

The impact of food allergy: the real “fear factor”

Food allergy affects up to 8% of children and 2% of adults in the United States,¹ with the incidence of food allergy, in particular peanut allergy, increasing during the last 10 to 20 years.² Adverse reactions to food allergens are the leading cause of emergency department admissions for anaphylaxis in the United States,³ yet the current available standard of care includes only dietary avoidance and ready access to injectable epinephrine. Otherwise, there is no definitive treatment for food allergy. Food allergens are ubiquitous in our environment but must be strictly avoided to prevent life-threatening anaphylaxis in sensitized patients. Comprehensive patient and caregiver education is a vital component in the management of food allergic patients. This extensive instruction includes wide-ranging topics such as dietary restriction, food label reading, avoidance of cross-contamination, maintenance of a safe home and school environment, education of schools and extended care providers, and appropriate and timely use of medications for symptoms of anaphylaxis. Patients and families with food allergy are therefore bombarded with significant lifestyle changes to prevent potentially life-threatening episodes of anaphylaxis and maintain their health and safety in our world. These changes are often a source of tremendous anxiety and stress for both patient and family, representing a true “fear factor” for daily living among food allergic individuals.

In this issue of the *Annals*, Bollinger and colleagues⁴ have actively addressed this important issue. The purpose of their study was to develop and conduct a preliminary evaluation of a new questionnaire designed to evaluate parents’ perceptions of the degree to which food allergy interferes with various aspects of their children’s and family’s daily lives. Previous assessments have been conducted by other investigators using a variety of health evaluation tools.^{5–8} All of these studies have documented some level of psychological, social, emotional, and/or lifestyle impact of food allergy on children and families. However, few tools currently exist that are specific and comprehensive for food allergy. Bollinger and colleagues are the first to develop a food allergy–specific questionnaire that measures parents’ perceptions of the impact of food allergy on the daily activities of food allergic children and their families. This new scale is also the first to identify specific child and family activities that are avoided because of food allergy.

The Food Allergy Impact Scale is a 32-item questionnaire based on a 7-point Likert scale that was designed using a

variety of survey tools for food allergy, chronic disease, quality of life, and family impact of disease. The Food Allergy Impact Scale was tested in 101 children ages 8 months to 17 years (mean age, 5.14 years) recruited from the Allergy Clinic at the University of Maryland Medical Center. The study group is unique, with the broadest age range of patients studied to date, and representative of diverse racial and socioeconomic backgrounds. Most patients studied also had comorbid allergic disease. This is the first group of patients evaluated for social-emotional outcomes that encompasses the spectrum of food allergy in a subspecialty allergy practice.

Questionnaires were returned by 86% of the participants, with most (69%) completing the 15-minute survey during the clinic visit. This finding indicates the ease of administration and utility of this survey in a clinical practice setting. The investigators documented many important social-emotional issues within their study population. One of the most important findings was the impact of food allergy on meal preparation and meal preparation activities in almost 70% of participants. Of even greater interest is the finding that 50% to 60% of participants reported that the child’s and/or the family’s social activities were significantly altered. In particular, children’s activities were modified or eliminated with respect to out-of-home play times with friends, participation in sleepovers, camp and birthday party attendance, sports participation, and school field trip activities. The primary family behaviors that were altered included avoidance of going to restaurants and allowing their children to participate in play activities at a friend’s house. A significant proportion of parents (41%) also reported increased stress related to their child’s food allergy. Many also reported difficulty separating from their children. However, parental employment, finances, and family relations were not as significantly affected. Most of the child and family stressors were positively correlated with the number of involved food allergens, with greater impact associated with increased numbers of food allergens avoided. Interestingly, association of findings with a specific food allergen or with a prior history of anaphylaxis was not seen. By controlling for comorbid factors during data analysis, the investigators demonstrated that food allergy remained the key factor associated with their findings.

Findings from this study point toward social, psychological, and emotional consequences for both children and families that require further large-scale investigation. Most clini-

cians who treat and counsel food allergic children and counsel their parents are acutely aware of the significant life impact of food allergy. Investigators have reported continued avoidance of foods (eg, peanut) to which children have become tolerant despite medical advice to remove diet restriction.⁹ Others have indicated "food fears" and associated food aversion among children with food allergy. These observations further emphasize the impact of food allergy. We, as clinicians, contribute to the psychological and lifestyle consequences associated with food allergy by implementing aggressive, yet necessary, dietary changes, as well as providing extensive, potentially frightening, counseling regarding risks associated with inadvertent ingestion of implicated food allergens. Clinicians, however, are poorly equipped with the appropriate evaluation tools to evaluate the emotional and psychological impact and needs of our food allergic patients.

The Food Allergy and Anaphylaxis Network (FAAN) has worked diligently as an advocacy and support organization to provide families with appropriate education in consistent formats. Some of these formats include monthly newsletters, Web-based information, support and advocacy groups, informational meetings, and national seminars. However, not all patients have or seek access to FAAN or work within any support network. In addition, FAAN resources are meant to be used in conjunction with clinical evaluation of individual patients and their specific problems encountered because of food allergy, further highlighting the need for development of applicable evaluation tools and interventions for the clinical setting.

Findings from this study indicate that a diagnosis of food allergy has a significant influence on the child's and family's activities, resulting in potentially serious implications for the child's psychosocial development and the psychological well-being of the family. Since these associated stressors could potentially lead to adverse long-term effects on the individual patient's life, further study is vital to provide an accurate evaluation of both the short- and long-term consequences. This ground-breaking work by Bollinger and colleagues provides an important framework for future studies. Their work was conducted through the collaborative efforts of investigators with expertise in child psychology and pediatric allergic disease. This collaboration likely contributes to their fresh perspective on the social-emotional impact of food allergy and their overall concern about the long-term consequences for affected children and families. The Food Allergy Impact Scale is an exciting new tool that will help to better evaluate needs and tailor care for food allergic children and their families. Larger cohort studies in independent, diverse populations are essential to better understand the depth of this problem and to further validate this novel instrument. Further study is needed to examine the implications of restricting family activities among food allergic children, their parents,

and their siblings. In particular, does this restriction affect the social development of children and does it have psychological consequences in either the short or long term? More work is needed to evaluate the child's perspective in association with the parental perspective and to incorporate the perspective and impact on other family members, such as siblings. Additional work is also needed to examine the parents' emotional needs and the impact of disease on their own mental health, including their relationships with their children, spouses, family members, health care team, and others in society.

As allergy specialists, we must continue our advocacy efforts for children and families dealing with food allergy through progressive education, provocative research, and comprehensive clinical care. Overall, more objective data and new interventions are needed to improve the quality of life and overall health for children and families affected by food allergy.

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REFERENCES

1. Sampson HA. Update on food allergy. *J Allergy Clin Immunol*. 2004;113:850–819.
2. Sampson HA. Managing peanut allergy. *BMJ*. 1996;312:1050–1051.
3. Sampson HA. Anaphylaxis and emergency treatment. *Pediatrics*. 2003;111(6 pt 3):1601–1608.
4. Bollinger ME, Dahlquist LM, Mudd KE, 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;96:415–421.
5. Cohen BL, Noone S, Munoz-Furlong A, Sicherer SH. Development of a questionnaire to measure quality of life in families with a child with food allergy. *J Allergy Clin Immunol*. 2004;114:1159–1163.
6. Primeau MN, Kagan R, Joseph L, et al. The psychological burden of peanut allergy as perceived by adults with peanut allergy and the parents of peanut-allergic children. *Clin Exp Allergy*. 2000;30:1135–1143.
7. Sicherer SH, Noone SA, Munoz-Furlong A. The impact of childhood food allergy on quality of life. *Ann Allergy Asthma Immunol*. 2001;87:461–464.
8. Avery NJ, King RM, Knight S, Hourihane JO'B. Assessment of quality of life of children with peanut allergy. *Pediatr Allergy Immunol*. 2003;12:378–382.
9. Fleischer DM, Conover-Walker MK, Christie L, Burks AW, Wood RA. Peanut allergy: recurrence and its management. *J Allergy Clin Immunol*. 2004;114:1195–1201.