

A survey of patients with self-reported severe food allergies in Japan

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Food allergies have increased in recent years in Japan. Details of causative foods, places where anaphylaxis developed, and other allergic factors remain unknown, and we investigated them. A 'questionnaire survey for the prevention of food allergies' was conducted using a nationwide group of patients with food allergies. A total of 1383 patients from 878 families (including 319 patients who experienced anaphylaxis) provided valid answers to the questionnaire. The average age of the first anaphylactic attack was 3.20 ± 6.327 yr. The most common allergens causing anaphylaxis were in order milk, eggs, wheat, peanuts, and soybeans, followed by sesame and buckwheat. The most common place where anaphylaxis developed was the patient's own home, followed by fast food restaurants, places visited, restaurants, and schools. In patients' own homes, fast food restaurants (buffet), places visited and schools, the most common allergens were milk, eggs, and wheat. In restaurants and accommodation facilities, eggs were the most common allergen followed by milk. As possible food allergies can cause anaphylaxis, it is necessary to provide precise information for consumers regarding packaged and processed foods.

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Introduction

Surveys of allergens can cause food allergies, and food allergies can cause anaphylaxis have been conducted in Japan (1–3). In Europe and in the United States, some studies have investigated the mechanisms and substances that cause food allergies (4–17), but there is no study of the behavioral patterns of patients. Thus, examination of factors such as modes of sale of allergy-inducing foods, places where symptoms develop, and treatment measures may be beneficial for the prevention of problems related to allergies.

Materials and methods

A survey for prevention of food allergies was conducted by sending questionnaire forms to 1510 families affiliated with the allergy nation-

wide network, a nationwide group of patients with food allergies.

The survey was conducted between 1 and 31, July 2003. The questionnaire was designed to be answered on behalf of the whole family. The survey questioned families about allergic symptoms that had developed in family members who had experienced food allergies, and about allergens. When family members had experienced anaphylaxis, one or two members of each family were asked to indicate up to three allergens that caused anaphylaxis, and the places where anaphylactic symptoms developed. In Japan, an allergen labeling regulation was introduced in 2002 in line with the food sanitation law. The present study was conducted just after the introduction of this labeling system.

Contents of the questionnaire

The questionnaire could be divided into two parts:

(i) Questions for patients with food allergies

Patients who had experienced anaphylaxis were asked the following questions: At what age did you first develop anaphylactic shock? What were the allergens that caused anaphylaxis? Where did the symptoms of anaphylaxis develop? What was the treatment given for anaphylaxis and did it include hospitalization? Did the doctor diagnose food allergy? What were the symptoms?

(ii) Questions for patients and their families regarding food buying behavior: Which ingredients listed on the label prevented you and your family from buying a product? Did you notice a relationship between the price of the food and the number of items listed on the label? Did this influence your buying behavior?

Results

From this questionnaire survey, responses were obtained from 878 families (response rate: 58.1%) with 1403 patients nationwide. However, as 20 responses did not have adequate answers, the total number of valid surveys was for 1383 patients. Valid patients included 778 males and 529 females (gender was unknown for 76 patients). Average patient age was 11.25 yr (range, 0–93 yr). 5 yr old was the most frequently recorded age. The average number of food ingredients causing allergies was five per person and the total number of allergens was 6906.

Survey of anaphylaxis patients

A total of 453 patients who had suffered from anaphylaxis were covered in the responses to the questionnaire. Patients were then narrowed down to 319 analytical subjects (212 males, 101 females and 6 unknown gender) who were diagnosed as having a food allergy by a doctor and had experienced any of the symptoms of anaphylaxis, including wheezing, hypotension, dyspnea, and loss of consciousness.

Average age at first experience of the anaphylactic attack and for diagnosis was 3.20 ± 6.327 yr ($\pm$ s.d.) (range, 0–42 yr) (Table 1). The most frequent age for an attack was less than 1 yr of age. The average number of allergens that caused anaphylaxis was 2.46 per person. Therefore, we listed a total of 785 ingredients as allergens causing anaphylaxis.

Table 1. Age of first onset of anaphylaxis in patients who were diagnosed as having a food allergy by a doctor and reported that they experienced the symptoms of anaphylaxis – data from 1383 members of the Allergy Patient Group in Japan

Age	Number	%
< 1 yr	80	25.1
1 yr	72	22.6
2 yr	52	16.3
3 yr	34	10.7
4 yr	22	6.9
5 yr	16	5.0
6 yr	2	0.6
7 yr	10	3.1
8 yr	4	1.3
9 yr	1	0.3
10–19	7	2.2
20–29	1	0.3
30–39	4	1.3
40–	4	1.3
Unknown	10	3.1
Total	319	100.0

The number of anaphylaxes experienced by a patient was not investigated.

We gathered information on allergens that caused anaphylaxis from 319 people. Some of these people had multiple food allergies, hence the number of anaphylactic cases. At the time of the survey, some patients were seeking a definitive diagnosis from a medical specialist. Foods that caused anaphylaxis were milk, eggs, wheat, peanuts, soybeans, sesame, and buckwheat (Table 2). Eight-five patients had one causative agent and 72 had two.

Many respondents experienced several types of anaphylaxis symptoms, and so provided us multiple answers. A total of 319 respondents

Table 2. Allergens related to self-reported anaphylaxis in Japan

Allergen	Number	Percentage of study patients (319 patients) (%)
Milk	221	69.3
Eggs	144	45.1
Wheat	92	28.8
Peanuts	27	8.5
Sesame	25	7.8
Kiwi fruit	13	4.1
Soybean	13	4.1
Buckwheat	11	3.4
Shrimps	9	2.8
Walnuts	9	2.8
Gelatine	9	2.8
Bananas	9	2.8
Salmon roe	7	2.2
red sea bream	6	1.9
Tuna	5	1.6
Others	119	37.3
Unknown	66	20.7
	785	

experienced symptoms and the total number of symptoms recorded was 1530. Two patients had only one symptom. There was a mean of 4.8 symptoms per patient.

With regard to anaphylactic treatment and time required for improvement, 228 of 319 cases (71.5%) with total anaphylaxis required a hospital visit; 182 cases (57.0%) visited the hospital on their own or accompanied by others, and 46 cases (14.4%) were transferred to hospital by ambulance. Of the other 72 cases, 37 cases (11.6%) required no medical treatment, and 35 cases (11.0%) used unperceived medicine; no information was available in 19 cases. With regard to hospitalization, responses for 208 of the 319 patients were – 45 patients (21.6%) had been hospitalized and 163 (78.4%) responses covered people who had not been hospitalized. The leading causes of hospitalization due to allergens causing anaphylaxis were in order: milk, eggs, and wheat.

Patients indicated that anaphylaxis occurred at their own home, at fast food restaurants, at a place visited, at restaurants (buffet), and at schools (Fig. 1).

Survey of patients and their families regarding food buying behaviors

To clarify how buying behaviors of patients with food allergies and of their families might be related to descriptions on food labels that assisted food choice, and to investigate changes in food prices resulting from improvements of descriptions on labels, we conducted a survey.

Eighty percent of patients and/or their families answered that they would not buy products when allergens were present in the list of ingredients, at least when labels suggested the use of allergens, or when labels indicated the use of even minute amounts of allergens. Moreover, 644 families (75.7%) answered that they would not purchase a product indicating the presence of several allergens.

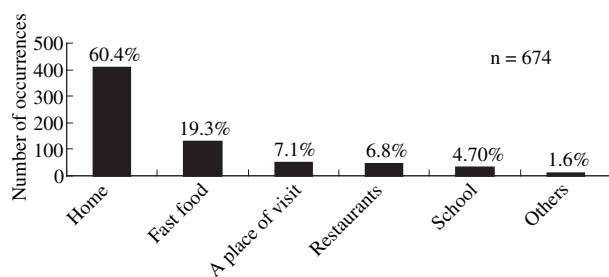


Fig. 1. Place of onset of self-reported anaphylaxis in Japan.

As well, 548 families (66.4%) answered that they would not purchase products with labels indicating the use of allergens on the same production line; 294 families (34.5%) answered that they would not purchase products that indicated the use of allergens in the same factory, and 191 families (22.4%) answered that they would not purchase products that indicated the use of allergens even on a different production line. These results suggested that detailed information of the constituents of products could influence the range of products available for purchase by patients affected by allergies.

It is possible that requests by allergic patients and other concerned people for more details on labels could lead to a rise in costs. A total of 324 families (37.5%) answered 'I will buy for sure' if the label was more substantial, five families (0.6%) answered 'I won't buy anyway,' 458 families (52.2%) answered 'according to the price,' and 77 families (8.8%) answered 'I don't know.' This indicated that more detailed labels would probably affect buyers' behaviors.

Discussion

Recent surveys have shown that the incidence of food allergies varies according to region and age; food allergies affect 2–10% of the population (3, 15). It is also assumed that anaphylaxis occurs in approximately 1–3 individuals per 10,000 people (12, 13), and the most common cause is food allergies (14). Mortality from food allergies is 0.006 individuals per 100,000 children in the UK (13), while 150–200 individuals die from food allergies every year in the USA (10).

In Japan, the most common allergen involved in anaphylaxis is milk, followed by eggs and wheat in order of frequency; whereas in the USA, peanuts are the most common allergen, followed by eggs, fruit/vegetables, wheat, and cow milk (10). The French Allergy Vigilance Network survey conducted by Moneret-Vautrin et al (16) in France, demonstrated that peanuts, nuts, shellfish, lupine flour, and wheat flour were the main allergens in severe anaphylaxis. Thus, it is fair to conclude that allergens vary by region. With regard to food allergies, causative foods for anaphylaxis are different from those for food allergies. Allergens responsible for food allergies and allergic symptoms have been surveyed (1–12). However, our survey was unique and different from those surveys as it included the investigation of the modes of sale of foods that cause allergy, and the locations where symptoms first develop.

Results of the present survey demonstrated that the most common place of occurrence of anaphylaxis was in the patient's home, followed by fast food restaurants, places visited, restaurants (buffet), and schools. Despite the well established Japanese school meal system and the opportunities to eat school-provided meals, the occurrence rate of food allergies as regards school lunches was low. This may have resulted from measures taken against food allergies at schools, and this could have been associated with the higher percentage of kindergarteners among those noted in the responses to our questionnaire. Anaphylaxis frequently occurs in fast food restaurants, from foods sold in shops, restaurants (buffet), and others. This may be due to inadequate measures against food allergies in these places, suggesting the need for future measures directed at such places.

In Japan, a food allergy labeling system began in 2001. As a result of this, information is to be provided to consumers, including those with allergies, patients and their families, through food labeling (18–20). This system prohibits the indication of possibilities such as 'Allergens may be contained.' Thus, we conducted a survey of the relationship between food labeling methods and patients' understanding level. We found that food allergy patients interpret: 'Allergens are registered in the list of ingredients,' 'Indication of the use of minute amounts of allergens (ex. This product contains minute amounts of eggs/milk)' and 'Indication of the mixed presence of allergens (ex. It can't be denied the probability that this product may contain eggs)' in almost the same way. However, accurate food allergy indications cost a lot of money for a retrospective survey of raw materials, label revision, etc. Even if the cost is added to the product price, 90% or more families expressed their willingness to buy the product, but this depended on the price. Food labels are an important information source for food allergy patients to safely select foods. Appropriate methods of expression are needed to clearly indicate the product constituents and to improve future food labels system.

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Author contributions

T. Imamura, Y. Kanagawa and M. Ebisawa jointly conceived the idea for the study. T. Imamura and Y. Kanagawa analyzed the data and all authors interpreted the results. T. Imamura and Y. Kanagawa drafted the manuscript. All authors revised the paper and approved the final version.

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