

*Original article***Risk-taking and coping strategies of adolescents and young adults with food allergy**Margaret A. Sampson, BA,^a Anne Muñoz-Furlong, BA,^b and Scott H. Sicherer, MD^a*New York, NY, and Fairfax, Va***Background:** Fatal food-allergic reactions are most common among adolescents and young adults.**Objective:** To gain insight toward devising interventions, we queried risk-taking behaviors and coping strategies of persons age 13 to 21 years with food allergy.**Methods:** We used an Internet-based anonymous questionnaire devised on the basis of data from focus groups.**Results:** Participants (174 subjects; 49% male; mean age, 16 years) reported the following: 75% had peanut allergy, 75% had 2 or more food allergies, and 87% had been prescribed self-injectable epinephrine. Regarding risk taking, 61% reported that they "always" carry self-injectable epinephrine, but frequencies varied according to activities: traveling (94%), restaurants (81%), friends' homes (67%), school dance (61%), wearing tight clothes (53%), and sports (43%). Fifty-four percent indicated purposefully ingesting a potentially unsafe food. Willingness to eat a food labeled "may contain" an allergen was reported by 42%. Twenty-nine participants were designated at high risk because they did not always carry epinephrine and ate foods that "may contain" allergens. The high-risk group, compared with the rest of the participants ($P < .05$), felt less "concern" about and "different" because of their allergy and had more recent reactions. The high-risk group was not distinguishable ($P =$ not significant) by age, sex, or number or severity of reactions. Participants variably (60%) tell their friends about their allergy, but 68% believe education of their friends would make living with food allergy easier.**Conclusions:** A significant number of teens with food allergy admit to risk taking that varies by social circumstances and perceived risks. The results imply that education of teenagers and, importantly, those around them during social activities might reduce risk taking and its consequences.**Clinical implications:** Our survey of adolescents and young adults with food allergy revealed risk-taking behaviors that vary by social circumstances and perceived risks, indicatingthat education of teenagers and their peers might reduce risk taking and its consequences. (*J Allergy Clin Immunol* ■■■■;■■■;■■■-■■■.)**Key words:** Food allergy, adolescent, risk taking

There are an estimated 150 to 200 fatalities in the United States each year caused by food-allergic reactions.^{1,2} Case series of fatal reactions indicate that a high proportion of victims are teenagers and young adults.^{3,4} For example, among 32 fatalities in a registry of food-induced anaphylaxis, 69% occurred in patients between the ages of 13 and 21 years.³ Victims of fatal food-induced anaphylaxis usually have asthma and a diagnosed food allergy, and there is often a significant delay in or lack of administration of epinephrine.^{3,4} Concern about risks is increasing because food allergy is increasing in prevalence,⁵ and 2.3% of teenagers have food allergy.⁶

One can assume that there are several explanations for the observation that adolescents and young adults appear to be at increased risk for fatal food-allergic reactions. With reduced parental oversight, teens with food allergy need to make decisions about food choices, and the burden of recognizing and treating an allergic reaction is placed on them or those around them, often persons other than their parents. Adolescence is the time when young people spend more time without direct parental supervision, explore their independence, and take risks. Risk-taking behaviors in teenagers have been studied and are generally attributed to a reduced appreciation of potential dangers and a belief that consequences can be controlled.⁷ In support of this explanation for risk-taking behaviors, we found in a previous study that teenagers listed social isolation as the hardest part of living with a food allergy.⁸ In contrast, parents of these teens listed fear of death as the most difficult issue.

The intent of the current study was to identify and evaluate risk-taking behaviors and coping strategies of teens with food allergy as a first step toward devising better strategies and further studies to increase safety for this high-risk group.

METHODS

A professional market research company (Cogent Research, LLC, Cambridge, Mass) was engaged by the Food Allergy & Anaphylaxis Network (FAAN) and conducted four 90-minute focus

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Abbreviations used

FAAN: Food Allergy & Anaphylaxis Network

SIE: Self-injectable epinephrine

groups in Cambridge, Massachusetts, and Minneapolis, Minnesota, with persons with food allergies (groups of ages 13-16 and 17-21 years) to identify areas of risk taking, the effect of food allergy on quality-of-life issues, and coping strategies. From the qualitative data provided by the focus groups, 42 close-ended questions, including demographic questions, were developed into a survey designed for Internet-based administration. Areas of importance identified by focus groups and incorporated into the questionnaire included circumstances that influence diet decisions and medication adherence, interactions with friends and social circumstances in regard to food allergies, preferences for food allergy management, and emotional concerns.

Open calls for participation in the survey were made through an advertisement in a FAAN newsletter, a posting on the FAAN Web site, and postings on 2 Canadian food allergy organizations' Web sites. The survey was available for online administration for a 7-week period. Participation was voluntary and anonymous. Participants were queried for age and specific food allergies and excluded from participation if they did not indicate a food allergy or were outside of the age range of 13 to 21 years. The results of the study were evaluated by using descriptive statistics, and comparisons were made by using χ^2 analysis. A *P* value of less than .05 was considered significant. Consent was obtained for focus groups by Cogent Research, LLC; all focus group data were anonymized; the self-administered questionnaire was anonymous; and the evaluation of data was approved by the Mount Sinai Institutional Review Board.

RESULTS**Demographic features, reaction, and treatment history**

In total, 174 adolescents and young adults (mean age, 16 years; range, 13-21 years) with food allergy completed the survey; 86 (49%) were male, and 88 (51%) were female. Food allergies included peanut (75%), tree nut (56%), shellfish (21%), milk (20%), egg (16%), and fish (14%). Two or more food allergies were reported by 75% of participants. The majority of the group (54%) reported 2 to 5 reactions in their lifetime, and 17% indicated having more than 10 reactions in their lifetime. Eighty-two percent of the group indicated that they considered themselves to be at risk to experience "anaphylaxis," 86% considered their allergy "life-threatening," and 87% had been prescribed self-injectable epinephrine (SIE). Most (67%) had experienced an allergic reaction in the preceding 5 years. Thirty-six percent of 162 who recalled their most recent reaction considered themselves to have experienced "anaphylaxis." However, the participants' use of the term "anaphylaxis" did not necessarily match typical severe symptoms. For example, individual symptoms were queried, and 58% reported tongue or throat swelling, 54% trouble breathing, and 4% loss of consciousness. Of those not self-reporting "anaphylaxis," 61% reported at least one of these severe symptoms.

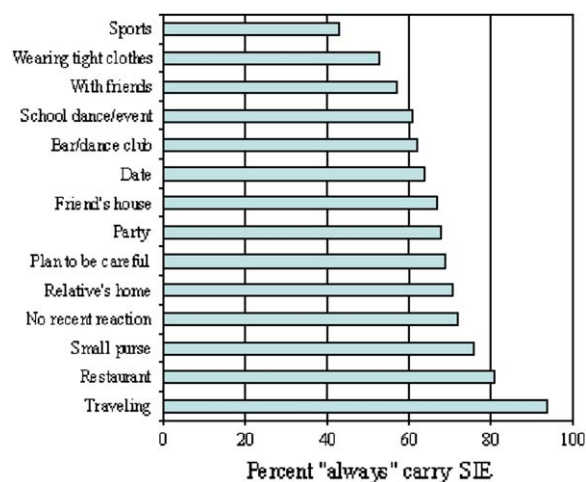


FIG 1. Percentage of respondents who "always carry" SIE during various activities.

Considering these severe symptoms in addition to self-reported "anaphylaxis," 71% of the group had anaphylaxis. Of those with "anaphylaxis," severe symptoms, or both, 37% did not receive epinephrine. During the "last reaction," 38% did not have SIE with them. Although the location or circumstance of a reaction was not queried, those who described their most recent reaction were asked who they notified first about the reaction, with the following results: parent (66%), no one/self-managed (12%), friend (11%), school staff (10%), and called 911 (1%).

Carrying and using emergency medication

In regard to feeling prepared for self-treatment, 60% considered themselves "very," 36% somewhat, 4% "not very," and less than 1% "not" prepared. Overall, 61% reported carrying SIE at all times, 28% most of the time, 5% half of the time, and 5% less than half of the time. Those who always carried SIE were more likely to have reported previous anaphylaxis (*P* = .03) but not more likely to have experienced a large (>10) number of previous reactions (*P* = not significant). When asked about the frequency of carrying their SIE during certain activities, the numbers varied. Fig 1 shows the rate of carrying SIE according to various circumstances. Although rates are high for activities such as travel and restaurants (presumably higher-risk situations that for many participants would include more parental oversight), rates decrease for social activities (parties and dances), situations of presumed lower risk (sports), and inconvenience (tight clothing). Fourteen percent had ever used SIE.

Food selection regarding label reading

Respondents indicated that they read labels always (64%), most of the time (18%), half the time or less (4%), or only for foods never eaten before (15%). In regard to provisional labeling, for labels that indicate "may contain" an allergen, most (58%) indicated they avoid the food. However, 5% eat these foods because they believe the risk is low, 19% eat it because they had no prior

reactions when doing so, and 13% tasted it and continued to eat it if they had no symptoms.

High-risk behaviors and levels of concern

Participants rated their concern about food allergy as not at all (1%), not very (15%), somewhat (44%), and very (40%) concerned. Compared with other aspects of life for these participants, concern about food allergy was ranked lower than concerns for doing well in school, making friends, and staying physically fit. However, food allergy concern was rated stronger than concern about dating (queried only for those age >15 years) and dealing with peer pressure. Participants rated 10 items for degree of risk on a 10-point scale from 1 ("not a risk at all") to 10 ("a very high risk"; Fig 2). Although it is reassuring to observe that teens are aware of and concerned about risks of kissing a person who just ate an allergen, it is worrisome that several potentially high-risk situations (parties, friend's homes, and restaurants) were lower on the list.

A total of 54% admitted to eating at least a tiny amount of a food that was known to contain an allergen. Seventeen percent of these risk takers did this a few times a month or more, 44% a few times a year, and 39% only once or twice in their lifetime. Reasons associated with risk taking included (cumulative per explanation) that similar foods had not caused a reaction (57%), "it looked good and I wanted to eat it" (49%), presence of "may contain" label (33%), did not want to ask about ingredients (23%), "hanging out" with friends (23%), testing to see if still allergic (23%), and "all of my friends were eating the food" (18%).

We defined a high-risk group as a group that consisted of teens who do not always carry SIE and will eat a food despite labeling that indicates it "may contain" an allergen. We selected these factors as surrogates for 2 key areas previously identified as risks for fatalities,^{3,4} specifically lack of prompt treatment with SIE and unsafe food selection. This group consisted of 29 individuals (17% of the total group). Neither age nor sex affected the likelihood of being in this group. The high-risk group reported ingesting "at least a tiny bit" of high-risk foods at the same rate as the remainder of the study population. There was no significant difference between the number of lifetime reactions or anaphylaxis. Even though the symptoms and number of lifetime reactions were similar, adolescents in the high-risk group reported being "less concerned" about their allergy than the rest of the group ($P = .047$). Overall, 71% of the high-risk group had a reaction within the previous 2 years compared with 51% of the rest of the group ($P = .047$). Participants were asked how having a life-threatening food allergy made them feel, and several emotions were listed. Adolescents in the high-risk group reported feeling cautious, alert, limited, frustrated, vulnerable, responsible, and unique at rates similar to the rest of the group. However, high-risk teens were more likely to report feeling "different" than the rest of the group ($P = .01$). High-risk teens also believed that eating a food with a label that said it "may

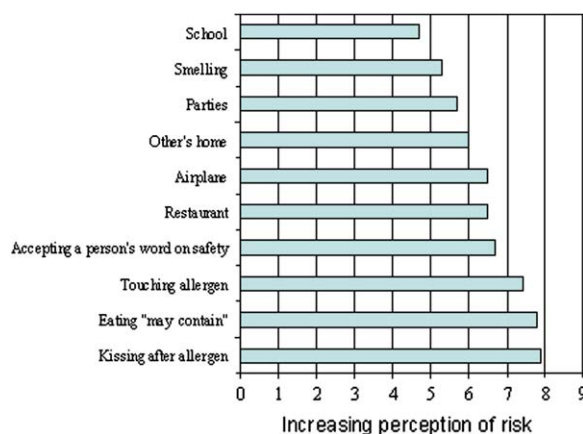


FIG 2. Mean scores for estimated risk for triggering an allergic reaction (scale: 1 = "not a risk at all" and 10 = "a very high risk").

contain" an allergen was much less of a risk than reported by the rest of the group ($P = .001$).

Communication

In regard to informing friends, 61% indicated all of their friends knew about their food allergy, 33% indicated some knew, and 6% indicated that none knew about their food allergy. Among those who indicated that any friends knew about the allergy, the specific points known were distributed as follows: the causal foods (96%), symptoms (55%), to call 911/get help if there is a reaction (51%), and how to administer SIE (38%). Sixty-two percent indicated that they had at least sometimes been teased about their food allergy.

The survey queried for preferences and targets for communication and education about food allergies. When asked to select the single most needy group in regard to education, the majority (53%) selected individuals in their school (ie, classmates, friends, and teachers), 17% indicated other persons' parents, 10% indicated themselves, and 5% indicated their parents.

Younger participants (age 13-17 years) were asked to select strategies they would like instituted in school to make living with food allergy "easier." Sixty-eight percent thought educating other students would be helpful, and only 21% indicated that either a special table designated for eating allergens or excluding allergens would be helpful. Older participants (ages 18-21) still in school ($n = 47$) indicated their preferences, including wider meal selection options (62%), specific allergen-safe areas in the cafeteria (36%), preselected staff members with whom to discuss meals (57%), and increased education of students (49%); only 6% thought nothing needed to be done.

Participants thought that the best modalities for them to learn more included e-mail (58%), Web sites/Internet (55%), school (54%), and magazines (42%), whereas fewer selected support groups (26%) or meetings (21%). The participants performed the study on the Internet, which might have biased the preference selection toward this modality for education.

DISCUSSION

This is the first study of its type to attempt to identify potentially rectifiable aspects of risk taking in a group of teenagers and young adults with food allergy. Teenagers and young adults with food allergies are at highest risk for fatal allergic reactions, and this risk is apparently partly attributable to increased risk-taking behaviors, poor awareness of potential risks, and lack of timely treatment with epinephrine.^{3,4} Although the psychology literature and common knowledge identify the teenage years as ones characterized by experimentation and a feeling of “invincibility,” in this study we have identified a number of issues that can be addressed immediately to possibly increase the safety of teenagers and young adults with food allergy.

The study population included persons with a high degree of severity of food-induced allergic disease, with numerous food allergies, frequent and severe reactions, and, similar to population-based studies, apparent underuse of SIE (37% with severe symptoms did not receive epinephrine, and 38% did not have it with them during severe reactions).^{9,10} Therefore the study population represents one at particular risk for fatal reactions^{3,4} and a good focus for investigation of risk factors and coping strategies. Although a definition of “anaphylaxis” has been debated and recently proposed,¹¹ it is interesting to note that only about half of the participants who had experienced severe reaction symptoms described themselves to have experienced “anaphylaxis.” If it is true that teenagers are taught to use epinephrine for “anaphylaxis,” then our results underscore the need to discuss with patients exactly what symptoms or circumstances (eg, a more specific means of explaining “anaphylaxis”) warrant treatment with SIE.¹² Education involved with this approach might reduce underuse of SIE.¹³

We found that rates of carrying SIE varied by social circumstances, convenience, and perceived risks. Situations of travel and restaurant eating were associated with greater rates of carrying SIE than events that were more peer group oriented. Teenagers might consider certain activities, usually without food, as lower risk (sports), but social pressures were evident because low rates of having SIE were reported for social activities with foods or for fashion concerns (tight clothing). One response to these observations would be to emphasize to patients that food is often a part of all group activities, and an accidental exposure could occur, making it necessary and safest to always have SIE available. Teaching parents to remind teenagers about carrying SIE to social events would be advisable. Parents might also advise their teenager to carry a fashionable purse or hidden SIE holster if clothing is tight fitting.

Perceived risk was assessed for several aspects of daily living in regard to food allergies. As shown in Fig 2, teenagers, on average, perceive school, parties, eating at others' homes, and restaurants as lower risk than certain specific exposures, such as eating a food labeled “may

contain” an allergen, kissing a person who ate an allergen, or even touching a food to which they were allergic. Although it could be argued that all of these situations carry some risk, it is concerning that certain situations of actual ingestion were considered lower risk than simply touching an allergen. Because at least some risk-taking behavior is associated with the level of perceived risks, additional education about various circumstances (discussions about obtaining safe meals at restaurants, label reading, and understanding of cross-contact of allergens with food during meal preparation) might help teenagers better assess the risks. Misconceptions about label reading can also be addressed because many participants thought that they do not need to read labels each time they used a product and were inconsistent in label reading.

More than half of the participants had knowingly eaten at least a small amount of a food known to contain/possibly contain an allergen, and 17% did so a few times a month or more. The reasons for doing so included previous indiscretions without reactions, a simple wish to eat the food, consideration that “may contain” labeling was not a deterrent, reluctance to ask questions, curiosity, and peer pressure. These observations underscore the need for a variety of approaches to reduce such behavior. For example, a clear communication about risks, giving teens practice opportunities when ordering food or reading labels to obtain a safe meal, providing substitutions, and educating friends about their allergy to reduce peer pressure.

To better characterize determinants of risk taking, we evaluated participants who do not always carry SIE and ate foods despite a “may contain” allergen warning. These individuals were, as might be expected, less likely to perceive “may contain” labeled food as risky. Surprisingly, they were not more experimental in regard to actually trying unsafe foods compared with the rest of the group. However, they were “less concerned” about their allergy and felt “different.” These findings suggest that parents, educators, and physicians should discuss, in concrete terms, the potential risks of a food allergy and take steps to make certain that there are as few impediments as possible to social activities. Further research would be needed to establish underlying emotional risk factors associated with risk taking, but an increased need to fit in seems likely.

Participants indicated a strong interest in having their friends educated about food allergy as a means to improve their own lives. However, many (39%) indicated that all of their friends did not know about their allergy, and the ones who were informed typically did not know details about symptoms or treatment. In addition, most reported teasing (which presumably could increase risk taking or reduced communication). Therefore it seems that teenagers with food allergy would like education of their peers but are not able to easily provide this information themselves. Such education, undertaken at least initially by a third party, such as a school nurse, might improve safety in several ways: reduced peer pressure, reduced teasing/bullying, and provision of additional persons available to help the

TABLE I. Summary of key study observations and their implications

Study observations	Suggested remedial action, educational objective, or research objective
Misperception of “anaphylaxis”	Teach symptoms, not just the word <i>anaphylaxis</i>
Low rate of SIE use	Educate about treatment circumstances, SIE injector technique, and actions to take (eg, use SIE, inform others, call 911)
Rates of carrying SIE vary by social circumstances, perceived risks, convenience	Impress need for consistency Provide reminders to carry, especially during social activities Offer carrying alternatives (eg, purse, holster) Have SIE on site when appropriate (eg, coach)
Risk assessments: “may contain allergen” labeling, dining out, testing foods for safety by taste, social activities, sports, kissing	Review risks of exposures and discourage risky behavior Practice obtaining safe foods under supervision early to instill good habits Encourage peer education
Emotional risk factors: feeling “different” or “less concerned”	Note as area for further research Discuss emotional effect
Quality-of-life easements	Increase safe food choices Have “point person” for safe meals
Poor communication of allergy to friends	Offer third-party education about allergy directed to friends
Preferred modalities for education	Make questionnaire administration Internet-based

allergic individual monitor food choices, symptoms, and treatments and provide encouragement for safe practices. In addition, efforts to teach teenagers with food allergy how to inform their friends, including romantic partners, about their allergies might increase safety. Finally, it is apparent from our study that teenagers might turn to friends during an allergic reaction, and having them knowledgeable about what to do in an emergency would likely be helpful. These and additional study results, with suggested actions, are shown in Table I.

There are a number of limitations of this study. Teenagers and young adults were asked to report their own risk-taking behavior and medication adherence. Such self-reports might underrepresent risk taking, and we could not externally validate the actions of participants in this anonymous survey. The fact that the study was anonymous should have reduced the chance of underreporting. As one means to check the internal validity of responses, the number of persons without SIE at the time of their last reaction matched the reporting rate of not carrying SIE all of the time. Nonetheless, if there was underreporting of nonadherence, the study implications are at least the same. Another potential limit is that the group studied might be more educated about food allergy than average because they were recruited through an allergy Web site/newsletter, and they therefore might not be representative of all teenagers with food allergy. However, this possible limitation only underscores the likely more extreme situation regarding risk taking for teens who have not been exposed

to additional educational materials. Although we did not directly evaluate the participants to verify food allergies in this questionnaire study, the described foods (eg, peanuts and tree nuts), symptoms (eg, urticaria and wheezing), and recurrent nature of reactions indicate that the participants were likely to have true food allergies.

In summary, we have documented risk-taking and coping strategies of a group at high risk for fatal food-allergic reactions. We have identified a number of areas in which immediate intervention might help to reduce risks and areas in need of additional research toward protecting this group. Key among the findings is that education of peers is favored by adolescents with food allergy, but they are reluctant to do so themselves. Educated peers might provide a resource to increase safety for their friends with food allergy in many ways. FAAN presents a PAL (Protect a life) Program in this regard (www.foodallergy.org; 800-929-4040) and maintains a Web site for teenagers and young adults in an effort to provide support, raise awareness, and increase education among teenagers with food allergies and their peers.

REFERENCES

1. Yocum MW, Butterfield JH, Klein JS, Volcheck GW, Schroeder DR, Silverstein MD. Epidemiology of anaphylaxis in Olmsted County: a population-based study. *J Allergy Clin Immunol* 1999;104:452-6.
2. Sampson HA. Update on food allergy. *J Allergy Clin Immunol* 2004; 113:805-19.
3. Bock SA, Munoz-Furlong A, Sampson HA. Fatalities due to anaphylactic reactions to foods. *J Allergy Clin Immunol* 2001;107:191-3.

4. Sampson HA, Mendelson LM, Rosen JP. Fatal and near-fatal anaphylactic reactions to food in children and adolescents. *N Engl J Med* 1992; 327:380-4.
5. Sicherer SH, Muñoz-Furlong A, Sampson HA. Prevalence of peanut and tree nut allergy in the United States determined by means of a random digit dial telephone survey: a 5-year follow-up study. *J Allergy Clin Immunol* 2003;112:1203-7.
6. Pereira B, Venter C, Grundy J, Clayton CB, Arshad SH, Dean T. Prevalence of sensitization to food allergens, reported adverse reaction to foods, food avoidance, and food hypersensitivity among teenagers. *J Allergy Clin Immunol* 2005;116:884-92.
7. Rolison MR, Scherman A. Factors influencing adolescents' decisions to engage in risk-taking behavior. *Adolescence* 2002;37:585-96.
8. Noone S, Muñoz-Furlong A, Sicherer SH. Parent and adolescent perceptions on food allergy [abstract]. *J Allergy Clin Immunol* 2003; 111(suppl):S133.
9. Sicherer SH, Muñoz-Furlong A, Burks AW, Sampson HA. Prevalence of peanut and tree nut allergy in the US determined by a random digit dial telephone survey. *J Allergy Clin Immunol* 1999;103:559-62.
10. Sicherer SH, Muñoz-Furlong A, Sampson HA. Prevalence of seafood allergy in the United States determined by a random telephone survey. *J Allergy Clin Immunol* 2004;114:159-65.
11. Sampson HA, Muñoz-Furlong A, Campbell RL, Adkinson NF Jr, Bock SA, Branum A, et al. Second symposium on the definition and management of anaphylaxis: Summary report. *J Allergy Clin Immunol* 2006; 117:391-7.
12. Sicherer SH, Simons FE. Quandaries in prescribing an emergency action plan and self-injectable epinephrine for first-aid management of anaphylaxis in the community. *J Allergy Clin Immunol* 2005; 115:575-83.
13. Kim JS, Sinacore JM, Pongratic JA. Parental use of EpiPen for children with food allergies. *J Allergy Clin Immunol* 2005;116:164-8.