Published in final edited form as:

Pediatr Allergy Immunol. 2011 September ; 22(6): 575–582. doi:10.1111/j.1399-3038.2011.01152.x.

Developing A Food Allergy Curriculum for Parents

Perla A. Vargas, PhD¹, Scott H. Sicherer, MD², Lynn Christie, RD³, Maureen Keaveny, MA¹, Sally Noone, RN², Debra Watkins, BA³, Suzanna K Carlisle, RN³, Stacie M Jones, MD³, and Consortium of Food Allergy Research (CoFAR)

¹Arizona State University, Social and Behavioral Sciences, Glendale, AZ, United States

²Mount Sinai School of Medicine, Pediatric Allergy and Immunology, Jaffe Food Allergy Institute, New York, NY, United States

³University of Arkansas for Medical Sciences, Pediatric Allergy and Immunology, and Arkansas Children's Hospital, Little Rock, AR, United States

Abstract

Food allergy (FA) is potentially severe and requires intensive education to master allergen avoidance and emergency care. There is evidence suggesting the need for a comprehensive curriculum for food allergic families. This paper describes the results of focus groups conducted to guide the development of a curriculum for parents of food allergic children. The focus groups were conducted using standard methodology with experienced parents of food allergic children. Participants were parents (n=36) with experience managing FA recruited from allergy clinics at two academic centers.

Topics identified by parents as key for successful management included as expected: 1) early signs/symptoms, 2) "cross-contamination", 3) label-reading, 4) self-injectable epinephrine; and 5) becoming a teacher and advocate. Participants also recommended developing a "one pageroad map" to the information, and to provide the information early and be timed according to developmental stages/needs. Suggested first points for curriculum dissemination were emergency rooms, obstetrician and pediatrician offices. Participants also recommended targeting pediatricians, emergency physicians, school personnel, and the community-at-large in educational efforts. Parents often sought FA information from non-medical sources such as the Internet and support groups. These resources were also accessed to find ways to cope with stress. Paradoxically, difficulties gaining access to resources and uncertainty regarding reliability of the information added to the stress experience. Based on reports from experienced parents of food allergic children, newly diagnosed parents could benefit from a comprehensive FA management curriculum. Improving access to clear and concise educational materials would likely reduce stress/anxiety and improve quality of life.

Keywords

children; food hypersensitivity; qualitative; education; quality of life

INTRODUCTION

There is evidence that food allergy is common and increasing, particularly among infants and children,(1) which means that healthcare professionals are being faced with an

increasing burden to care for children with food allergies. Currently, the only way to manage food allergy is through a food allergen avoidance diet and medical management of symptoms. Dietary avoidance is complex and requires thorough education regarding cross-contamination, label reading, and food substitution. This education must often be provided by pediatricians and other primary health care professionals providing healthcare for these children. Previous studies have shown that parents caring for children with food allergies often do not know how to appropriately use emergency medications(2) and experience accidental exposures to foods caused by various errors in purchasing and preparing meals for their children(3). Additionally, assessments of physician's food allergy knowledge shows deficits in the same areas attributable to errors made by families(2, 4). In general, primary care providers may not have the tools needed to educate families of food-allergic children.

We selected focus groups as the first step in the curriculum development process because it is an empirically-based methodology(5) successfully used to identify the educational needs of patients with atopic dermatitis(6), asthma (7–9), and food allergy(10,11). Our main objective was to investigate the parental perspective regarding their food allergy educational needs. This information was then to be used to design a comprehensive food allergy curriculum for parents. A secondary goal was to gather recommendations for effective dissemination of the curriculum to parents of food allergic children. Unsolicited information regarding psychological/behavioral skills and resources sought by parents to effectively cope with the demands of food allergy management was a recurrent theme and is incorporated in this analysis.

METHODS

We conducted four focus groups using a semi-structured interview format following standard methodology(12). Twelve open-ended questions were prepared to elicit responses pertinent to the study goals (Table 1). Questions were developed by a multidisciplinary team of food allergy experts including a dietitian (LC), two nurses (SN, SC), two allergists (SHS, SMJ) and a psychologist (PAV). We opened the discussion with the question *what information you think helped you the most to manage your child's food allergies?* Then questions listed in Table 1 were used to prompt and re-direct the discussion.

The study was approved by the Institutional Review Boards of the University of Arkansas for Medical Sciences (UAMS) and Mount Sinai School of Medicine. A convenience sample of parents of children 1 year old with 1 year of experience managing food allergy who were not enrolled in the observational study of the Consortium of Food Allergy Research (<http://www.cofargroup.org>) were invited to participate by the clinic dietitian at Arkansas Children's Hospital and the clinic nurse at the Jaffe Food Allergy Institute in NY. Participating parents were consented and asked to fill out a brief demographic questionnaire. They then participated in a focus group session that lasted 60 – 90 minutes.

The focus group sessions were conducted in conference rooms at each institution by the same moderator (PV) and assistant moderator (DW) who took field notes. Drinks and snacks were served at an informal social gathering preceding the focus group sessions. Participants were compensated \$40 for their time. All focus groups took place within a 3-month period. The sessions were audio-taped, transcribed verbatim, and coded using qualitative analytic techniques. Preliminary analysis began in a debriefing session between the moderator and assistant moderator immediately after each session.

Transcripts were analyzed by hand independently by two coders (MK and PV); no software was used. Coding consisted of systematically reading the transcripts, grouping similar

responses, and extracting themes. After reading the transcripts several times a preliminary outline of the codes was developed. Coding categories were discussed and agreed upon. Transcripts were re-read and core themes were further analyzed and subcategories emerged. This process was repeated until the final coding system was agreed upon and reviewed by all authors. Recurrent themes emerged during the discussions across questions (Table 1); therefore the results are presented as core themes and subcategories rather than as direct responses to each question. Samples of representative quotes from the parents were selected from among many similar comments to illustrate each theme and subcategory. Discrepancies were discussed and resolved, PV was responsible for all final coding decisions.

RESULTS

Thirty-six parents of children with food allergy (89% mothers) with a median of 5.25 years of experience managing food allergies (range, 1–19 yrs) participated in four focus groups, two in each city --Little Rock, AR and New York, NY. Only two husband and wife couples participated in the focus groups, one in NY and one in Arkansas. Detailed demographic information is presented in Table 2.

Three core themes and subcategories emerged from all four focus groups. Results are presented as core themes and subcategories rather than as direct responses to the questions: 1) curriculum content, 2) recommendations regarding characteristics of the curriculum, and 3) psychological/behavioral issues associated with food allergy management.

Curriculum Content

Four subcategories emerged regarding the curriculum content. Samples of representative quotes from the parents are presented in Table 3

Understanding Early Signs/Symptoms—For most parents, the diagnosis of food allergy was not immediate after the first food allergic event. Both parents and primary care providers struggled with the diagnosis, and in many cases it was not until a severe reaction that the food allergy diagnosis was suspected and later confirmed. Parents agreed that understanding the pattern of symptoms for food allergy early on would have helped them identify the problem and seek out specialized care earlier *e.g., realize that eczema is not normal*. They recommended designing handouts with the risk factors and early signs and symptoms of food allergy using “a grid” to allow parents to see the pattern of symptoms and expedite an early diagnosis. Parents recommended distributing these handouts at multiple settings particularly for expecting parents (see distribution mode below).

Understanding Issues of Allergen “Cross-Contamination”—Most parents acknowledged making multiple mistakes before being able to implement the dietary restrictions recommended by their healthcare provider. Key to the successful implementation was understanding the concept of “cross-contamination” (when an allergen contaminates a safe food during processing/handling) and the fact that dietary avoidance meant avoidance of the “protein” in the offending food and not just the specific offending food (e.g., avoiding “milk” includes not only liquid milk but also cheese, butter, ice cream, and products containing milk proteins (casein, whey) such as baked goods (*e.g. I would lift the cheese off the pizza and keep feeding her pizza*).

Understanding Label Reading—Parents were very cognizant of the importance of label reading for appropriate food preparation. Mastering reading labels provided parents some sense of control and allowed them to shop for groceries with some confidence. Parent

indicated that learning to read labels is a first step, but doing it consistently is a critical point to prevent mistakes.

Understanding use of Self-Injectable Epinephrine—Most families in the focus groups have used epinephrine injections suggesting personal experience with at least one anaphylactic reaction. Parents recommended the inclusion of information covering the need for this skill and the fact that self-administered epinephrine is safe and has very few contraindications.

Characteristics of the Curriculum

Three related subcategories emerged with regard to parents' recommendations of the characteristics of the curriculum: timing, complexity and length, and distribution mode (Table 4)

Timing—Participants suggested that the curriculum should cover different stages of food allergy management (e.g., early identification, diagnosis & management) and child development (e.g., infancy, early childhood, adolescence). Participants stressed the importance of recognizing that as the families progress in the process of food allergy management, their needs change (e.g., from symptom identification to food preparation), and their educational needs also change. On the other hand, as children developed, the needs and challenges that families encounter also change (e.g., going to daycare, summer camp, dating, etc). Finally, parents also recommended extending this education to pediatricians, emergency department physicians, school personnel, and the community at-large.

Length and complexity—Participants had specific recommendations concerning the complexity and length of the educational materials. Most parents reported being overwhelmed by the prospect of having to manage severe food allergies. Some were overwhelmed by the amount of information they had to digest after the diagnosis, often without clear educational materials and/or guidance. Although the internet was mentioned often as a great resource of information, the difficulty and amount of time spent sorting out “the good” from “the bad” was also mentioned as a source of stress. So, the key recommendations included preparing a curriculum with “layers” of information using simple language that parents could access when their needs arise and including a “one page-road map” summarizing the steps to successfully manage food allergy.

Educational Formats and Modes of Distribution—Regarding the dissemination of the curriculum, parents recommended distributing the information in multiple settings such as medical offices (e.g., obstetricians/gynecologists, pediatric, and emergency departments) and hospitals at parents' training and meetings (e.g., CPR training, childbirth classes, La Leche League meetings). Acknowledging differences in learning styles and resources, parents suggested that materials should be available in a variety of formats: printed, video-based, and web-based. Finally, to create confidence among families, parents also recommended having a federal agency or a well know medical institution endorsing the curriculum.

Psychological/behavioral Issues

Becoming Teacher and Advocate—In addition to specific food allergy information, parents reported also benefiting from specific behavioral strategies and resources to effectively manage food allergy (Table 5). Parents reported that learning to be advocates for their children was critical for successful food allergy management. Parents described the role they are forced to play in educating others around them about food allergy and food allergy management.

Coping—Several coping strategies also emerged as part of the core of psychological issues associated with food allergy management. Particularly important was having a support group and/or “buddy system” to help with the ongoing learning to effectively manage food allergies and the stress associated with managing food allergy. Parents emphasized how ongoing learning empowered them, and made them advocates for their children. Parents often sought food allergy information from non-medical resources such as the Internet and support groups. These resources were also accessed to search for ways to cope with stress. Paradoxically, difficulties accessing these resources and uncertainty regarding reliability of the information sometimes added to the stress experience.

Framing—Parents described two general outlooks or “framing” approaches of their experience managing food allergy. Although, both strategies were mentioned in all groups there was a different emphasis among the different focus groups by region: Parents’ “framing” [i.e., a decision maker’s perception of a problem, the outcomes, and the consequence(13)] of the issues associated with food allergy management seemed to have an impact on the level of stress reported. A positive framing as a coping strategy was a core theme that emerged strongly among the parents in Arkansas and was confirmed by some parents in New York. Positive framing was characterized by statements such as *“I think it’s made us better parents... with my boy having his allergies I find myself caring more about what’s going on in his environment.”* On the other hand, a more negative framing and hyper-vigilance (i.e., an ever-present sense that you must watch-out or you might fall victim to harm) was a coping strategy strongly expressed by parents in the New York focus groups and with less intensity mentioned by parents in Arkansas. These parents reported a great sense of loss. They described going to great lengths to provide their children with a “normal” childhood (e.g., *he was going to be able to purchase food outside of my house and feel like a halfway normal kid so if I had to spend 50 hours doing it, I was going to do it*). This sense of loss and hyper-vigilance seemed associated with high stress levels. Hyper-vigilant parents were very much aware of the reaction of others toward them (e.g., *the insane looks I got*).

DISCUSSION

Based on evidence that effective health communication can empower people to make informed health-related decisions and improve their quality of life, and parents’ recommendations, we concluded that parents of newly diagnosed children could benefit from a comprehensive food allergy management curriculum. The curriculum should include a “one page-road map” of the information and skills necessary to successfully manage food allergy including: food allergy signs and symptoms, treatment, use of self-injectable epinephrine, food avoidance, label reading, cross-contamination, and guidance on management outside the home. Recommendations regarding strategies to cope with stress and improve quality of life should also be included. The information should be user-friendly, succinct, using lay terms. Consistent with previous findings (10), parents reported experiencing different phases in their need for information: when first symptoms appeared, when first diagnosed, when they start facing managing issues at follow-up, and at new events and milestones. Thus, the curriculum should be tailored to these different “stages” of food allergy management and child development (e.g., risk assessment for expecting parents, newly diagnosed, going to school, etc.). A curriculum forewarning parents of these stages of change, as well as the resources necessary for such transitions should help families prevent errors. Each step to be mastered should have succinct information and use lay terms with appropriate links to more in-depth information, if needed. Also consistent with Hu (10), was the preference for information in a variety of formats. To fit different needs and learning styles participants recommended using video/DVDs and printed formats as well as a web-based format for distribution. Data from the National Telecommunication and

Information Administration (NTIA) and the Pew Center support the use of the internet as an efficient strategy for distribution of educational materials. In 2010, the NTIA found that approximately 70% of the US population access the internet regularly either from home or work. (14) On the other hand, the Pew Center found that 80% of American internet users, or some 113 million adults, have searched for information on at least one of seventeen health topics and 53% of health seekers report that the most recent health information session had an impact on a health-related decision (15). Compared with traditional methods of health education, web-based formats appeal to patients with different learning styles and educational backgrounds, are easy to use, video clips do not need additional expensive hardware, quality patient hand-outs containing text and graphics can be generated and kept up-to-date inexpensively compared to printed materials and DVDs, and can be tailored to different groups (e.g., pediatricians, nurses, parents) (16–18). Information and links to the web-based curriculum, including materials about early diagnosis, could be made available at different settings such as medical offices (e.g., obstetric/gynecologic, pediatric, and emergency departments) and hospitals (e.g., during birthing classes and CPR training). Although these reflect the parental suggestions, the scope and impact of such materials would need to be investigated. To inspire confidence, the curriculum should be endorsed by highly respected academic and/or research institutions.

Although the study was not designed to inquire about the psychological factors associated with food allergy, the distress experienced by parents due to the lack of reliable food allergy information emerged as a core theme and was thus included in the results. To cope with the stress and anxiety resulting from food allergy management, parents sought multiple pathways including seeking social support and following a pro-active, assertive style to seek-out care and information, advocate for their children, and teach others. Parents described two general outlooks or “framing” approaches of the food allergy experience that seemed to be related to their coping strategies and levels of stress. A hyper-vigilant framework seems to be associated with a sense of loss and high stress levels; while a more optimistic-positive outlook seems to help achieve a sense of normalcy and reduced stress. These different framing styles might be the result of cultural differences due to life-style demands (NY vs. Little Rock) or other factors such as aversion to risk, personality, or the families’ traumatic experiences regarding food allergic events (19). Similarly, Cornelisse-Vermaat and colleagues (20) found differences in the problem solving strategies and levels of frustration reported by patients with food allergies of Greek and Dutch origin.

Food allergy may have a significant impact on quality of life(21–24). Extreme and/or prolonged exposure to negative emotions can trigger some psychological problems (25). Several characteristics of food allergy might elicit high levels of emotional distress, anxiety, and burden for parents. The most critical is the possibility of a fatal anaphylactic reaction to the offending food. Other challenges for families managing food allergies include the ambiguity of food allergy symptoms, the pervasiveness of some food items in the food supply (e.g., milk, egg) and the food-centric nature of most cultures. Despite families efforts to avoid the offending food, unintentional ingestions frequently occur(26). There is evidence showing that caregivers of food allergic children suffer some degree of anxiety in response to the potential for severe reactions and the perceived lack of control in some situations(21, 24). Fear of exposure after a food allergy diagnosis may lead to severe social isolation of the child(23). On the other hand, clinicians might contribute to the psychological distress associated with food allergy by implementing aggressive, yet necessary, dietary changes, as well as providing extensive, potentially frightening, counseling regarding risks associated with unintentional ingestion of the offending food allergens(27). Research has shown the benefit of eliciting positive emotions as a therapeutic intervention to reduce/prevent psychological problems (28). In particular, hope and optimism have been found to buffer against depression (29). Additionally, there is also evidence that the “framing” (i.e.,

emphasizing the benefits of taking action or the costs of not taking action) of a health message might influence people's health behavior.(30) Research exploring successful food allergy management behaviors and the process that shapes them is very limited. Thus, research assessing the psychological factors mediating the families' coping strategies and their quality of life as well as the strategic use of framed messages to promote appropriate food allergy management without high levels of stress among parents and their children is warranted.

The purpose of this study was to investigate the parental perspective regarding their food allergy educational needs. The focus group methodology allowed us to obtain in-depth understanding of the educational needs of parents' managing their children's food allergies, collect their recommendations for newly diagnosed families, and identify their preferences regarding dissemination methods. This methodology was crucial for this initial study. Pre-conceived questionnaires or surveys about preferences may have missed identifying key information generated here such as preferences for management "roadmaps", emphasis on understanding concepts such as "cross contact", preference for "branded" materials, and suggestions to disseminate information beyond pediatricians so that parents can be alert to possible food allergies prior to a doctor diagnosis, among others. We included enough descriptive detail in the results to evoke a vivid picture of the educational needs, concerns and experiences described by the participants. Although some specific suggestions about management voiced by individual participants requires caution (e.g., parental comment that all children with atopic dermatitis require a food allergy evaluation is incorrect), the overall requested approaches to education reflect valid concerns.

Limitations

Focus groups have several limitations. Sometime it is difficult to quantify or draw conclusions from information collected in a group setting. To overcome this limitation, we conducted a thorough analysis of the scripts by categorizing and coding comments. This approach allowed some appreciation of the relative importance of parents' needs and lessons learned. Comments that were repeated across groups were more likely to reflect the consensus of parents. Another limitation is that focus group data may not be generalizable to other populations because participant selection is both nonrandom and potentially non-representative. We were cognizant that participants in the two cities, Little Rock, AR and New York, NY, represented populations with different geographical and cultural influences; however collecting data in both places enhanced the possibility of uncovering experiences and perceptions that supersede local influences. We recruited parents through allergy clinics to include experienced parents that could identify the key information that help them improve/understand food allergy management and make recommendations regarding the format of the educational material as well as methods of dissemination. Our sample may therefore be biased toward highly motivated families of children with more severe food allergies and ready access to healthcare.(31) In addition, participants were predominantly comprised of affluent, non-minority families, and therefore, these results might not be generalized to less affluent, minority parents and children. Focus groups are further influenced by personal motivation to participate (interest in giving opinions, interest in a topic, interest in meeting others to discuss a topic, seeking additional information about a topic, monetary compensation, etc.). Despite these limitations, the range of specific comments about pitfalls and opportunities for educational approaches appears to have been comprehensive and reflects a broad range of past educational exposures (or lack thereof) leading to successes and failures in management.

Acknowledgments

Supported by NIH-NIAID U19AI066738 and U01AI066560, the Consortium of Food Allergy Research. We thank the participating parents and S. Cushing and the EMMES Corporation for their help facilitating the editing of this manuscript.

Reference List

1. Branum AM, Lukacs SL. Food Allergy Among Children in the United States. *Pediatrics*. 2009; 124:1549–1555. [PubMed: 19917585]
2. Sicherer SH, Forman JA, Noone SA. Use assessment of self-administered epinephrine among food-allergic children and pediatricians. *Pediatrics*. 2000; 105:359–362. [PubMed: 10654956]
3. Joshi P, Mofidi S, Sicherer SH. Interpretation of commercial food ingredient labels by parents of food-allergic children. *J Allergy Clin Immunol*. 2002; 109:1019–1021. [PubMed: 12063534]
4. Wang J, Sicherer SH, Nowak-Wegrzyn A. Primary care physicians' approach to food-induced anaphylaxis: a survey. *J Allergy Clin Immunol*. 2004; 114:689–691. [PubMed: 15446292]
5. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII. Qualitative research in health care B. What are the results and how do they help me care for my patients? Evidence-Based Medicine Working Group. *JAMA*. 2000; 284:478–482. [PubMed: 10904512]
6. Gore C, Johnson RJ, Caress AL, Woodcock A, Custovic A. The information needs and preferred roles in treatment decision-making of parents caring for infants with atopic dermatitis: a qualitative study. *Allergy*. 2005; 60:938–943. [PubMed: 15932385]
7. Rhee H, Wyatt TH, Wenzel JA. Adolescents with asthma: learning needs and internet use assessment. *Respir Care*. 2006; 51:1441–1449. [PubMed: 17134525]
8. Raynor DK, Savage I, Knapp P, Henley J. We are the experts: people with asthma talk about their medicine information needs. *Patient Educ Couns*. 2004; 53:167–174. [PubMed: 15140456]
9. Kuiper S, Maas T, van Schayck CP, Muris JW, Schonberger HJ, Dompeling E et al. The primary prevention of asthma in children study: design of a multifaceted prevention program. *Pediatr Allergy Immunol*. 2005; 16:321–331. [PubMed: 15943596]
10. Hu W, Grbich C, Kemp A. Parental food allergy information needs: a qualitative study. *Arch Dis Child*. 2007; 92:771–775. [PubMed: 17488760]
11. Turke J, Venter C, Dean T. Maternal experiences of peanut avoidance during pregnancy/lactation: an in-depth qualitative study. *Pediatr Allergy Immunol*. 2005; 16:512–518. [PubMed: 16176399]
12. Kreuger, RA.; Casey, MA. *Focus groups: a practical guide for applied research*. 3rd ed. Thousand Oaks, CA: SAGE; 2000.
13. Tversky A, Kahneman D. The framing of decisions and the psychology of choice. *Science*. 1981; 211:453–458. [PubMed: 7455683]
14. [Accessed January 2011] U.S. Department of Commerce: National Telecommunication and Information Administration. Digital Nation: 21st Century America's Progress Toward Universal Broadband Internet Access, by the, February 2010. http://www.ntia.doc.gov/reports/2010/NTIA_internet_use_report_Feb2010.pdf
15. Fox, S. [Accessed January 2011] Online Health Search 2006, Pew Internet & American Life Project, Oct 29, 2001. <http://www.pewinternet.org/Reports/2006/Online-Health-Search-2006/01-Summary-of-Findings.aspx>.
16. Richards B, Colman AW, Hollingsworth RA. The current and future role of the internet in patient education. *Int J Med Inform*. 1998; 50:279–285. [PubMed: 9726524]
17. Nicholas D, Huntington P, Williams P, Blackburn P. Digital health information provision and health outcomes. *J Inform Sci*. 2001; 27:265–276.
18. Vargas PA, Robles E, Harris J, Radford P. Using information technology to reduce asthma disparities in underserved populations: a pilot study. *J Asthma*. 2010; 47:889–894. [PubMed: 20846082]
19. Wilson-Forrest KM. 'Never Really Free': Anaphylaxis and the Family Leisure Experience University of Waterloo. 2007

20. Cornelisse-Vermaat JR, Voordouw J, Yiakoumaki V, Theodoridis G, Frewer LJ. Foodallergic consumers' labelling preferences: a cross-cultural comparison. *Eur J of Public Health*. 2008; 18:115–120. [PubMed: 17584733]
21. Sicherer SH, Noone SA, Munoz-Furlong A. The impact of childhood food allergy on quality of life. *Ann Allergy Asthma Immunol*. 2001 Dec.87:461–464. [PubMed: 11770692]
22. Marklund B, Ahlstedt S, Nordstrom G. Health-related quality of life in food hypersensitive schoolchildren and their families: parents' perceptions. *Health Qual Life Outcomes*. 2006; 4:48. [PubMed: 16901348]
23. Klinnert MD, Robinson JL. Addressing the psychological needs of families of foodallergic children. *Curr Allergy Asthma Rep*. 2008; 8:195–200. [PubMed: 18589837]
24. Bollinger ME, Dahlquist LM, Mudd K, Sonntag C, Dillinger L, McKenna K. The impact of food allergy on the daily activities of children and their families. *Ann Allergy Asthma Immunol*. 2006 Mar.96:415–421. [PubMed: 16597075]
25. Fredrickson BL, Tugade MM, Waugh CE, Larkin GR. What good are positive emotions in crisis? A prospective study of resilience and emotions following the terrorist attacks on the United States on September 11th, 2001. *J Pers Soc Psychol*. 2003; Vol 84(2):365–376. [PubMed: 12585810]
26. Nowak-Wegrzyn A, Conover-Walker MK, Wood RA. Food-allergic reactions in schools and preschools. *Arch Pediatr Adolesc Med*. 2001; 155:790–795. [PubMed: 11434845]
27. Jones SM, Scurlock AM. The impact of food allergy: the real "fear factor". *Ann Allergy Asthma Immunol*. 2006; 96:385–386. [PubMed: 16597070]
28. Seligman ME, Steen TA, Park N, Peterson C. Positive psychology progress: empirical validation of interventions. *Am Psychol*. 2005 Jul.60:410–421. [PubMed: 16045394]
29. Cutuli JJ, Chaplin TM, Gillham JE, Reivich KJ, Seligman ME. Preventing co-occurring depression symptoms in adolescents with conduct problems: the Penn Resiliency Program. *Ann NY Acad Sci*. 2006; 1094:282–286. [PubMed: 17347362]
30. Leader AE, Weiner JL, Kelly BJ, Hornik RC, Cappella JN. Effects of information framing on human papillomavirus vaccination. *J Womens Health*. 2009; 18:225–233.
31. Hu W, Loblay R, Ziegler J, Kemp A. Attributes and views of families with food allergic children recruited from allergy clinics and from a consumer organization. *Pediatr Allergy Immunol*. 2008; 19:264–269. [PubMed: 18221466]

Table 1**Focus Group Guide**

1	Let's start with what information you think helped you the most to manage your child's food allergy? Like the "AHA" moment for you.
a.	Where did you find "the answers" and how do you think it should be given to parents of newly diagnosed children to make the process a little bit easier, less stressful?
2	Now, what resources did you find or develop that help you the most to manage your child's food allergy?
a.	Where did you find it/them and how and when do you think it should be given to parents of newly diagnosed children?
b.	Are there resources that you have been disappointed with? What are the problems and how could things have been better?
3	What skills do you think you have developed that help in managing food allergies?
a.	How, when, and where should parents of newly diagnosed children learn these skills?
4	Let's say we want to write the "essential or most important" things to know for food preparation at home for children with food allergies what would you include?
5	What about the "very most important things to know" for "crisis" or emergency management and medication use for an allergic reaction?
6	What about the most critical "need to know" information about shopping for foods?
7	What problems, for example trouble spots you experienced and wished you knew about in advance?
a.	Would you warn newly diagnosed families about?
b.	How would you pass this information along?
8	What about tips regarding dealing with health insurance, schools, ER, doctor's office?
9	If you learn that a friend's child just has been diagnosed with food allergies, is there anything we have not talked about that you would warn her/him about?
10	Is there anything you feel you have not been able to address yet regarding understanding and managing your child's food allergy?
11	Have you joined any support group?
a.	What has been your experience? Did it help?
b.	Have you heard of FAAN?
12	Is there anything else regarding your experience managing your child's food allergy that you think is important to share with us in our goal to create educational materials and supportive resources?

Table 2

Demographic characteristics of focus group participants. Data are presented as percentages and raw numbers (n) unless otherwise noted.

Characteristic	Percentages (n)
Mothers	88.9 (32)
Race - White	94.4 (34)
College graduates	86.1 (31)
Family history of FA	38.9 (14)
Diagnosed by allergist	41.7 (15)
pediatrician	41.7 (15)
Age in years	Median 39.5 yrs Range 30–55 yrs
Length of experience managing FA in years	Median 5.25 yrs Range 1–19 yrs

Table 3

Parents' comments on curriculum content.

CURRICULUM CONTENT	
Understanding Early Signs/Symptoms	
▪	And for the first 1 ½ year, ... I didn't know what my daughter [had], I didn't have Epi pens at home because I just didn't get it... I just didn't know the symptoms.
▪	... it's really important for parents to realize that eczema is not normal. Not all kids get it, not all kids should have it and cradle cap sometimes isn't just cradle cap.
Understanding Issues of Allergen "Cross-Contact"	
▪	A thorough explanation from Dr. [X] about cross-contamination because once I had the big picture in my head ... I felt better navigating the grocery store. But had he not spelled that out very clearly for me I would have made lots of errors
▪	She is allergic to dairy. ... I would lift the cheese off the pizza and keep feeding her pizza. I didn't understand...
Understanding Label Reading	
▪	I was stirring a can of beans ... picked up the can just to see what was in it and had to dump the beans in the trash because it had a nut warning on it ... even if it's a product I've been using for a while I still need to go back and check the labels... So just really realizing that you've got to check the labels.
Understanding Use of Self-Injectable Epinephrine	
▪	... people are terrified of using it because it's a needle ... if this came in a teaspoon or a chewable ... would you think twice ... They look at it as gun.
▪	And I tell everybody shoot him first, call 911 and then call me. Don't call me first

Table 4

Parents' comments on characteristics of the curriculum.

CHARACTERISTICS OF THE CURRICULUM	
Timing	
▪	... there should be almost layers of educational materials, there should be the one that's for the parents who are about to be parents.
▪	What I would like to see eventually... if you have a kid that you even suspect has a food allergy, maybe like a 'kit', like a welcome pack
▪	I think timing is what's so critical here. ... the day you find out about the allergy you need all your emergency stuff
▪	it would help parents if there could be an information packet for third parties [baby-sitter, daycare, school, summer camp, church, etc.]
Length and complexity	
▪	You can't digest it all at once ... you need something concrete to follow-up
▪	...almost 2 months have gone by since her bad reaction ... I really needed like the one pager
Format	
▪	[It should be organized] like a grid almost that if your child has this and this and so that the more likely to go this route
▪	...for your child was just diagnosed packet or now what packet so you should be sort of layers. ... break points.
▪	it's got to be also in plain enough language that people are really gonna understand how to implement it, whatever their education level is
▪	for adults like booklets...[for teens] a web site ...on my Space.
▪	I don't get to [use the Internet]. I don't like computers at all ... I'd rather read a book or it could be something in the mail.
Modes of distribution	
▪	There should be a pamphlet for new parents given by the doctor, the hospital or pediatrician;... like a first aid kit
▪	What about the information package when you leave the hospital?... the NICU?
▪	It has to be at the OB/GYN they gave me loads of sheets every single visit. There had been one where they said, you know, here are the many different signs of food allergy.
▪	It just struck me, oh, a really big, uh, distribution point and I just realized, what about the HMO's and managed care
▪	... something else with a stamp of authority on it from [various well known academic centers], like some collaborative tool to teach parents... one central governmental source...

Table 5

Parents' comments on psychological and behavioral strategies needed for food allergy management.

PSYCHOLOGICAL/ BEHAVIORAL ISSUES	
Becoming Teacher and Advocate	
■	Another piece of advice I wished someone had convinced me of early on was don't be afraid to go to bat for your child... Everyone has something that they'll have to worry about at some point in their life whether it's an illness or an allergy or a disability or a situation and this just happens to be our thing
■	Do not just say my son is allergic to this. If you go into a little bit more detail that if he does eat this, he could die or here's the EpiPen. Like you said just give them a little bit more knowledge instead of just saying well they might break out, they can have a little bit of this it won't hurt them. That's how my father-in-law was, "...a little bit of this won't hurt him". We've come a long way since then...
■	... you are going to be an educator year in and year out with all their friends, every teacher, every bus driver, every principal and none of them know about this. They think of an allergy, they think they sneeze and cough and that's it....
Coping	
■	<i>you got to leave the office with all your emergency stuff...[but you need to] discuss how do you actually carry out your daily living with this. you need something[somebody] concrete</i>
■	...we want our child to fit in ...[talking] to other adults that have the same anxiety and fears ... was helpful.
■	Having some kind of emotional support was important to give you a sense of normalcy...
Framing	
<i>Positive framing</i>	
■	One of my biggest fears was that she'll never be able to go to a birthday party...but that's not true. You learn what's safe for them and what isn't and there's a learning curve, but once you get past that, it'll be okay.
■	Food is just the highlight of so many events... You have to rethink...we don't make our outings always about eating... So trying to figure out activities and places to go and things to do that really aren't about food.
■	When she started school we would look at the menu and try to have a similar meal to what the kids might be eating at school until finally (it was probably the end of last year) she was like, "That is so much trouble! I'd just rather have a roast beef sandwich."
<i>Hyper-vigilance</i>	
■	I'm hyper vigilant about that stuff. And every restaurant I go to, I call ahead they bring out the ingredients for me. I get to look at the packages, it's something I do. So, I think it's also if we're talking about new parents...something I wish I could even balance better is hyper vigilance vs. complacency. Like even in my own house is different, like the amount of times I have to call and say please....
■	... for the first couple years of his life I probably spent on average 5 hours a week on the phone with [food] manufacturers by choice. I just absolutely refused to go down the path that I wasn't...I'm a cook so cooking for him didn't bother me, but he was going to be able to purchase food outside of my house and feel like a halfway normal kid so if I had to spend 50 hours doing it, I was going to do it.
■	I can't go to a park without parents thinking I'm crazy as I'm wiping everything down so that [my children] don't touch anything and there's a peanut butter sandwich at the next table so I have to wipe everything down. You can't go to a restaurant without somebody thinking you're insane.