

# Food Allergy Educational Needs of Pediatric Dietitians: A Survey by the Consortium of Food Allergy Research

Marion E. Groetch, MS, RD<sup>1</sup>; Lynn Christie, MS, RD<sup>2</sup>; Perla A. Vargas, PhD<sup>3</sup>; Stacie M. Jones, MD<sup>2</sup>; Scott H. Sicherer, MD<sup>1</sup>

## ABSTRACT

**Objective:** To determine pediatric dietitians' self-reported proficiency, educational needs, and preferences regarding food allergy (FA) management.

**Design and Setting:** An Internet-based, anonymous survey was distributed to the Pediatric Nutrition Practice Group (PNPG) of the American Dietetic Association.

**Participants:** Respondents (n = 311) were registered dietitians and members of the PNPG.

**Analysis:** Results are presented using descriptive statistics. Chi-square tests were applied for subgroup analyses. Percentage responses were calculated per question based on the number of respondents answering the question.

**Results:** On a 4-point scale of proficiency ("high," "moderate," "low," and "none"), respondents primarily rated themselves "moderate" for educating families, creating diets, and evaluating safe food items, and "low" for creating diagnostic food challenges. Education was primarily self-taught (75%). Preferences for future resources included handbooks (77%) and Web-based instructional programs (53%). On a 4-point scale ("very" to "not at all" needed) among practices that included >10% patients with FA, ratings of "very" were defined as need resources to update FA knowledge (87%) and need for a FA "tool kit" (84%).

**Conclusions and Implications:** Pediatric dietitians manage FA for a substantial patient base although their self-reported proficiency is overall only moderate. Dietitians would prefer and likely benefit from Internet-accessible management handbooks and patient handouts.

**Key Words:** food allergy, food intolerance, immune response, diagnostic food challenge, placebo, elimination diet (*J Nutr Educ Behav.* 2010;42:259-264.)

## INTRODUCTION

Food allergy, defined as an adverse immune response to a food item, is estimated to affect approximately 5% of infants and children.<sup>1</sup> In contrast to food intolerance, food allergy (FA) can be severe and possibly fatal.<sup>2</sup> Recent epidemiologic studies indicate that FA may be increasing<sup>3</sup> and becoming more persistent,<sup>4,5</sup> with fewer children outgrowing egg or milk allergies in the first years of life. Although almost any food item can cause an allergic reaction, 8 food

items/food groups are responsible for 90% of significant food allergic reactions in the United States (US): milk, egg, wheat, soy, peanut, tree nut, fish, and shellfish.<sup>1</sup> In some cases, a trace amount of the food item can trigger an allergic reaction. Currently, strict avoidance remains the only treatment option available.

The dietitian can play a central role in caring for a patient/family with FA.<sup>6</sup> Medical nutrition therapy for those with FA should be individualized and include assessment of nutritional status followed by nutrition

therapy that includes comprehensive avoidance education and ensures adequacy of nutrients provided through nutrient-dense alternative food sources, allergen-free supplemental feedings, and/or dietary supplements.

Dietary avoidance is complex and requires thorough education in identification of allergenic ingredients, careful reading of manufactured food product labels, and preventing allergen contamination through cross-contact.<sup>7</sup> Studies show that food-allergic consumers experience allergic reactions caused by errors in avoidance.<sup>8,9</sup> Patients must be taught, for example, that avoiding milk requires the elimination of not only fluid milk, but all dairy products such as cheese, yogurt, butter, ice cream, and many packaged and processed milk-containing food items such as breads, cookies, crackers, prepared meats, and cold cuts.

Patients also need instruction on obtaining safe meals in restaurants, school cafeterias, and other public eating venues.<sup>10</sup> The dietitian can

<sup>1</sup>Jaffe Food Allergy Institute, Division of Allergy and Immunology, Department of Pediatrics, Mount Sinai School of Medicine, New York, NY

<sup>2</sup>Division of Allergy and Immunology, Department of Pediatrics, University of Arkansas for Medical Sciences and Arkansas Children's Hospital, Little Rock, AR

<sup>3</sup>Division of Social and Behavioral Sciences, Arizona State University, Glendale, AZ

Address for correspondence: Marion E. Groetch, MS, RD, CDN, Mount Sinai School of Medicine, One Gustave L. Levy Place, Box 1198, New York, NY 10029; Phone (212) 241-8925; Fax (212) 426-1902; E-mail: [marion.groetch@mssm.edu](mailto:marion.groetch@mssm.edu)

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**Table 1.** Characteristics of the Study Population by Years of Practice, Percentage of Pediatric Patients With Food Allergies, and Type of Practice Setting (n = 311)

| Characteristic                                                                   | Response (%) |
|----------------------------------------------------------------------------------|--------------|
| <i>Years in practice</i>                                                         |              |
| 0-5                                                                              | 20.6         |
| 6-10                                                                             | 14.8         |
| 11-15                                                                            | 15.1         |
| >15                                                                              | 49.5         |
| <i>Percentage of practice composed of pediatric patients with food allergies</i> |              |
| None                                                                             | 10.0         |
| < 10                                                                             | 47.6         |
| 10-24                                                                            | 28.6         |
| 25-49                                                                            | 7.1          |
| 50-74                                                                            | 4.5          |
| 75-100                                                                           | 2.2          |
| <i>Type of practice settings (respondent could choose more than 1)</i>           |              |
| Clinic/ambulatory                                                                | 46.0         |
| Hospital inpatient                                                               | 37.6         |
| Private practice                                                                 | 13.2         |
| Other                                                                            | 28.3         |

evaluate and ensure the nutritional adequacy of allergen-elimination diets and suggest appropriate supplements and substitutions.<sup>11</sup> Christie et al showed that children with milk allergy or 2 or more FA were shorter based on height-for-age percentiles than their nonallergic peers.<sup>12</sup> Therefore, comprehensive education should include not only how to avoid specific allergens, but also how to safely and appropriately substitute for eliminated food items and the nutrients inherent in those food items.<sup>6</sup>

Lastly, the dietitian can be invaluable in assisting with diagnostic tests for FA, including arranging appropriate allergen elimination dietary trials and oral food challenges. Oral food challenges are physician-supervised graded feedings performed to confirm an FA diagnosis. These tests may require masking the tested food, for example placing egg white powder in apple sauce, and preparing placebo challenges to reduce bias.

It is evident that there is a growing need for trained registered dietitians (RD) to assist patients with FA to effectively avoid the identified allergen as well as meet the nutritional needs within the context of an allergen-restricted diet. The authors undertook the current study to determine pediatric dietitians' self-reported proficiency,

educational needs, and preferences regarding methods of distribution for FA educational resources.

## METHODS

### Survey Development

An Internet-based survey was developed by a group with expertise in FA. This group was composed of 3 RD, 2 board-certified pediatric allergist/immunologists, and 2 registered nurses all from the Consortium of Food Allergy Research (CoFAR). The Consortium of Food Allergy Research was established in July 2005 by the National Institute of Allergy and Infectious Diseases of the National Institutes of Health to conduct multicenter clinical trials, observational studies, mechanistic studies, and basic research toward development of novel therapies for FA. An additional goal of the CoFAR is to create educational materials for families with children with FA.

The present survey was designed to measure self-reported proficiency and educational needs and preferences of pediatric dietitians, information that would also be useful in preparing educational packages for families. The 7 experts developed the initial questionnaire identifying relevant topics in FA and common sources of educa-

tion, and with the assistance of a health psychologist, they developed the final questionnaire, which was piloted for relevance and readability and adapted to an on-line format. Piloting included 6 dietitians who confirmed the content validity and ease of use. Ten FA proficiency areas were identified (see Table 2). For evaluation of self-described proficiency levels, participants were asked to select among the terms "high," "moderate," "low," and "not at all" for each of the 10 areas. Additional survey questions related to current educational resources used to learn about FA management, updating one's knowledge base on FA, and resources used to educate patients with FA were included. A question was included to assess the validity of the questionnaire approach: "How relevant/applicable to your practice were the questions in this survey?" Development and piloting was completed in approximately 4 months. The survey included free-text boxes to capture participants' suggestions of additional resources or areas of need in the event that the preconstructed survey had missed an area of interest.

### Participants

A link to the Web-based survey was distributed via the listserv of the Pediatric Nutrition Practice Group (PNPG) of the American Dietetic Association. The PNPG is a dietetics practice group of more than 3,000 dietetic nutrition professionals who have a specific professional interest in the nutritional health of infants, children, and adolescents. The listserv of the PNPG has a membership of approximately 1,780. Responses were anonymous. The survey was closed to further respondents 4 weeks following the e-mail. The study was approved by the Institutional Review Boards of the participating medical schools.

### Statistical Analysis

Results are presented using descriptive statistics. Chi-square tests were applied for subgroup analyses. A *P* value less than .05 was considered significant. Percentage responses are calculated per question based on the number of respondents answering

**Table 2.** Study Population's Self-reported FA Management Proficiency in 10 Key Competence Areas

| Proficiency Area                                                       | Self-reported Proficiency Level (% response) |          |     |            |
|------------------------------------------------------------------------|----------------------------------------------|----------|-----|------------|
|                                                                        | High                                         | Moderate | Low | Not at All |
| Understands food intolerance definition                                | 59                                           | 39       | 2   | 0          |
| Understands FA definition                                              | 57                                           | 41       | 2   | 0          |
| Providing avoidance education (eg, label reading and cross-contact)    | 42                                           | 46       | 12  | 1          |
| Identifies adverse reactions to food items and clinical manifestations | 29                                           | 58       | 12  | 2          |
| Managing dietary needs with multiple FA                                | 28                                           | 49       | 20  | 3          |
| Understands the steps involved in diagnosis of FA                      | 19                                           | 53       | 24  | 4          |
| Evaluating safe food items in schools and hospitals                    | 18                                           | 43       | 34  | 5          |
| Intervening for feeding/behavioral problems                            | 17                                           | 39       | 33  | 10         |
| Developing elimination diet                                            | 14                                           | 40       | 31  | 14         |
| Creating diagnostic food challenge                                     | 8                                            | 35       | 38  | 19         |
| FA indicates food allergy.                                             |                                              |          |     |            |

the question. All statistical analyses were conducted using SPSS (version 15.0, SPSS, Inc., Chicago, IL, 2006).

## RESULTS

### Participant Characteristics

A total of 311 surveys were completed, indicating a response rate of 17.5%. Ten percent of respondents indicated that they do not currently care for infants/children with FA, and 48% indicated that less than 10% of their practice was composed of pediatric patients with FA. Respondent demographics are shown in Table 1. Respondents worked primarily in ambulatory (46%) and inpatient (37%) settings, and 50% had greater than 15 years of experience working as an RD.

Although participants were given the opportunity to indicate any additional areas of proficiency or resources, no unique suggestions were made confirming that the survey had saturated the topic areas.

### Proficiency

Respondents' self-reported proficiency in various areas of FA management is shown in Table 2. There were

10 FA topics and activities in which respondents were asked to rate their proficiency on a 4-point scale ("high," "moderate," "low," "not at all"). Respondents primarily rated themselves "moderate" for educating families on avoidance, managing the dietary needs of children with multiple FA, identifying adverse reactions to food items and clinical manifestations, and understanding the steps involved in diagnosing FA. Overall, most respondents (>50%) rated themselves less than high proficiency in all areas except for understanding the definition of FA and food intolerance. Very few respondents (<20%) rated their proficiency level high for understanding the steps involved in an FA diagnosis, creating a diagnostic food challenge, developing an elimination diet, evaluating safe food items in a school or hospital setting, and intervening for feeding/behavior problems caused by FA. Only 8% of respondents rated their proficiency high in creating a diagnostic food challenge.

Food allergy affects approximately 5% of infants/children,<sup>1</sup> and so participants who indicated that greater than 10% of their practice is composed of children with FA (ie, 42% of the respondents) likely are seeing referrals

for FA and may be a group with greater expertise and interest in these topics. The authors therefore compared the proportion of respondents with greater than 10% of their practice composed of infants/children with FA to those reporting fewer, with regard to rating their proficiency "high" for each of the 10 knowledge areas. For 9 of the 10 categories (not for creating a diagnostic food challenge), a significantly higher proportion of respondents whose practice included 10% or more with FA rated themselves of "high" proficiency compared to respondents with <10% FA clients (eg, 10% to 67% compared to 5% to 40%, respectively; all *P* values < .05).

### Needs Assessment

The results of queries regarding current educational resources of participants are shown in Table 3, reported as the 5 highest-rated responses for the 268 individuals who answered these queries. Participants were primarily "self-taught" about FA, updated their knowledge through reading professional publications, and used handouts to educate clients.

Respondents were also asked their preference for new materials or

**Table 3.** Current FA Resources Used by Study Population (n = 268)

| Topic                                    | Response for 5 Most Common Resources (%) |
|------------------------------------------|------------------------------------------|
| <i>Education about management</i>        |                                          |
| Self-taught                              | 75.0                                     |
| FA and Anaphylaxis Network               | 58.6                                     |
| Continuing education course              | 51.9                                     |
| Curricular course work                   | 31.0                                     |
| Specialized FA conference                | 24.6                                     |
| <i>Resources for updating knowledge</i>  |                                          |
| Professional/academic publications       | 85.1                                     |
| Advocacy groups written materials        | 72.4                                     |
| Internet academic Web sites              | 59.3                                     |
| Conferences                              | 56.0                                     |
| Advocacy group Web sites                 | 45.5                                     |
| <i>Modalities for educating patients</i> |                                          |
| Handouts                                 | 91.8                                     |
| Individual teaching                      | 75.8                                     |
| Internet based Web sites                 | 36.6                                     |
| Referral to support groups               | 9.7                                      |
| Group teaching                           | 6.0                                      |
| Audiovisuals                             | 6.0                                      |
| FA indicates food allergy.               |                                          |

resources they would most likely use to educate themselves and their clients (Figure). Top preferences for future resources included a handbook on FA management (77%) and Web-based instructional programs (53%). Regarding preference for materials to use to educate their patients with FA, handouts (89%) and an FA management and education handbook (66%) were preferred. Among various modalities to obtain the resources, Internet access was preferred (60.3%) compared to a video/CD (24.2%), a professional publication (19.7%), and availability at a regional conference/lecture (5.5%).

On a 4-point scale ("very," "moderately," "slightly," and "not at all") among practitioners whose practice included 10% or more patients with FA, 87% rated as "very" important the relevance of an easily-accessed resource to update FA knowledge, and 84% rated as "very" important the availability of an easy-to-use "tool kit" to help manage and educate patients with FA. The corresponding rates for practitioners with <10% of their practice composed of clients with FA was 63% ( $P = .08$ ) and 60% ( $P = .07$ ), respectively. Overall, 89% of respondents rated the survey topics moderately to very applicable to their

practices, and among those with practices composed of 10% or more patients with FA, 69% rated the topics "very" applicable (vs 40% among those with less than 10% of their practice having FA,  $P < .05$ ).

## DISCUSSION

This survey was developed to identify the self-reported FA management proficiency and educational needs and preferences of a group of nutrition professionals working with a pediatric population. The genesis of this project stems from recognition of the central role that a dietitian may play in management of children with FA,<sup>6,11,13,14</sup> and the interest of the CoFAR in addressing educational needs of families with children who have FA. Indeed, among the dietitians responding to this survey, 90% indicated that they currently manage children with FA, and 42% have practices where over 10% of their clients have FA.

Despite the high frequency of management of children with FA, the overall study population of dietitians responding to the survey reported only moderate proficiency in a number of areas of importance for management, including identifying the clinical

manifestations of FA, developing elimination diets, educating families about avoidance, managing the dietary needs of children with multiple FA, evaluating the safety of food in schools or hospitals, or managing feeding problems caused by allergies. As the authors observed in the subanalysis, even among dietitians with >10% of their practice composed of children with FA, overall the percentage indicating "high proficiency" was still low for the competency areas (eg, from 10% for creating a diagnostic food challenge to 67% for understanding the definition for food intolerance). One can speculate that when necessary, dietitians will improve their knowledge and sense of proficiency working with food-allergic patients or by seeking out more education on the topics. However, FA appears to be increasing in prevalence,<sup>1</sup> and more dietitians are likely to be called on for management.

These management issues are not simple, and ongoing training is needed to maintain proficiency. In the US, labeling laws have recently changed and dietitians must understand the effects of the law and their limitations.<sup>15</sup> For example, precautionary labeling such as "may contain peanut" is not regulated by the laws, and companies use these provisional labels voluntarily and without guidance.<sup>16</sup> A recent study showed that 7% of products with precautionary labels for peanut had detectable peanut protein and the types of warnings, for example, "may contain" compared to "made in a facility that also processes," did not relate to the risks.<sup>16</sup> Data such as these are not typically known to patients' families and underscore the relevance of guidance, on an ongoing basis, from a knowledgeable dietitian.

Food-allergic children also experience allergic reactions in schools,<sup>17,18</sup> restaurants,<sup>19</sup> and in the home resulting from issues such as poor communication and cross-contact with allergens during meal preparation. In some patients, these reactions may have fatal consequences.<sup>2,20,21</sup> Families rely on detailed instructions to avoid errors, and the dietitian is in a key role to provide the information necessary to ensure safety.

In addition, for children on limited diets, nutritional adequacy must be

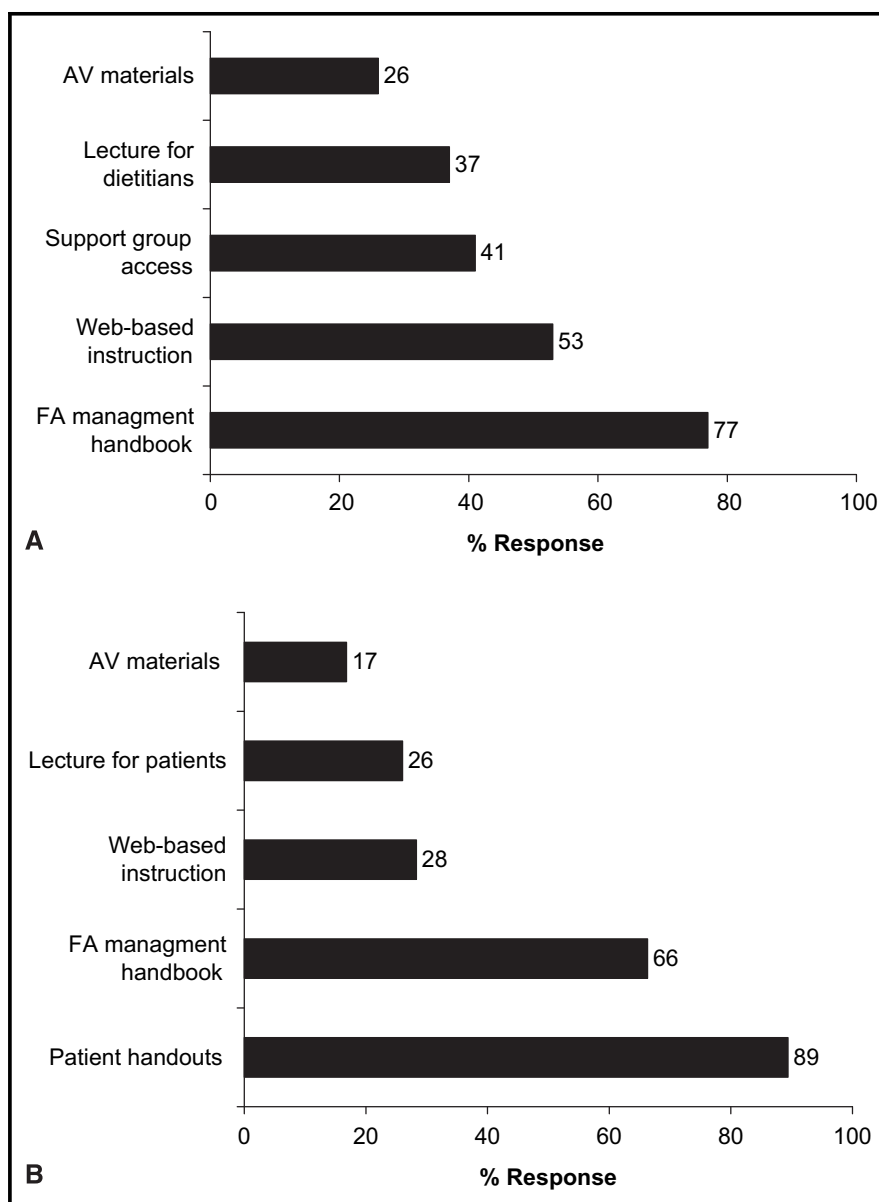


**Figure.** Educational resource more likely to be used by the pediatric dietitian's of the Pediatric Nutrition Practice Group of the American Dietetic Association to (A) update their food allergy (FA) knowledge and (B) to educate their clients with FA. AV indicates audio/visual.

assessed and addressed to promote growth and avoid malnutrition.<sup>11</sup> Various studies have shown nutritional deficiencies resulting from food allergen elimination diets,<sup>12,22-24</sup> but this situation can be avoided by appropriate attention to the nutritional aspects of the diet and by increasing substitutions and supplementation for lost nutrients.<sup>6</sup>

For dietitians who partner with physicians who perform diagnostic oral food challenges, additional expertise is required. The "gold

standard" diagnostic test is the double-blind, placebo-controlled oral food challenge that requires that food items be masked and dosed appropriately.<sup>25,26</sup> Possibly because of lack of familiarity or need to perform the procedure, creating diagnostic food challenges was the skill area rated with the lowest proficiency by dietitians in this study. Currently, information about this procedure is available from several primary sources<sup>25,27</sup> and a handbook for medical professionals created by

the Food Allergy and Anaphylaxis Network.

Approximately 75% of respondents indicated that it is "very" important to have easy-to-access resources available to update their FA knowledge, and a handbook on FA management and patient handouts ranked among the resources most likely to be used. Internet accessibility was rated as the best modality to obtain information. These preferences may explain why current Internet resources were ranked high as a source of information on these topics.

There are several limitations to the current study, primarily because this was an Internet-based survey. The response rate was only 17.5%, although this rate is typical for this type of survey.<sup>28,29</sup> It is possible that persons completing an on-line survey about FA may have a greater interest in this topic than dietitians who did not participate. However, the self-reported rates of clients with FA seem reasonable given that approximately 5% of the general pediatric population has an FA and an even higher number suspect an FA. Another limitation is that participants in an Internet-based survey might be more technology savvy compared to nonparticipants and therefore may have a stronger preference for on-line educational materials rather than resources that are not computer based (eg, journals, books).

In summary, the authors found that pediatric dietitians manage FA for a substantial patient base. However, overall, their self-reported proficiency in key management areas is only moderate. In addition, the survey respondents showed interest in obtaining additional resources.

Food allergy is a growing problem in the pediatric population, and RD who are trained to assist families and children with FA are greatly needed. Managing FA currently requires dietary elimination of the identified allergen, a difficult task in and of itself. The RD, as the nutrition expert, is uniquely qualified to address the nutritional needs of pediatric patients. Those working with patients and families with FA should be expertly trained to provide both the elimination diet instruction, as well as to ensure that the diet is nutritionally complete within the confines of

the allergen-restricted diet. The pediatric dietitians responding to this survey would prefer and likely benefit from Internet-accessible management handbooks and patient handouts.

## IMPLICATIONS FOR RESEARCH AND PRACTICE

Based on some of the identified needs and preferences for FA education identified in this survey, the CoFAR is developing downloadable informational materials for patients that dietitians may use in educating their clients. Additional resources should include Web-based instructional programs such as downloadable handbooks for dietitians and increased attention to FA management in professional society publications and training. These resources may better prepare RD for excellence in FA management.

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