

Short Communication

An internet-based survey on the circumstances of food-induced reactions following the diagnosis of IgE-mediated food allergy

Background: Despite careful avoidance measures, food allergic patients have a significant risk of anaphylactic episodes. Risk situations need to be identified for more efficient preventive measures.

Methods: Responders to an internet-based survey on the awareness of food anaphylaxis were invited to relate the circumstances of their most severe reaction following the diagnosis of IgE-mediated food allergy. Items of the questionnaire included the circumstances of the reaction and the treatment, as well as questions related to reactions occurring at specific categories of sites (i.e. home, schools, or restaurants).

Results: Fifty-one of the returned questionnaires (34.1%) corresponded to the study criteria. The median age of the subjects was 7 years (range 0.5–61), with 33/51 (64.7%) being less than 16 years of age. Reactions were reported to peanuts (24/51; 47.1%), milk (12/51; 23.5%), tree nuts (6/51; 11.8%), fish and shellfish (5/51; 9.8%), and others (3/51; 5.8%). Reactions occurred at home (13/51; 25.5%), in restaurants (9/51; 17.6%), at school or daycare or kindergarten (8/51; 15.7%), at a relative or friend's home (7/51; 13.7%), at sites of leisure activities (6/51; 11.8%), at work (3/51; 5.9%), in church or a hospital ward (2/51; 3.9% each), or in a food store (1/51; 2.0%). In severe reactions (37/51; 72.5%) epinephrine was administered in 28/37 (75.7%) of the responders. Finally, while most reactions happened after ingestion of the food (40/51; 78.4%), others were reported after skin contact exclusively (8/51; 16%), or after inhalation (3/51; 5.9%).

Conclusion: Food induced-anaphylaxis in patients aware of their allergy happens most often at sites considered as safe (i.e. home, schools, workplace, hospitals). Better strategies to avoid accidental reactions include clear labelling of forbidden foods and increased information at all levels. These might dramatically reduce the risk of food-induced anaphylaxis in food allergy sufferers.

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Key words: anaphylaxis; epidemiology; epinephrine; food hypersensitivity; home; human; internet; restaurant; school.

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Accepted for publication 2 January 2002

Foods are one of the leading identifiable causes of anaphylactic reactions (1, 2). Extrapolations from epidemiological data suggest that there are approximately 29 000 episodes of food-induced anaphylaxis in the USA, with an estimated 150 fatalities per year (3). In the last decade, anaphylactic reactions to foods have been identified as a major health problem, with a large impact of food avoidance on daily life (e.g. in schools) and the constant risk for potential reactions (4).

The prevention of accidental ingestion relies mostly on adequate counselling by physicians and lay organizations. The patients (or their parents) will be provided with instructions to take adequate measures in various risk situations to avoid exposure to the food. They will also be provided with medication for emergency self-treatment in case of an allergic reaction. Identification

of risk situations for food-induced anaphylaxis might allow enhancement of preventive efforts. However, most reports do not specifically analyze the characteristics of reactions occurring after the diagnosis has been established. Recently, Sicherer et al. obtained characteristics for subsequent reactions from a peanut and tree nut registry (5). They noticed that reactions occurring after the diagnosis of IgE-mediated food allergy (6) was established were more common in restaurants, or locations outside the home. Further studies are necessary and need to include allergies to other foods.

The low number of subjects with food-induced anaphylaxis in a given population makes it necessary to consider other means of recruitment for study subjects than by chart reviews, or phone or mail

surveys. The internet is a valuable tool that has so far been only very rarely utilized (7, 8). A first internet-based survey on the management of anaphylactic reactions to foods provided data from a large set of responders (9). For the current study, we re-contacted all participants and asked them to provide further information on the circumstances of the most severe reaction following the diagnosis of IgE-mediated food allergy.

Methods

The first survey on the management of anaphylactic reactions was conducted from August 1999 to April 2000 using an internet-based questionnaire hosted on a world-wide-web site with information on food allergies (10). Potential responders were asked to fill out the survey only when their symptoms were matching the definition of anaphylaxis provided in the text. Symptoms had to include *at least one* of the following: throat and mouth swelling, difficulty swallowing or speaking, difficulty breathing, blood pressure drop, or fainting. For the current survey, responders matching the definition for anaphylaxis to food were contacted by E-mail in May 2001 and were asked to fill out an internet-based questionnaire on their most severe reaction *subsequent* to the diagnosis of IgE-mediated food allergy.

The questionnaire included the following groups of items: personal data, data on the diagnosis of the food allergy, data on the circumstances of the reaction and the treatment given, as well as more specific questions on reactions which happened at schools, restaurants, or at home. The reaction reported was graded as *mild* when redness of skin, itchiness, nausea or vomiting were reported, as *moderate* when there was difficulty of swallowing, swelling of mouth or throat, irregular heart beats, abdominal cramps or three mild symptoms, and as *severe* when there was difficulty of breathing, fainting or three moderate symptoms. At the end of the questionnaire, responders were invited to add any important information to an open-text frame. A second message was sent to the initial study participants who did not respond within two weeks. All data were treated confidentially. The study was reviewed and approved by the Ethical Committee of the Department of Paediatrics.

Results

Two hundred and sixty-four initial study participants were contacted by E-mail. Based on message-delivery failure counts (messages automatically returned), 35 initial study responders did not receive either of the E-mail messages, 32 responders received the message once, and the remaining participants were contacted twice. The overall response rate was 34.1% (78/229) when including all participants contacted at least once. Sixty-four percent (51/78) of the returned questionnaire matched the requirements for this study. Questionnaire exclusion resulted mostly from responders reporting the circumstances of their first reaction, despite clear instructions on the criteria to match to participation to the second study.

The median age of the 51 subjects was 7 years (range: 0.5–61 years) with a female to male ratio of 0.5, and most were less than 16 years old (33/51; 64.7%). The responders were either residents of the USA or Canada

(44/51; 86.3%), Europe (4/51; 7.8%) or Australia (3/51; 5.9%). The median time elapsed from diagnosis to the most severe reaction was 24 months (range: one month to 30 years). The diagnosis was established by an allergist in 34/51 (66.7%) responders, by an internist or a pediatrician in 11/51 (21.6%), by a general practitioner, another physician or by the patient himself in 2/51 (3.9%) each. The diagnosis was confirmed by a positive skin test, blood test or physician-supervised food challenge in 45/49 (91.8%) of the responders. Instructions on how to deal with a new episode of anaphylaxis were given to most responders (45/49; 91.8%). Foods responsible for anaphylaxis were the following: peanuts (24/51; 47.1%), milk (12/51; 23.5%), tree nuts (6/51; 11.8%), fish and shellfish (5/51; 9.8%), navy beans, corn, soy and banana in one case (2.0%) each.

Most responders reacted after ingestion of the food (40/51; 78.4%), while others reacted after skin contact exclusively (8/51; 15.7%), or after inhalation (3/51; 5.9%). Allergic reactions after ingestion occurred after a regular meal (19/37; 51.4%), or a snack (18/37; 48.6%). Severe symptoms were observed in 31/40 (77.5%) reactions after ingestion of the food, and in 3/8 (37.5%) after inhalation. Almost one fourth of the reactions (11/51) were reported after skin contact or inhalation only. Two children were kissed on the cheek: the first child was allergic to milk and was kissed by an adult who had eaten a pizza containing cheese, and the second, allergic to nuts, was kissed by another child who had eaten walnuts. Another reaction happened in a playground due to contact with a football touched by another child who had just eaten fish. Reactions after ingestion or contact with "safe" foods having been contaminated by contact were also reported several times. In a restaurant, shellfish stored next to fish resulted in a very severe reaction in a woman with fish, but no shellfish allergy. Other reports included a reaction to a peanut-free ice-cream stored in a container previously used for peanuts, and a reaction after eating a banana that had been stored next to an open peanut bin. Finally, a fully nursed infant allergic to nuts reacted with swelling of the face, hives and wheezing after her mother inadvertently ate a snack that had been in contact with walnuts.

Oral antihistamines were administered as a first treatment in 21/51 (41.2%), epinephrine in 19/51 (37.3%), another medication in 8/51 (15.7%), or nothing in 3/51 (5.9%) of the reactions. For the treatment of severe reactions, 16/37 (43.2%) received epinephrine as the first treatment, and 28/37 (75.7%) did receive it at all. The first treatment was self-administered or given by a parent in 57.1% (28/49), by a physician or an emergency team in 13/49 (26.5%), by a teacher or a care-giver in 4/49 (8.2%), or by a nonspecified person in 4/49 (8.2%). A total of 32/50 (64.0%) of the responders

Table 1. Specific reactions for each reported site

Site (total number of responders $n=51$)	Number of children (≤ 16 years)	Foods	Severe reactions	Type of event
Home 13 (25.5%)	12/13	Peanut or nut 6/13 Milk 5/13 Fish or shellfish 1/13 Fruit/vegetable 1/13	9/13	Regular meal 6/13 Snack 5/13 Contact 2/13
Restaurants 9 (17.6%)	2/9	Peanut or nut 5/9 Fish or shellfish 2/9 Milk 1/9 Corn 1/9	6/9	Regular meal 3/9 Contact 3/9 Snack 2/9 N/A 1/9
School or kindergarten 8 (15.7%)	8/8	Peanut or nut 5/8 Milk 2/8 Navy bean 1/8	5/8	Contact 3/8 Snack 3/8 Regular meal 2/8
Relative/friend's home 7 (13.7%)	5/7	Peanut or nut 5/7 Milk 1/7 Soy 1/1	5/7	Regular meal 3/7 Contact 2/7 Snack 2/7
Leisure 6 (11.8%)	1/6	Peanut or nut 4/6 Fish or shellfish 2/6	4/6	Snack 3/6 Regular meal 2/6 Contact 1/6 Inhalation 1/6
Work 3 (5.9%)	0/3	Peanut or nut 3/3	3/3	Regular meal 2/3 Snack 1/3
Church 2 (3.9%)	2/2	Peanut or nut 1/1 Milk 1/1	2/2	Regular meal 1/2 Snack 1/2
Hospital 2 (3.9%)	2/2	Milk 2/2	2/2	Regular meal 2/2
Store 1 (2.0%)	1/1	Peanut or nut 1/1	1/1	Snack 1/1

received epinephrine at all. When the medication was given, the median time to the injection was 20 min (range: 1 min to 4.5 h).

The reactions occurred either at home (13/51; 25.5%), in a restaurant (9/51; 17.6%), at school, daycare or kindergarten (8/51; 15.7%), at a relative or friend's home (7/51; 13.7%), during leisure activities (6/51; 11.8%), at work (3/51; 5.9%), at church or during a hospital stay (2/51; 3.9% each), or in a food store (1/51; 2.0%). The type of reactions for each site is listed in Table 1. The sites of reactions were then grouped into two categories. Home, school, daycare, kindergarten, work or hospitals were considered as *safe sites* since adequate instructions could be given to avoid the food with a reasonable time to enforce food avoidance measures, and all other sites were considered as *nonsafe sites*. Around half of the reactions (25 and 26, respectively) occurred at each category of sites. The foods responsible for reactions according to the category of sites are listed in Table 2. The distribution

of reactions classified by severity scores, either mild and moderate, or severe, was similar for each category of sites.

Specific questions were asked for reactions occurring at home/relative or friend's home, in restaurants, or at school/daycare/kindergarten. Processed food products were responsible for 6/20 (30.0%) of the reactions happening at home/relative or friend's home. Contamination during cooking (e.g. with a spoon or a spatula spoiled with food residues) was reported in 4/19 (21.1%) reactions (when this information was available). Insufficient information was also a cause of reaction, a father gave his milk-allergic child a formula made of nonhydrolyzed casein, not knowing that casein is a milk protein. In four cases the child reached the reaction-causing food while unattended. For reactions occurring in restaurants, only 4/9 (44.4%) responders informed the staff of their food allergy. When the staff were informed, none of the responders considered the response or the action taken to be sufficient or adapted. Finally, information and treatment plans were available to the teachers and caregivers of all children who had suffered from reactions at schools or daycare/kindergartens. The parents felt that the instructions were followed correctly by the staff in 7/8 (87.5%). A ban on the food (i.e. peanuts) was enforced in 1/7 schools (14.3%). A self-injectable epinephrine device was available on 5/8 (62.5%) sites. It was used in two children who had severe reactions, and was not used for treating the remaining three reactions reported as moderate. Despite correct information given to the

Table 2. Foods responsible for reactions in sites considered safe (home, school, daycare, work and hospital) and nonsafe (restaurant, leisure, church, store)

Foods (total $n=51$)	Safe site (total $n=26$)	Nonsafe site (total $n=25$)
Peanut ($n=24$)	11 (42.3%)	13 (54.2%)
Milk ($n=12$)	9 (75.0%)	3 (25.0%)
Tree nuts ($n=6$)	3 (50.0%)	3 (50.0%)
Fish and shellfish ($n=5$)	1 (20.0%)	4 (80.0%)
Others ($n=4$)	2 (50.0%)	2 (50.0%)

children's caregivers, there were some reports of inadequate responses to reactions by the school staff. One father had to rush to the school to administer the first treatment. A mother insisted on giving epinephrine for throat symptoms, which was refused by the school nurse and the pediatrician consulted over the phone. A visit to the allergist was necessary to have a signed action plan authorizing epinephrine for respiratory symptoms. In one patient, despite the fact that the child did not directly touch the food, a severe reaction occurred when food containing nuts was brought in by a chef for a "food exploration class".

Discussion

In patients with food allergy, constant care for adequate food avoidance is required. Not only during regular meals, but also during daily activities where foods are most often present in various forms. Responses to this survey on food-induced anaphylaxis revealed that more than half of the reactions happened outside the setting of a regular meal, i.e. after a snack or after skin contact or inhalation. Although all responders were aware of their allergy, most reactions were facilitated by inadequate preventive measures. Furthermore, adequate life-saving treatment was not available to all responders.

Data for this study was obtained through the internet, which provides an interesting tool for gathering epidemiologic data for uncommon diseases. A large potential population sample can be contacted in a cost-effective way. However, a recruitment bias is inevitable, as connection to the internet is mostly limited to developed countries and to educated participants. Therefore, our data should not be interpreted as a study reporting the true frequency of anaphylactic events to specific foods, but more as a series of events teaching prevention of critical risk situations.

When considering the management of food-induced anaphylaxis, a clear distinction can be made between the first reaction that usually leads to the diagnosis, and subsequent reactions due to accidental ingestion despite food avoidance measures. In this survey we considered only the most severe reactions following the diagnosis of allergy. The foods reported here are those most commonly observed in IgE-mediated food allergy (11). Peanuts and tree nuts accounted for 60% of the reactions and milk for 22%. Reactions to milk were mostly reported in children ≥ 4 years (10/12) with more severe milk allergies and who were less likely to outgrow it (12). Surprisingly, no reactions to egg were reported, although this food represents one of the most common allergen in children. The natural history of egg allergy is quite similar to milk (13–15), suggesting a similar number of food allergic children with a potential risk of reaction to eggs. Whether egg is more easily avoided is questionable.

Most sites of reactions correspond to those where reactions are usually reported. Home was the most frequent (25%), with almost all reactions reported in children (92%). Among the different sources of accidental ingestion, processed foods were often cited. Ingredient labelling was either not correctly checked, or the child actually reached for the food. One reaction was due to ingestion of a processed food from a brand eaten regularly without problems, but a new flavour was purchased and the fact that it contained nuts was not noticed due to the small print. Alleged food contamination during cooking was also reported in 21% of the reactions. The need for adequate cleaning of cooking utensils was commonly underestimated. In contrast to our findings, the study by Sicherer et al. on peanut and tree nut allergy (16) showed home to be less commonly the scene of allergic reactions subsequent to diagnosis.

Restaurants were a particular danger to adults with allergies to nuts or peanuts. In only half of the reactions were the restaurant staff informed of the food allergy when the order was placed. There is clearly a tendency for self-management of food allergy by most subjects, together with an overestimation of the ability to recognize "problem" dishes. The actions taken by the restaurant staff were considered to be inappropriate by all participants, revealing underestimation of the potential severity of food allergy by restaurant staff. Similar observations were reported in data from the peanut and tree nut allergy registry (17).

The risk of reactions at schools or in daycare is a major source of anxiety for parents of children with food allergy. Adequate information for the teachers or caregivers is essential and they should be provided with sufficient guidance to make an adequate response without needing the parent's input. Most parents were rapidly contacted in cases of an allergic reaction, however, actions taken by the staff were not always sufficient. Our data are similar to those in peanut and tree nut allergic children, as 40% of the reactions in schools or daycare were due to skin contact or inhalation, often happening during peanut-butter craft projects (16).

Among the less common sites of reactions, two responders indicated a hospital ward. Reactions followed ingestion of milk, or food containing milk, despite correct instruction of the nursing staff. The large number of persons involved in food delivery in hospitals necessitates precise instructions and rigorous checks at all levels. Moreover, the great variety of situations faced by parents of a food-allergic child is illustrated by this case: a 2-year-old child had a severe reaction in a store after a woman in the check-out line quickly popped a peanut-butter candy in the child's mouth while the mother turned her head away to pay.

Lessons have to be learned from these "food allergy scenes". First, places rated as safe are not always as safe

as they might be thought, especially the home. The use of coloured stickers to mark forbidden foods clearly, such as those provided by lay organizations, might diminish the risk of giving a food inadvertently. Second, food providers (i.e. staff in restaurant or food stores) should be correctly informed of the potential risks of food allergy, and of appropriate food handling, in order to avoid accidental reactions. Increasing awareness of food allergy in the community diminishes the risk of being singled out and should encourage food-allergic individuals to inform the food providers. Third, teachers are usually well informed about food allergies

of children in their classes, but this information is not always given by adults to restaurant staff, or to friends or relatives prior to visits. Finally, schools should be more aware of the potential risk of reactions following contact alone, and while the efficiency of a total ban of a specific food (e.g. peanuts) might be questionable, craft projects using potentially allergenic foods should definitely be prohibited. A few well-aimed measures may dramatically diminish the number of severe anaphylactic reactions in the community and provide a much safer environment for food allergy sufferers.

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