (1.30)	3.37 (1.32)	2.98 (1.27)	2.54 (1.17)	n.s.	*	2.63(1,20) n.s.
Anxiety about children's interpersonal relationships	3.45 (1.23)	3.28 (1.29)	3.28 (1.29)	2.31 (1.29)	n.s.	**	0.24(1,20) n.s.

Anxiety about diagnosis	2.74	2.72	2.70	2.69	n.s.	n.s.	0.00(1,20)
and testing	(1.08)	(1.09)	(1.19)	(1.12)			n.s.
Anxiety about the	2.00	2.00	0 71	0.50	n.s.	n.s.	0.05(1.00)
implementation of the	2.68	2.80	2.51	2.70			0.05(1,20)
instructed treatment	(1.23)	(1.17)	(1.07)	(1.10)			n.s.

*: p < 0.05, **: p < 0.01

the anaphylaxis experience when he or she is older than school age (F(1, 20) = 10.07, p<0.01) and the average score of anxiety was higher for those who had experienced anaphylaxis than for those who had never experienced it. The simple main effect (F(1, 20) = 4.25, p<0.05) was also significant at the age of the children with no previous experience of anaphylaxis, and the average score of anxiety was significantly higher for infants and toddlers than for children of school age and beyond. In other words, if the child has a history of anaphylaxis, there is an increased anxiety about coordination and collaboration with the school when the child is a school-age child and beyond, as compared to being an infant.

(4) Level of knowledge about food allergies and means of collecting specialized knowledge/information

The percentage of knowledge associated with each food allergy is shown in Table 5. The average values were higher for the following categories: food allergy as a disease 4.20 (SD=0.68), how to read processed food allergy labels 4.00 (SD=0.90), and how to treat food allergy 3.98 (SD=0.64). On the other hand, the average response to disasters was 2.74 (SD=1.09). Regarding knowledge of EpiPen use, only parents with children prescribed an EpiPen (n=65) were asked to respond, with an average of 4.65 (SD=0.48). When respondents were asked to selectively answer the means of collecting expertise and information (multiple responses n=211), the most common response was "Ask the doctor" (199 respondents, 94.3%), followed by "Look it up on the Internet" (151 respondents, 71.6%). The smaller percentage of respondents were 24 (11.4%) who participated in "workshops and training sessions" and 3 (1.4%) who "participated in parents' meetings".

(5) Confidence in raising a child with food allergies

Table 6 shows each degree of confidence in raising a child with food allergies The average score for confidence was higher in the following order: preparing and managing meals 3.70 (SD=0.97), consulting a health care provider 3.69 (SD=0.77), and implementing the indicated treatment 3.68 (SD=0.83) On the other hand, the average values for confidence in responding to disasters were lower than the other items for 2.58 (SD=0.97) and 2.83 (SD=1.16) in responding to the appearance of serious symptoms.

Table 5. Knowledge related to food allergies

n=214 (only for those who have knowledge about how to use EpiPen n=65)

Item	Average value (SD)
How to use EpiPen	4.65(0.48)
Disease called food allergies	4.20(0.68)
How to read processed food allergy labeling	4.00(0.90)
How to treat food allergies	3.98(0.64)
What to do when serious symptoms appear (emergency)	3.76(1.08)
Cooking according to the degree of removal	3.29(1.15)
Response in case of disaster	2.74(1.09)

Table 6. Confidence in raising a child with food allergies

n=214

Item	Average value (SD)
Meal preparation and management	3.70(0.97)
Consultation with medical professionals	3.69(0.77)
Implementation of treatment as instructed	3.68(0.83)
Coordination and cooperation with preschools and schools	3.45(0.93)
Decision of intake when eating out	3.34(0.90)
Consultation with others	3.30(0.88)
Explaining to children	3.26(0.97)
Dealing with an accidental eating mistake	3.16(0.99)
Dealing with emergence of serious symptoms	2.83(1.16)
Dealing with disasters	2.58(0.97)

(6) Participation status and expectations in workshops and seminars

Sixty-one (28.5%) had ever attended a study session or workshop on food allergy. Regarding future participation, 149 (69.6%) respondents indicated that they would like to participate in the future, with 114 (76.5%) reporting on specific methods of food management, 113 (75.8%) on what to do in the event of a wrong food intake, 112 (75.2%) on what to do in the event of a disaster, 107 (71.8%) on general knowledge of food allergies, 105 (70.5%) on emergency Countermeasures were requested.

IV. Consideration

(1) Child care anxiety for parents

Although parents have a variety of anxiety about raising a child with food allergies, anxiety about accidental eating had the highest average score compared to the other items. For children, meals not only supply the energy and nutrients necessary for life

and daily activities, but also play an important role in promoting physical and mental growth and development, and are fundamental to daily life. Therefore, children are exposed to food on a daily basis at home, outside, at preschool, school, and many other places. However, for children who are allergic to food, this can be a potentially life-threatening aspect of their lives. Especially the younger a child is, the less he or she is able to fully understand what is dangerous to him or her, and it is impossible for him or her to avoid it on his or her own. There are also times when the unexpected happens in the lives of siblings and friends, no matter how careful the adults are. In this situation, we believe that anxiety about accidental eating is an ever-present anxiety for parents raising children with food allergies. Also, food allergies should be treated with extreme caution, as symptoms can occur even after intake of a small amount of the offending food, or depending on the physical condition of the day, can be triggered by the amount of food that should be safe to consume. In the midst of these constant dangers of everyday life, parents are likely to be over-sensitive and highly anxious.

The average level of anxiety about dealing with serious symptoms when they appeared was also higher than the other items. Symptoms of food allergy can present with cold-like symptoms, and there is a great deal of individual variation in the type and degree of symptoms that appear (Ito, 2016). Since children cannot accurately report symptoms on their own, objective information must be used to determine whether or not they are allergic. Furthermore, children are also characterized by a rapid progression of worsening symptoms, which requires an appropriate response. In particular, if anaphylaxis occurs, it can be fatal, so a quick response is required. However, the response is not an easy one, and it requires a high level of knowledge and skill to respond calmly in a tight situation. Ogg, Wong, Wan, Davis & Arkwright (2017) reported that parents' anxiety is increased when their child has a history of anaphylaxis. The results of this study also showed that anxiety about the appearance of symptoms and anxiety about how to respond when symptoms appeared was significantly higher among parents who had experienced anaphylaxis in the past. The fact that they had overcome such experiences in the past did not inspire confidence in their parents, but rather created fear that it would happen again, revealing the reality that they were living with a strong sense of anxiety.

The average value of anxiety about the future progress was 3.94, which was higher than the other items. Parents caring for infants and toddlers in particular tended to be significantly more anxious about the future progress of their children. A fundamental cure with evidence for the treatment of food allergies have not yet been established. As they age, they may be cured, and a certain number may continue into school age and beyond. It is also not uncommon for people to develop allergic reactions to new foods or to develop other allergies, such as an allergy march. Parents are likely to be anxious about when their child's allergies will be cured, and vaguely worried about how long this burdensome and unsettling situation will continue.

(2) Children's age, experience of anaphylaxis and association with anxiety

It was found that each degree of anxiety varied depending on the age of the child with food allergies and the experience of whether or not the child had ever had anaphylaxis. Depending on which life stage your child is in, the situations and circumstances they face will differ. Infancy is a time of food expansion as a result of the transition to baby food, and it is not easy to adapt food management to the treatment of food allergies. Therefore, we believe that parents feel a strong sense of anxiety in the process of exploring and managing the meals. Also, treatment of food allergies takes a long time, sometimes showing the state of keeping getting better and worse again. This makes it difficult for children of a younger age to realize the benefits of treatment shortly after it is initiated. Faced with this kind of reality with no way out, they tend to feel anxiety with no hope for the cure.

In addition, parents who had experienced anaphylaxis had a strong range of anxieties towards those who had not. Experience with anaphylaxis often means that the child's food allergies are severe. As such, many things require a more cautious handling. Furthermore, it can be inferred that parents who have had a life-threatening experience are always irritable, fearing that the experience will be repeated again. The results of the analysis of variance also showed clearly that a history of anaphylaxis tends to increase the anxiety about coordination and collaboration with the school as the child goes to school. When there is a history of anaphylaxis, there will be a need to coordinate with the school on a variety of matters, such as the management of the EpiPen and an appropriate and prompt response to an emergency. Coordination is also essential for emergency response. Whether or not that coordination and collaboration is made smooth depends on the acceptance and perceptions of the school, and furthermore, the actual response must be left to the school. Guidelines for dealing with children with food allergies at school have been prepared, but the response differs from one municipality to another and from school to school. In this situation, parents have to pay attention to many different things, and it is presumed that their anxiety has not been relieved

(3) About support for parents

As described above, parents raising children with food allergies are living with a variety of anxieties, and there is an urgent need to provide support for parents to reduce the psychological burden. There are various ways to provide support, but in order to alleviate a wide range of anxieties, we believe it is useful to focus on the specific anxieties that parents hold most strongly. Particularly, while anxiety about how to respond to the appearance of symptoms was high, the level of knowledge and confidence was lower than the other items. It can be assumed that this anxiety about how to respond to the appearance of symptoms is also related to the ambiguity of recognition of what kind of symptom should appear in a child and how to deal with it.

Although the providing of knowledge is not necessarily the only way to reduce anxiety, as stated by Aika, Ito & Yamamoto (2014), the acquisition of knowledge and skills is necessary to improve coping skills to determine the symptoms of food allergy and respond appropriately, which can lead to improved confidence and reduced anxiety. Similar results were observed for anxiety, knowledge and confidence in responding to disasters, which suggested that the provision of knowledge is important. Moreover, the results of this survey show that less than 30% of parents participate in workshops and training sessions, and about 70% of parents indicated that they would like to attend such meetings, which suggests that opportunities to provide correct information directly are necessary. In addition, when supporting parents, we believe it is important to take into account the characteristics of each child's situation, as the degree of anxiety varies according to the age and severity of the child's disease.

V. Limits of study

This study was conducted in a limited geographical area and the subjects were recruited through the opportunity method. Therefore, generalizability is limited, and it is necessary to broaden the scope of the survey and to conduct interviews and other surveys in order to find out more about what kind of anxiety the respondents had and at what period of time.

VI. Thanks

We would like to express our deepest gratitude to all the parents who participated in this survey. We would also like to thank Dr. Mitsuhiro Nishida of Hamamatsu Medical Center and Dr. Osamu Natsume of Hamamatsu University School of Medicine for their guidance and cooperation in the preparation of the questionnaire and other aspects of this study, as well as many other people who have helped us.

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Child Care Anxiety for Parents of Children with Food Allergies

- From the Questionnaire Survey-

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A questionnaire survey was conducted with the aim of clarifying the anxiety of parents caring for children with food allergies. Parents had a variety of anxieties, but they were particularly concerned about what to do in the event of accidental eating and the appearance of serious symptoms, and about how to respond in the event of disasters. On the other hand, children tended to have lower levels of anxiety about interpersonal relationships, diagnoses and tests, and treatment implementation than the other items.

Analysis of the relationship between the age of the child and whether or not the child had experienced anaphylaxis and each of the anxiety categories showed that parents with children in infancy were significantly more anxious about two items: food preparation and management and anxiety about the future progress of the child compared to those in school age and thereafter. Parents with previous experience of anaphylaxis tended to be significantly more anxious than those with previous experience of anaphylaxis for a total of eight items, including anxiety about accidental feeding and anxiety about how to respond to serious symptoms when they appeared. These results clearly showed that parents caring for children with food allergies are living with a variety of anxiety and suggested the need for support for parents to reduce the psychological burden of their children. The degree of allergy severity varies depending on the age of the child and the severity of the allergy, so we believe that measures must be adapted to each individual situation.