

Short communication

An Internet-based survey of anaphylactic reactions to foods

Background: A favorable outcome of anaphylaxis depends on the rapidity of adequate initial management and epinephrine injection. However, few data on the management of anaphylactic reactions are available. The aim of this study was to investigate the management and awareness of anaphylaxis to foods by mean of an Internet-based survey.

Methods: Visitors to a website with information on food allergy were invited to join the survey. Items in the survey included the management of anaphylactic reactions, investigations done by the diagnosing physician, and information given to the responder in anticipation of a new anaphylactic reaction.

Results: Almost all of the 264 responders were from North America, Europe, Australia, or New Zealand (263/264). The most recent reaction was treated by epinephrine injection in 68.7% (180/262) of cases, or by antihistamines in 14.1% (37/262). Epinephrine was the first treatment for the most severe reaction in only 43.9% (101/230), while antihistamines were given first in 43.5% (100/230). One-third (62/210 = 29.5%) of the responders diagnosed by a physician received neither a diagnostic blood test nor a skin test. Responders diagnosed by an allergist were more often investigated (91/105 = 86.7%) than those diagnosed by a pediatrician or an internist (29/44 = 65.9%), a general practitioner (22/45 = 48.9%), or another physician (6/16 = 37.5%) ($P < 0.001$). Most responders had received instructions on how to deal with a new episode of anaphylaxis (244/263 = 92.8%). Responders instructed by an allergist were most frequently satisfied with the instructions (115/131 = 87.8%).

Conclusions: A large number of responders did not receive epinephrine for treatment of their most severe, or most recent anaphylactic reaction, and did not undergo allergy tests. The conventional management of anaphylaxis might still be improved.

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Anaphylaxis is a life-threatening condition resulting from mast-cell degranulation, and is often associated with hypersensitivity to foods (1, 2). The estimated incidence of the disease in specific populations is 3.2–360 events per 100 000 person per year. The standard immediate medical management includes early administration of epinephrine, and close monitoring in a medical emergency facility. Delays in administering epinephrine may significantly worsen the prognosis of the reaction (5). Furthermore, the risk of new anaphylactic episodes suggests that the culprit allergen should be identified and carefully avoided, and the patient correctly instructed in the rapid initial self-management of the reaction (by using an epinephrine autoinjector), and to seek help at the first symptoms. However, several studies on anaphylaxis have seriously questioned physician awareness of the potential severity of anaphylaxis, as well as the adequacy of instructions given to patients (3, 6).

Most epidemiologic data on anaphylaxis were

obtained by reviewing medical records in geographically selected populations. Furthermore, the low incidence of anaphylaxis supposes that a survey including an appropriate number of patients should reach a very large population sample. To overcome the geographic bias and to increase the sample size, we conducted an Internet-based survey to investigate management of anaphylaxis to foods.

Material and methods

The survey was conducted with an Internet-based questionnaire hosted on a Worldwide Web site with information on food allergies (7). Visitors accessed the site mostly through major US and European search engines by submitting the following key words: “anaphylaxis”, “food”, “allergy”, and “food allergy”. Other visitors accessed through links located on various sites on food allergy and anaphylaxis, particularly the website of the American Academy of Allergy, Asthma and Immunology, and the Food Allergy Network.

From August 1999 to April 2000, a flashing banner on the welcome page of the website invited visitors to participate in a survey on anaphylaxis. An introductory text explained the aim of the

survey, and gave a definition of anaphylaxis. Potential responders were asked to complete the survey only if their symptoms matched the definition of anaphylaxis provided in the text. The symptoms should include *at least one* of the following: throat and mouth swelling, difficulty in swallowing or speaking, difficulty in breathing, blood pressure drop, or fainting.

The questionnaire included the following groups of items: personal data, data on the most recent reaction, data on the most severe reaction, and data on anaphylaxis awareness. At the end of the questionnaire, responders were invited to add any important information to an open text frame. All data were treated confidentially and consulted only by the investigating physicians. The study was reviewed and approved by the ethics committee of the Department of Pediatrics.

Statistics

The demographic characteristics of the population were described with proportion, or medians and range. As not all responders answered every question, the numbers used to determine proportions are systematically provided. Contingency tables were analyzed by the chi-square test. Fisher's exact test was used to compare proportions. A *P* value of <0.05 was considered significant.

Results

A total of 397 questionnaires were collected during the study period, and 264 questionnaires (66.5%) were further evaluated, after excluding those reporting symptoms not matching the definition of anaphylaxis, or not related to a food, and those who lacked indications for age, sex, and the first or more severe symptom. The demographic characteristics of the responders are given in Table 1. One-third (96/264 = 36.4%) of the questionnaires corresponded to subjects younger than 16 years of age, and in this subgroup the survey was completed by a parent in 95.8% (92/96) of cases.

Most recent anaphylactic reaction and other allergies

The median number of anaphylactic reactions was 2 (range: 1–100). The first and most severe symptoms during the most recent reaction are listed in Table 2. Anaphylaxis occurred most often at home (*n* = 123), or at locations not suggested in the questionnaire (*n* = 101). Only 13 reactions happened at school, and 27 at work. The severity of the most recent reaction was indicated by the responders on a visual scale from 1 to 10 (10 being the most severe). The median for all questionnaires was 8 (range 1–10).

Anaphylaxis was diagnosed by an allergist in 105/264 (39.8%), an internist or pediatrician in 44/264 (16.7%), a general practitioner in 45/264 (17.1%), and another physician in 16/264 (6.1%) of subjects; it was a self-diagnosis in 54/264 (20.5%). The diagnosis was confirmed by a diagnostic test (skin test and/or a blood test) in 63.3% (167/264) of responders. One-third (62/210 = 29.5%) of the responders diagnosed by a physician had undergone neither a skin test nor a blood test. Overall, 86.7% (91/105) of responders diagnosed by

an allergist had a diagnostic test done; 65.9% (29/44) of those diagnosed, by an internist or pediatrician; 48.9% (22/45) of those diagnosed by a general practitioner; and 37.5% (6/16) of those diagnosed by another physician (chi-square test: 3 d.f., $\chi^2 = 32.1$, *P* < 0.001).

The treatment of the most recent reaction was injection of epinephrine in 68.7% (180/262) of responders, while antihistamines were given in 14.1% (37/262) and steroids in 7.3% (19/262). Another medication or no treatment was given in 5.7% (15/262) of responders.

No other allergies were reported in 15.9% of responders (41/258), while 28.3% (73/258) also suffered from asthma, 9.3% (24/258) from hay fever, 7.0% (18/258) from atopic dermatitis, 2.7% (7/258) from episodes of urticaria, and 36.8% (95/258) from more than one of these.

Most severe reaction

When experiencing their most severe reaction, 46.0% (121/263) of responders contacted first a family member or a friend, 27.0% (71/263) contacted an emergency service (e.g., 911), 14.1% (37/263) did not contact anybody, and 12.9% (34/263) reported another contact. Among 230 responders, 13 (5.7%) had received no treatment for this reaction, while 217 (94.3%) were treated. The median time to the first treatment was 15 min (range from a few seconds to 8 h). The first treatment was epinephrine in 43.9% (101/230), antihistamines in 43.5% (100/230), β_2 -agonists in 3.5% (8/230), and corticosteroids in 3% (7/230) of responders. Patients contacting first an emergency service received more frequently epinephrine (42/62 [67.7%]) as first treatment than other responders (59/168 [35.1%]) (*P* < 0.001). In patients treated with epinephrine, the median time from the first symptoms to the injection was 20 min (range 0–480 min).

Table 1. Demographic characteristics of population

	Responders (<i>n</i> = 264)
Age (years): median (range)	25.7 (0.5–64)
Sex (female): number (%)	171 (64.8%)
Answer given by: number (%)	
Patient	148 (56.1%)
Parent	116 (43.9%)
Country: number (%)	
USA	207 (78.45)
Canada	28 (10.6%)
Europe	21 (8.0%)
Australia/New Zealand	7 (2.7%)
Other	1 (0.4%)
Occupation: number (%)	
Self-employed or college/university education	112 (42.4%)
Students	27 (10.2%)
Marketing/sales/tradesman/craftsman	47 (17.8%)
Others	78 (29.6%)

Table 2. Initial symptoms and most severe symptoms reported

	Initial symptom (total <i>n</i> =262)	Most severe symptom (total <i>n</i> =262)
Swelling of mouth/throat	93 (35.2%)	91 (34.5%)
Difficulty in swallowing/speaking	21 (8.0%)	26 (9.9%)
Difficulty in breathing	29 (11.0%)	104 (39.4%)
Fainting, coma	3 (1.1%)	17 (6.4%)
Abdominal cramps/nausea	21 (8.0%)	9 (3.4%)
Redness of skin/itchiness	89 (33.7%)	1 (0.4%)
Others	8 (3.0%)	16 (6.1%)

Anaphylaxis awareness

Among 263 responders, 244 (92.8%) had received instructions by a physician for treatment in the event of a new episode of anaphylaxis, while 19 (7.2%) had not received instructions. The proportion of responders receiving instructions was higher when the diagnosis was made by an allergist (100%) than by another physician or in cases of self-diagnosis (Table 3). In the 244 responders receiving instructions, these were given by an allergist in 138 (56.6%) cases, by an internist or pediatrician in 33 (13.5%), by a general practitioner in 49 (20.1%), or by another physician in 24 (9.8%). The physician providing instructions differed in some responders from the physician making the diagnosis of anaphylaxis. This may have been due to referral to the allergist by the diagnosing physician. To the question of whom should be contacted first in the event of a new reaction, 84.6% (193/228) said a doctor or the emergency services, 11.8% (27/228) said a family member or a friend, and 2.6% (6/228) did not know. To the question, "Are you satisfied with the instructions received to deal with an anaphylactic event?", 81.1% (185/228) responded affirmatively. This proportion was highest among the group of responders instructed by an allergist, followed by those instructed by an internist or pediatrician (Table 3). There was a statistically significant difference between responders instructed by an allergist and responders instructed by a general practitioner ($P=0.005$) or another physician ($P=0.01$). In the group of responders who received epinephrine for their most severe reaction, 83.3% (100/120) were satisfied with the instructions received.

Discussion

The favorable outcome of an anaphylactic reaction depends mostly on a rapid and adequate acute-phase management by both patients and physicians. In this study, we aimed to evaluate anaphylaxis management and awareness by a survey available to patients with anaphylaxis who consulted the Internet for disease-related information. The Internet has only rarely been used so far for epidemiologic studies. It is most useful to reach a large number of potential responders, as seen in a study on adult recreational drug usage which

Table 3. Proportions of patients receiving instructions or satisfied with them in cases of new anaphylactic reaction reported to physician providing the instructions

	A) Patients receiving instructions by diagnosing physician % (<i>n</i>)	B) Patients satisfied with instructions provided % (<i>n</i>)
Allergist	100.0% (105/105) ^{a,b,c,d}	87.8% (115/131) ^{b,c}
Internist/pediatrician	93.2% (41/44) ^a	83.3% (25/30)
General practitioner	93.3% (42/45) ^b	72.3% (34/47) ^b
Other physician	81.3% (13/16) ^c	55.0% (11/20) ^c
Self-diagnosis	81.1% (43/53) ^d	n.a.
Total	92.8% (244/263)	81.1% (185/228)

Chi-square test, A) 4 d.f., $\chi^2=22.1$, $P<0.0001$; B) 3 d.f., $\chi^2=15.2$, $P=0.002$.

^aAllergist vs internist/pediatrician, A) Fisher's exact test: $P=0.025$.

^bAllergist vs general practitioner, A) Fisher's exact test: $P=0.026$, B) Fisher's exact test: $P=0.021$.

^cAllergist vs other physician, A) Fisher's exact test: $P<0.002$, B) Fisher's exact test: $P=0.001$.

^dAllergist vs self-diagnosis, Fisher's exact test: $P<0.0001$.

recruited almost 1500 subjects (8), or in a study on injuries during windsurfing (9). The Internet also allows one to recruit responders without a bias for a specific medical affiliation, and permits one to contact a large number of patients suffering from diseases with a low incidence, such as anaphylaxis, estimated at 20 cases per 100 000 persons per year. The major bias is related to Internet access. This explains the large number of responders in our survey from the USA and Canada, Europe, and Australia/New Zealand.

We were first interested to investigate the initial treatment of the anaphylactic reaction. At their most severe reaction, most responders reacted adequately and were seeking help, as 85.9% reported having contacted first a family member, a friend, an emergency service, or another contact, while only 14.1% did not contact anybody. However, only half of the responders (43.9%) reported having received epinephrine initially for treatment of their most severe episode of anaphylaxis, while 46.5% received antihistamines and/or steroids. Moreover, 13 responders did not receive any medication. Even if some additional responders received injected epinephrine without their knowledge, a large number did not benefit from the most appropriate, potentially life-saving treatment (5, 10, 11). Epinephrine should be either self-administered or injected by an emergency rescue team. Similarly low numbers of patients treated with epinephrine were reported by Stewart & Ewan (1). In their series on anaphylaxis treatment in an emergency room in the UK, only 3/9 patients with severe anaphylaxis were treated with epinephrine, while corticosteroids and antihistamines were mostly used. Furthermore, all patients with anaphylaxis were discharged without investigations or advice given for further management. Responders in our survey reported investigations by skin prick testing and/or blood tests mostly when diagnosed by an allergist (86.7%), but fewer did so when

diagnosed by pediatricians or internists (65.9%) or by general practitioners (48.9%). Others reported even lower numbers of patients (40% vs 63.3% in our study) who underwent diagnostic procedures (3).

Moreover, correct management of anaphylaxis also requires counseling of patients, by providing a list of contacts in case of a new episode of anaphylaxis, by prescribing emergency medication for self-administration, and by teaching the proper use of a self-injectable epinephrine device (10, 12). Most responders (87.8%) who received instructions from an allergist for treatment in the event of a new episode of anaphylaxis were satisfied with the instructions. The proportion was similar in responders instructed by pediatricians or internists (83.3%), while those instructed by general practitioners and other physicians were less satisfied (72.3% and 55.0%). However, our questionnaire did not evaluate the quality of the instructions given. It is known from previous reports that patients are most often not correctly instructed in the use of devices for self-administration of epinephrine (6, 13). Furthermore,

only 25% of the physicians prescribing such devices may be able to demonstrate correct self-administration of epinephrine (14).

In conclusion, responders for this Internet-based survey on anaphylaxis to foods most often reported delay, or absence of adequate treatment with epinephrine. However, instructions in case of a new anaphylactic reaction were given to most responders (92.8%), and 81.1% were satisfied with the instructions given. It should be re-emphasized that epinephrine is the life-saving medication in anaphylactic reactions, and it should be available for self-injection to every patient at risk of a new episode. Only adequate allergy diagnosis and counseling may prevent further reactions.

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