The Development of Age-Based Food Allergy Educational Handouts for Caregivers and Patients: A Work Group Report of the AAAAI Adverse Reactions to Foods Committee

Jennifer S. LeBovidge, PhD,², Linda J. Herbert, PhD,² Ashley Ramos, PhD,², Nancy Rotter, PhD,², Scott H. Sicherer, MD,⁵, Michael C. Young, MD,³, Michael Pistiner, MD, MMS,³, Wanda Phipatanakul, MD, MS,³, Lisa M. Bartnikas, MD,³,⁴, and Theresa A. Bingemann, MD,²,⁴

Boston, Mass; Washington, DC; New York, NY; and Rochester, NY

BACKGROUND: Food allergy education is an ongoing process that must address unique safety concerns and psychosocial challenges at each developmental stage. Families require reliable information that is targeted to specific developmental stages to support the integration of food allergy management into daily life.

OBJECTIVE: The purpose of this project was to develop age-specific, evidence-based patient education handouts with practical recommendations for managing and coping with food allergies at different developmental stages.

METHODS: Handout content was based on: (1) practice guidelines for food allergy management; (2) literature addressing psychosocial and educational needs of patients with food allergy and their caregivers; and (3) clinical experience of the project team. Fifty-seven caregivers of patients (aged 0-21 years) with food allergy and 2 young adults with food allergy reviewed a draft of the handouts and completed an online survey to assess handout acceptability and usability and identify areas for improvement. Handouts were revised based on participant feedback.
Results: The majority of participants (79%) rated the amount of information in the age-specific handouts as “just right,” versus “not enough” (9%) or “too much” information (12%). Sixty-three percent reported that they would be “very likely” to use the handouts as a resource and 35% “somewhat likely.” Almost all participants (88%-100% by item) agreed that the handouts used elements of plain language writing and clear communication.

Conclusion: Caregivers rated the age-based food allergy education handouts as understandable and useful. We anticipate that these handouts could be used during health care visits and directly accessed online by families.

Key words: Food allergy; Education; Patient; Infant; Child; Adolescent; Parents; Caregivers; Quality of life; Child development

Effective food allergy management depends on allergen avoidance and preparedness to recognize and treat allergic reactions. Comprehensive food allergy education is essential to supporting families’ ability to integrate these management practices into daily life. At each stage of child development, families encounter unique safety concerns, psychosocial challenges, and roles for the child in their own food allergy self-management, highlighting the need for ongoing education that is tailored to the child’s and family’s needs at any particular time. National Institute of Allergy and Infectious Diseases (NIAID) Guidelines for the Diagnosis and Management of Food Allergy in the United States recommend that patients and caregivers be provided with information on allergen avoidance and emergency management that is age-appropriate, as specific quality of life concerns may change as patients mature. Similarly, American Academy of Allergy, Asthma and Immunology (AAAAI) Food Allergy Practice Parameters recommend that food allergy education should be an ongoing process, with specific management recommendations depending on the physical and developmental age of the patient at the time of diagnosis and changing over time.

Published reports of evidence-based educational resources for caregivers of children with food allergy (eg, videos and written materials) suggest that providing families with reliable educational materials can improve important outcomes such as food allergy knowledge, comfort in food allergy management, and patient and family quality of life. Educational materials from trusted sources are particularly important. Families commonly report seeking food allergy–related information on the internet but also report challenges determining which sources are reliable, which can increase stress and potentially compromise safety and quality of life. To our knowledge, there is no readily available food allergy education resource to address the specific needs of caregivers and children at different developmental stages.

This Work Group Report will review developmental aspects of managing and coping with food allergy.

Developmental aspects of managing and coping with food allergy

For young children (eg, infants, toddlers, preschoolers), caregivers are primarily responsible for food allergy management. Caregivers commonly experience anxiety about their ability to keep their child safe. Specific concerns may include introduction of new foods, monitoring for allergic reactions in preverbal children who cannot describe symptoms, and concerns about accidental exposures at a stage when children have frequent mouthing behaviors of their hands and objects. Such concerns may limit family social activities and inform choices about leaving the child in the care of other adults.

Caregivers of school-aged children are tasked with developing food allergy management strategies to enable the child’s safe participation in activities outside of the home (eg, playdates, school, before/after school care, extracurricular activities). Children at this age can play an increased role in food allergy self-management. However, normative developmental transitions, such as school entry, that require reliance on third parties and increased child responsibility for food allergy management may be a source of caregiver anxiety. Around the ages of 8 to 10 years, children may also experience increased anxiety about accidental exposure to allergens and allergic reactions in situations they previously navigated with confidence. Several factors may contribute to increased anxiety, including greater cognitive awareness of risks, misperceptions about the level of risk associated with casual contact with an allergen, and greater independence in food allergy management. Socially, school-aged children are developing a greater awareness of differences from peers due to food allergy, highlighting the need for management strategies that emphasize both safety and social inclusion to foster confidence. They may be at increased risk for bullying or teasing by peers, particularly in the school setting, with implications for self-esteem and anxiety about their physical safety.

For adolescents, there is a transition toward increased responsibility for food allergy self-care, requiring families to negotiate who is responsible for each management task based on the child’s readiness. Adolescents benefit from continued caregiver support, particularly around the planning, problem-solving, and decision-making required for effective food allergy management. As adolescents spend more time outside of direct adult supervision, there is greater concern for risk-taking behaviors (eg, eating foods with precautionary labeling, not reading food labels or asking about ingredients, not carrying their epinephrine autoinjector), particularly in social situations due to concerns about fitting in, feeling embarrassed, or being teased due to food allergies. Barriers to epinephrine carriage and use among teens may also include issues of convenience/size of the device, attitudes of others, beliefs about risk of allergic reaction (eg, low risk for a reaction requiring emergency treatment if they do not plan on eating), and uncertainty about symptoms of anaphylaxis and how and when to use the autoinjector.
addition, adolescents may encounter new situations (eg, romantic relationships, exposure to drugs and alcohol) that pose safety considerations related to food allergy management.

As older adolescents and young adults transition toward primary responsibility for day-to-day food allergy management, it is important for them to understand strategies for managing food allergies in shared living situations, college, the workplace, and romantic relationships, and also understand key aspects of managing their own health care (eg, scheduling medical appointments, filling prescriptions, understanding insurance coverage and copayments).30,60

Consistent with such developmental transitions in food allergy management, caregivers report the need for “roadmaps” for educating children about food and involving them in their own self-care over time.6,9,10,7,2,4,5 Common caregiver concerns include how to balance safety with social inclusion and how to teach children to be aware of possible consequences of allergic reactions without instilling excessive fear and anxiety in the child.5,9,13,18,23,42 Caregivers experiencing high levels of anxiety about food allergy or low levels of self-efficacy around food allergy management may be more likely to limit the child’s role in allergy management and participation in developmentally typical social, family, and school activities, with implications for the child’s quality of life, anxiety level, and sense of empowerment.22,41,43-45 In contrast, “balanced” family coping with food allergy (eg, having sufficient levels of vigilance to sustain allergen avoidance and emergency preparedness, while being able to regulate anxiety and integrate food allergy management into daily life) has been associated with positive quality of life and child involvement in food allergy self-care.63 Such findings highlight the need for educational materials that support caregivers in educating children about food allergies and preparing them for self-care in ways that promote balanced coping with food allergy at all stages of child development.

METHODS

Handout development

Handout content and recommendations were based on: (1) practice parameters/guidelines (Joint Task Force on Practice Parameters, NIAID Guidelines for the Diagnosis and Management of Food Allergy in the United States);5,6 (2) relevant published research literature addressing food allergy management, psychosocial burden of food allergy, educational needs of patients with food allergy and their caregivers, and developmental aspects of coping with food allergy; and (3) clinical experience of the project team (5 pediatric allergists and 4 pediatric psychologists with food allergy expertise). Our overarching goals were to support families in integrating food allergy management into daily life and support children in gradually assuming a larger role in self-management over time. An initial set of content areas/topics was developed by the authors. Two to three authors developed recommendations for each topic. Specific recommendations for each developmental stage were established in consideration of the child’s cognitive, language, social, and emotional development at that particular stage. Subsequently, all authors reviewed the recommendations for each age group and developed additional content as needed.

We based the age/developmental stage categories for the handouts on those used by the American Academy of Pediatrics for their Ages and Stages patient education handouts (www.healthychildren.org) and further divided the grade school and teen stages into 2 separate handouts to reflect changes in children’s self-management capacities across these stages. Stages included baby (0-12 months), toddler (1-3 years), preschool (3-5 years), early school age (5-8 years), late school age (8-11 years), early teen (11-14 years), late teen (14-18 years), and young adult (18-21 years).

We included information central to food allergy management at all developmental stages in a Food Allergy Basics for All Ages handout. Separate handouts were then created for each specific developmental stage, using the same topic headers across stages (when developmentally appropriate), with the specific recommendations tailored by stage. Handouts were caregiver-facing, with the exception of the Young Adult handout that was written directly for the young adult patient. Topics are listed in Table 1.

We used strategies for plain language writing and clear communication to meet caregivers’ varied health literacy needs and support families’ ability to understand and act on handout recommendations (eg, use of common, everyday words and short sentences, simplified definitions for technical terms, concrete examples, action-oriented material, and headers to organize information).

Caregiver/patient feedback

We used an electronic survey to obtain caregiver feedback on a draft of the handouts to assess acceptability and usability of the handouts and identify areas for improvement. The caregiver feedback survey was granted exemption status by the Institutional Review Boards of Boston Children’s Hospital, Children’s National Hospital, and the University of Rochester.

Participants. Eligible participants included caregivers of children with food allergy aged 0 to 21 years and young adults with food allergy receiving care for management of food allergies in the outpatient Allergy Clinics at Boston Children’s Hospital, Children’s National Hospital, and the University of Rochester. Participants were English speaking, as the handouts were available in English only during the development process.

Procedure. Participants were asked to read the Food Allergy Basics for All Ages handout, as well as the age-specific handout for the patient’s age. These drafts included handout content but did not yet include graphics/design elements. If the child’s age fell in the cutoff between 2 developmental stages (eg, 3-year-old who could be included in either the toddler or preschool range), the caregiver was asked to review the handout for the earlier stage. Participants were emailed a link to complete a brief online survey with questions about their opinions of the handouts as well as demographic background.
TABLE II. Demographic and clinical characteristics of survey respondents

<table>
<thead>
<tr>
<th>Caregiver characteristics (N = 57)</th>
<th>%, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver relationship to child</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>89.5, 51</td>
</tr>
<tr>
<td>Father</td>
<td>8.8, 5</td>
</tr>
<tr>
<td>Grandmother</td>
<td>1.8, 1</td>
</tr>
<tr>
<td>Caregiver ethnicity</td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latinx</td>
<td>10.5, 6</td>
</tr>
<tr>
<td>Non-Hispanic/Latinx</td>
<td>89.5, 51</td>
</tr>
<tr>
<td>Caregiver race</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>10.3, 6</td>
</tr>
<tr>
<td>Black or African American</td>
<td>15.8, 9</td>
</tr>
<tr>
<td>Native American or Alaska Native</td>
<td>3.5, 2</td>
</tr>
<tr>
<td>Native Hawaiian or other Pacific Islander</td>
<td>0, 0</td>
</tr>
<tr>
<td>White</td>
<td>75.4, 43</td>
</tr>
<tr>
<td>Other</td>
<td>1.8, 1*</td>
</tr>
<tr>
<td>Caregiver education level</td>
<td></td>
</tr>
<tr>
<td>High school degree</td>
<td>7.0, 4</td>
</tr>
<tr>
<td>GED or other high school equivalency certificate</td>
<td>3.5, 2</td>
</tr>
<tr>
<td>Junior/community college degree</td>
<td>7.0, 4</td>
</tr>
<tr>
<td>Undergraduate degree (4-y college degree)</td>
<td>40.4, 23</td>
</tr>
<tr>
<td>Graduate school degree</td>
<td>42.1, 24</td>
</tr>
<tr>
<td>Annual household income</td>
<td></td>
</tr>
<tr>
<td>&lt;$20,000</td>
<td>1.8, 1</td>
</tr>
<tr>
<td>$20,000-34,999</td>
<td>3.5, 2</td>
</tr>
<tr>
<td>$35,000-49,999</td>
<td></td>
</tr>
<tr>
<td>$50,000-74,999</td>
<td>5.3, 3</td>
</tr>
<tr>
<td>$75,000-99,999</td>
<td>14.0, 8</td>
</tr>
<tr>
<td>$100,000-149,999</td>
<td>22.8, 13</td>
</tr>
<tr>
<td>$150,000-199,999</td>
<td>19.3, 11</td>
</tr>
<tr>
<td>≥$200,000</td>
<td>29.8, 17</td>
</tr>
<tr>
<td>Missing</td>
<td>3.5, 2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child characteristics (N = 59)</th>
<th>%, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child/individual with food allergies, median (range)</td>
<td></td>
</tr>
<tr>
<td>Baby (0-12 mo)</td>
<td>6.8, 4</td>
</tr>
<tr>
<td>Toddler (1-3 y)</td>
<td>15.3, 9</td>
</tr>
<tr>
<td>Preschool (3-5 y)</td>
<td>16.9, 10</td>
</tr>
<tr>
<td>Early grade school (5-8 y)</td>
<td>13.6, 8</td>
</tr>
<tr>
<td>Late grade school (8-11 y)</td>
<td>11.9, 7</td>
</tr>
<tr>
<td>Early teen (11-14 y)</td>
<td>11.9, 7</td>
</tr>
<tr>
<td>Late teen (14-18 y)</td>
<td>11.9, 7</td>
</tr>
<tr>
<td>Young adults (18-21 y)</td>
<td>5.1, 3</td>
</tr>
<tr>
<td>Missing</td>
<td>6.8, 4</td>
</tr>
<tr>
<td>No. of food allergies, median (range)</td>
<td>4 (1-11)</td>
</tr>
<tr>
<td>Child’s food allergies</td>
<td></td>
</tr>
<tr>
<td>Tree nuts</td>
<td>74.6, 44</td>
</tr>
<tr>
<td>Peanuts</td>
<td>62.7, 37</td>
</tr>
<tr>
<td>Egg</td>
<td>57.6, 34</td>
</tr>
<tr>
<td>Cow’s milk</td>
<td>47.5, 28</td>
</tr>
<tr>
<td>Sesame</td>
<td>39.0, 23</td>
</tr>
<tr>
<td>Shellfish</td>
<td>18.6, 11</td>
</tr>
<tr>
<td>Wheat</td>
<td>16.9, 10</td>
</tr>
<tr>
<td>Soy</td>
<td>15.3, 9</td>
</tr>
</tbody>
</table>

(continued)
TABLE III. Participant feedback on handout acceptability

<table>
<thead>
<tr>
<th>What do you think about the amount of information included in the handouts?*</th>
<th>%, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>No enough information</td>
<td>Just right</td>
</tr>
<tr>
<td>Food Allergy Basics for All Ages Handout</td>
<td>1.7, 1</td>
</tr>
<tr>
<td>Handout for your child’s age</td>
<td>8.6, 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How likely would you be to use these handouts as a resource for managing your child’s food allergy?†</th>
<th>%, n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all likely</td>
<td>Somewhat likely</td>
</tr>
<tr>
<td>Food Allergy Basics for All Ages Handout</td>
<td>3.5, 2</td>
</tr>
<tr>
<td>Handout for your child’s age</td>
<td>1.8, 1</td>
</tr>
</tbody>
</table>

*Percentages based on 58 participants completing this question.
†Percentages based on 57 participants completing this question.

discussion

Participant responses to open-ended questions were organized into themes. The most commonly reported responses to the question about anything in the handouts that was particularly useful included clear writing/organization (n = 7), the developmental framework of the handouts (n = 7), information about addressing the emotional aspects of food allergy (n = 6), and comprehensive content (n = 5; see Table V). Some participants provided examples of information in the age-specific handouts that was helpful to them, such as information about ways that a toddler could come into contact with a food allergen and information about addressing kissing and alcohol use with teens. Participants also valued the Resources for Further Information section of the Basics for All Ages handout as a way to identify reliable websites if they have questions or want further details (n = 4). Other comments indicated that the handouts would be a good resource to share with family, friends, childcare providers, and school personnel (n = 4) and that participants wished the handouts were available when the child was younger/felt the handouts would be particularly useful for families of children newly diagnosed with food allergy (n = 6).

Participant responses to open-ended questions about anything in the handouts that was confusing, difficult to understand, or upsetting, as well as suggestions for additional content were used to revise the handouts. The most common comment was that although content was useful, draft handouts were text-heavy/wordy and would benefit from shorter phrasing of key points and incorporation of graphics/more white space (n = 10). No comments suggested any content that should be removed. Examples of changes/additions based on participant feedback included creation of a “definitions” section on the Basics for All Ages handout to clarify terms and reduce “wordiness” within the text; proposed graphics to provide additional information while reducing text (eg, symptoms of an allergic reaction, ways that allergens can be listed on an ingredient label); and specific suggestions for certain sections (eg, clear examples of brands/names for epinephrine autoinjectors, language for explaining food allergies to other people caring for the child, language for teens to use with peers at restaurants, greater acknowledgment of stress for parents of young children with food allergy). We updated the draft handouts to reflect participant feedback from the surveys. Final versions of the educational handouts may be found in Figure E2, available in this article’s Online Repository at www.jaci-inpractice.org.

TABLE IV. Participant responses to items adapted from the PEMAT

<table>
<thead>
<tr>
<th>Please tell us if you agree or disagree with the following statements</th>
<th>Agree with the statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>The purpose of the handouts is clear</td>
<td>%, n</td>
</tr>
<tr>
<td>The handouts use common, everyday language</td>
<td>98.3, 58</td>
</tr>
<tr>
<td>Medical terms are clearly defined</td>
<td>100, 58*</td>
</tr>
<tr>
<td>The material breaks or “chunks” information into short sections that are easy to follow/understand</td>
<td>88.1, 52</td>
</tr>
<tr>
<td>The section headings (eg, “Label Reading”) are clear/informative</td>
<td>94.9, 56</td>
</tr>
<tr>
<td>Material is presented in a logical order</td>
<td>96.6, 56†</td>
</tr>
<tr>
<td>The handouts give clear actions families can take to help children manage food allergies</td>
<td>96.4, 54†</td>
</tr>
<tr>
<td>The handouts break down actions families can take into manageable, clear steps</td>
<td>94.7, 54†</td>
</tr>
</tbody>
</table>

*PEMAT: Patient Education Materials Assessment Tool.
†Percentage based on 58 total responses to this item.
‡Percentage based on 56 total responses to this item.
§Percentage based on 57 total responses to this item.
The finalized handouts are available on the AAAAI website as a publicly available resource and can be accessed at https://www.aaai.org/Tools-for-the-Public/Conditions-Library/Allergies/Food-Allergy-Stages-Handouts. Handouts will be reviewed and updated periodically to ensure that families have access to accurate, up-to-date information. We envision that these handouts could be used by health care professionals as a teaching tool and educational resource in the clinic and easily disseminated to families in the context of telemedicine visits. A practical strategy to facilitate dissemination may include development of a 1-page flyer with QR codes linking to each handout, which could be available in the allergist’s or primary care provider’s office or posted in waiting and/or examination rooms for easy access by families. As highlighted by caregivers in the feedback survey, the handouts would also serve as a tool for educating other individuals caring for the child, such as daycare and school personnel, babysitters, family, and friends. The primary intent of this project was to create caregiver-facing educational handouts. Further work is needed to create patient-facing handouts for older children and adolescents.

It is important to note that the sample of caregivers reviewing the handouts was highly educated, high income, primarily White and non-Hispanic, and English-speaking. This is a limitation of the project, especially in light of disparities that affect health outcomes for children with food allergy and the importance of improving access to food allergy education in racial and ethnic underserved populations. Black and Hispanic children with food allergy in the United States food allergy education in racial and ethnic underserved populations. This is a limitation of the project, especially in light of disparities that affect health outcomes for children with food allergy and the importance of improving access to food allergy education in racial and ethnic underserved populations.

A primary goal when developing the handouts was to provide information that promotes child health and safety, as well as child and family empowerment and positive quality of life. Directions for future research include evaluation of the impact of these handouts on important outcomes, such as child and family confidence in food allergy management and food allergy—related anxiety and quality of life.

TABLE V. Participant open-ended responses about useful aspects of the handouts

<table>
<thead>
<tr>
<th>Theme</th>
<th>n</th>
<th>Representative examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clear writing/organization</td>
<td>7</td>
<td>The language was clear and gave good instructions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I like the way they are written using basic, everyday language</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The breakdown was incredibly helpful. The sections were concise but gave enough</td>
</tr>
<tr>
<td></td>
<td></td>
<td>information to help the reader feel comfortable in that area</td>
</tr>
<tr>
<td>Developmental framework</td>
<td>7</td>
<td>I like the messaging for how to talk to and engage your child in their allergy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>management based on their age</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I haven’t seen them tailored to age before and I think this helps with the mental/emotional side of managing an allergy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I found it helpful that it covered… tips on supporting your child and helping them understand at a young age</td>
</tr>
<tr>
<td>Information about emotional aspects of food allergy</td>
<td>6</td>
<td>Addressing stress and anxiety with food allergies is a good idea to have in the manuals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>How to help children ease their anxiety</td>
</tr>
<tr>
<td></td>
<td></td>
<td>References to not using scary language around food allergies</td>
</tr>
<tr>
<td>Comprehensive content</td>
<td>5</td>
<td>It covers everything, and if I used it, I wouldn’t feel like I was forgetting something</td>
</tr>
<tr>
<td></td>
<td></td>
<td>They covered a good breadth of topics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I found it helpful that the content was comprehensive</td>
</tr>
</tbody>
</table>

Note: Examples based on responses from 40 participants who responded to the questions about useful aspects of the handbook.

REFERENCES


