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

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INTRODUCTION

Food allergy, defined as an adverse immune response to a food, is estimated to affect approximately 5% of infants and children.⁽¹⁾ In contrast to food intolerance, food allergy can be severe and possibly fatal.⁽²⁾ Recent epidemiologic studies indicate that food allergy may be increasing⁽³⁾ and also becoming more persistent,^(4;5) with fewer children outgrowing egg or milk allergies in the first years of life. While almost any food can cause an allergic reaction, 8 foods/food groups are responsible for 90% of significant food allergic reactions in the US: milk, egg, wheat, soy, peanut, tree nut, fish and shellfish.⁽¹⁾ In some cases, a trace amount of the food can trigger an allergic reaction. Currently, strict avoidance remains the only treatment option available.

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The dietitian can play a central role in caring for a patient/family with food allergies.⁽⁶⁾ Medical nutrition therapy for those with food allergies should be individualized and include assessment of nutritional status followed by nutrition therapy that includes comprehensive avoidance education while ensuring 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 on identification of allergenic ingredients, careful label reading of manufactured food products and preventing allergen contamination through cross-contact.⁽⁷⁾ Studies show that food-allergic consumers experience allergic reactions due to errors in avoidance.^(8;9) Patients must be taught, for example, that avoiding milk requires the elimination not only of fluid milk, but all dairy products such as cheese, yogurt, butter, ice cream, and many packaged and processed milk-containing foods 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.⁽¹⁰⁾ The dietitian can evaluate and ensure the nutritional adequacy of allergen-elimination diets and suggest appropriate supplements and substitutions.⁽¹¹⁾ « Blinded for review »⁽¹²⁾ showed that children with milk allergy or two or more food allergies were shorter based on height for age percentiles than their non allergic peers. Therefore, comprehensive education should include not only how to avoid specific allergens, but also how to safely and appropriately substitute for eliminated foods and the nutrients inherent in those foods.⁽⁶⁾ Lastly, the dietitian can be invaluable in assisting with diagnostic tests for food allergy, including arranging appropriate allergen elimination dietary trials and oral food challenges. Oral food challenges are physician-supervised graded feedings performed to confirm a food allergy 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 to assist patients with food allergies to effectively avoid the identified allergen as well as meet the required nutritional needs within the context of an allergen restricted diet. We undertook the current study to determine pediatric dietitians' self-reported proficiency, educational needs and preferences regarding methods of distribution for food allergy educational resources.

METHODS

Survey Development

An internet-based survey was developed by a group with expertise in food allergy: 3 registered dietitians, 2 board certified pediatric allergist/immunologists and 2 registered nurses all from the Consortium of Food Allergy Research (CoFAR). CoFAR (www.cofargroup.org) was established in July 2005 by the National Institute of Allergy and Infectious Diseases (NIAID) of the National Institutes of Health to conduct multi-center clinical trials, observational studies, mechanistic studies and basic research toward development of novel therapies for food allergies. An additional goal of the CoFAR is to create educational materials for families with children with food allergies. 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 seven experts developed the initial questionnaire identifying relevant topics in food allergy, common sources of education and with the assistance of a health psychologist, developed the final questionnaire which was piloted for relevance and readability and adapted to an online format. Piloting included 6 dietitians who confirmed the content validity and ease of use. Ten food allergy 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 ten areas. Additional survey questions related to current educational resources used to learn

about food allergy management, updating ones knowledge base on food allergies, and resources used to educate patients with food allergies 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 participant's suggestions of additional resources or areas of need in the event that the pre-constructed 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 of the American Dietetic Association. The Pediatric Nutrition Practice Group (PNPG) is a dietetics practice group of more than 3000 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 1780. Responses were anonymous. The survey was closed to further respondents 4 weeks following the email. 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 are applied for subgroup analyses. A p-value less than 0.05 is considered significant. Percent responses are calculated per question based upon the number of respondents answering the question.

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 food allergies, and 47.6% indicated that less than 10% of their practice was comprised of pediatric patients with food allergies. Respondent demographics are shown in Table 1. Respondents worked primarily in ambulatory (46%) and inpatient (37%) settings and 49.5% had greater than 15 years of experience working as a registered dietitian (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 food allergy management is shown in Table 2. There were 10 food allergy topics and activities in which respondents were asked to rate their proficiency on a four point scale (High-Mod-Low-Not at all). Respondents primarily rated themselves "moderate" for educating families on avoidance, managing the dietary needs of children with multiple food allergies, identifying adverse reactions to foods and clinical manifestations, and understanding the steps involved in diagnosing food allergies. Overall, most respondents (>50%) rated themselves less than high proficiency in all areas except for understanding the definition of food allergy and food intolerance. Very few respondents (less than 20%) rated their proficiency level high for understanding the steps involved in a food allergy diagnosis, creating a diagnostic food challenge, developing an elimination diet, evaluating safe foods in a school or hospital setting and intervening for feeding/behavior problems caused by food allergies. Only 7.7% of respondents rated their proficiency high in creating a diagnostic food challenge.

Food allergy affects approximately 5% of infants/children⁽¹⁾ and so participants indicating greater than 10% of their practice being comprised of children with food allergies (i.e., 42.4% of the respondents) likely are seeing referrals for food allergy and may be a group with greater expertise and interest in these topics. We therefore compared the proportion of respondents with greater than 10% of their practice comprised of infants/children with food allergy 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 food allergies rated themselves of “high” proficiency compared to respondents with <10% food allergy clients, (e.g., 10% to 67% compared to 5% to 40%, respectively; all p -values<0.05).

Needs Assessment

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

Respondents were also asked their preference for new materials or resources they would most likely use to educate themselves and their clients (Figure 1). Top preferences for future resources included a handbook on food allergy management (77%) and web-based instructional programs (53%). Regarding preference for materials to use to educate their patients with food allergies, handouts (89%) and a food allergy 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%), or 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 food allergy, 87% rated as “very” important the relevance of an easy to access resource to update food allergy knowledge, and 84% rated as “very” important the availability of an easy-to-use “tool kit” to help manage and educate patients with food allergy. The corresponding rates for practitioners with <10% of their practice comprised of clients with food allergy was 63% ($p=0.08$) and 60% ($p=0.07$), respectively. Overall, 88.3% of respondents rated the survey topics moderately to very applicable to their practice and among those with practices comprised of 10% or more patients with food allergies, 69% rated the topics “very” applicable (versus 40% among those with fewer than 10% of their practice having food allergy, $p < 0.05$).

DISCUSSION

This survey was developed to identify the self-reported food allergy 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 food allergies,^(6;11;13;14) and the interest of the Consortium for Food Allergy Research in addressing educational needs of families with children who have food allergies (www.cofargroup.org). Indeed, among the dietitians responding to this survey, 90% indicated that they currently manage children with food allergies and 42.4% have practices where over 10% of their clients have food allergy.

Despite the high frequency of management of children with food allergies, 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 food allergy, developing elimination diets, educating families about avoidance, managing the dietary needs of children with multiple food allergies, evaluating the safety of foods in schools or hospitals, or managing feeding problems caused by allergies. As we observed in the sub-analysis, even among dietitians with >10% of their practice comprised of children with food allergies, the percentage indicating “high proficiency” was still overall low for the competency areas (e.g. 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, food allergy appears to be increasing in prevalence ⁽¹⁾ and more dietitians are likely to be called upon 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.⁽¹⁵⁾ 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.⁽¹⁶⁾ 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.⁽¹⁶⁾ Data such as these are not typically known to patient’s families and underscores the relevance of guidance, on an ongoing basis, from a knowledgeable dietitian.

Food allergic children also experience allergic reactions in schools, ^(17;18) restaurants⁽¹⁹⁾ and in the home due to issues such as poor communication and cross-contact with allergens during meal preparation. In some patients, these reactions may have fatal consequences.^(2;20;21) Families rely upon 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 assessed and addressed to promote growth and avoid malnutrition.⁽¹¹⁾ Various studies have shown nutritional deficiencies due to food allergen elimination diets^(12;22–24) but this can be avoided by appropriate attention to the nutritional aspects of the diet and by increasing substitutions and supplementation for lost nutrients.⁽⁶⁾

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 foods be masked and dosed appropriately.^(25;26) 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 our study. Currently, information about this procedure is available from several primary sources ^(25;27) and a handbook for medical professionals created by the Food Allergy & Anaphylaxis Network (www.foodallergy.org).

Approximately 75% of respondents indicated that it is “very” important to have easy-to-access resources available to update their food allergy knowledge, and a handbook on food allergy management and patient handouts ranked among the resources most likely to be utilized. 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 related to this being an internet-based survey. The response rate was only 17.5%, although this is typical for this type of survey.^(28,29) It is possible that persons completing an online survey about food allergy may have a higher interest in this topic than dietitians not participating. However, the self-

reported rates of clients with food allergy seem reasonable given that approximately 5% of the general pediatric population has a food allergy and an even higher number suspect a food allergy. Another limitation is that participants in an internet-based survey might be more technology savvy compared to non-participants and therefore may have a stronger preference for online educational materials rather than resources that are not computer-based (e.g. journals, books).

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

Food allergy is a growing problem in the pediatric population and registered dietitians who are trained to assist families and children with food allergies are greatly needed. Managing food allergies currently requires dietary elimination of the identified allergen, a difficult task in and of itself. The registered dietitian, as the nutrition expert, is uniquely qualified to address the nutritional needs of pediatric patients. Those working with patients and families with food allergies 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.

IMPLICATION FOR RESEARCH AND PRACTICE

Based upon some of the identified needs and preferences for food allergy education identified in this survey, the Consortium of Food Allergy Research 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 food allergy management in professional society publications and training. These resources may better prepare registered dietitians for excellence in food allergy management.

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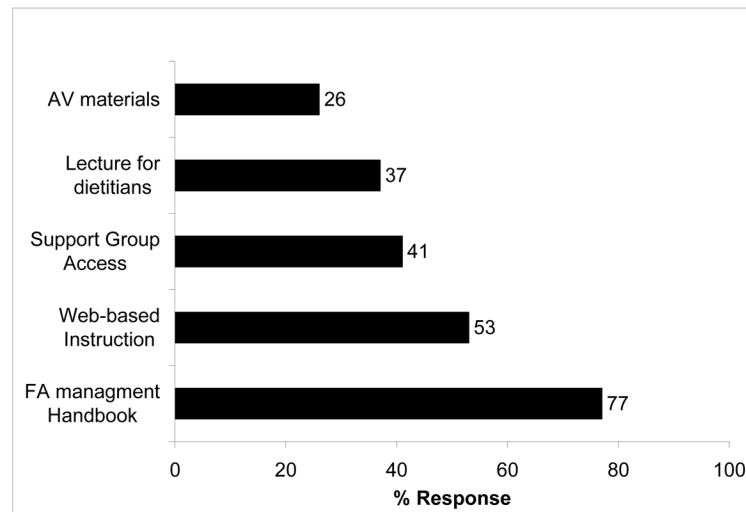
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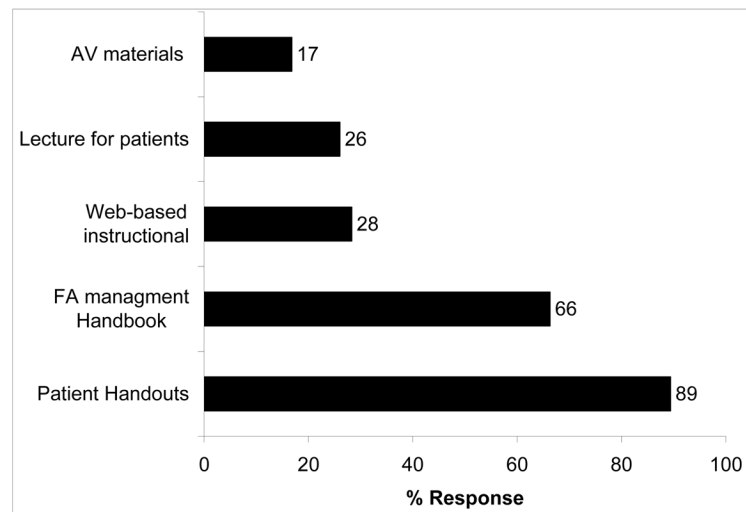
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1 (a) Resources to update FA knowledge



1 (b) Resources to educate clients with FA

**Figure 1.**

Educational resource more likely to be used by dietitians to update their FA knowledge (a) and to educate their clients (b).

Table 1

Characteristics of the study population (n=311)

Characteristic	Response
<i>Years in practice</i>	
0–5 yrs	20.6%
6–10 yrs	14.8%
11–15 yrs	15.1%
>15 yrs	49.5%
<i>Percent of practice comprised 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 one)</i>	
Clinic/Ambulatory	46.0%
Hospital inpatient	37.6%
Private Practice	13.2%
Other	28.3%

Table 2

Self-reported food allergy 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 food allergy (FA) definition	57	41	2	0
Providing avoidance education (e.g., label reading and cross contact)	42	46	12	1
Identifies adverse reactions to foods 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 foods 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

Table 3

Current resource utilization (n=268)

Topic	Response for 5 most common resources
<i>Education about management</i>	
Self-taught	75.0%
Food Allergy & Anaphylaxis Network	58.6%
Continuing education course	51.9%
Curricular course work	31.0%
Specialized food allergy conference	24.6%
<i>Resources for updating knowledge</i>	
Professional/academic publications	85.1%
Advocacy groups written materials	72.4%
Internet academic websites	59.3%
Conferences	56.0%
Advocacy group websites	45.5%
<i>Modalities for educating patients</i>	
Hand-outs	91.8%
Individual teaching	75.8%
Internet based web-sites	36.6%
Referral to support groups	9.7%
Group teaching	6%
Audiovisuals	6%