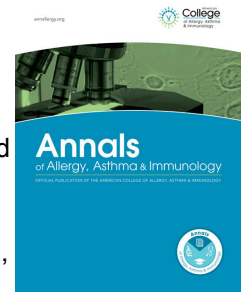


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Pediatric Allergists' Perspectives on the Psychosocial Challenges of Food Allergy and Factors that Support Coping

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Abbreviations: Food Allergy = FA,

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Tables: 1

1 Individuals with life-threatening food allergy (FA) often experience elevated anxiety as
2 they avoid accidental exposure to allergens, modify daily routines, and undergo treatments: In
3 sum, quality of life can be adversely impacted.¹⁻⁵ Allergists providing diagnostic and treatment
4 services for these patients frequently hear about these psychosocial struggles, however, little is
5 known about the interaction of the medical and psychosocial needs of FA children and families.³
6 Therefore, this study was conducted to explore the challenges children and families encounter
7 during their FA journey, and factors associated with better coping and adjustment from the
8 allergist perspective.

9 We conducted 6 semi-structured interviews with a convenience sample of board-certified
10 allergists who treat a high volume of children with FA (Table 1). Allergists who expressed
11 interest at an educational conference for patients with FA in Chicago, IL were recruited to
12 participate. A licensed clinical psychologist (with experience counseling FA patients) and a
13 research study coordinator (experienced conducting qualitative interviews) developed the
14 interview script (Supplemental Appendix 1) and conducted all interviews. The aim of the
15 interviews was to elicit allergists' perspectives on the following: 1) patients' psychosocial
16 progress through significant events in FA management, 2) major factors contributing to elevated
17 anxiety in FA patients, and 3) positive coping patterns utilized to improve psychosocial
18 outcomes. Interviews lasted 45 minutes to one hour, were audio recorded, transcribed,
19 and systematically analyzed using NVivo software to identify emerging themes.

20 Regarding psychosocial progress among children with FA, allergists consider diagnosis,
21 management, and treatment to occur along a spectrum that requires a flexible approach. As
22 several reported, "it is not a one size fits all" practice. Allergists engage in longitudinal
23 relationships with patients and their parents and described the importance of the patient at initial

diagnosis and the coinciding behavioral adaptations that follow. Allergists observed that with younger children, the child may not be especially anxious, while many of their parents are. Allergists also observed that starting school and eating without parental oversight are impactful transitions. Although older children may have a better understanding of FA, they participate in more independent activities, leading to heightened parental anxiety. These factors are connected to the youth's anxiety and calculation of FA-related risk.^{2,6-8}

From the allergist perspective, the major factors contributing to elevated anxiety in FA patients included: fear of the auto-injector needle, anaphylaxis, and apprehension of participating in food challenges or Oral Immunotherapy (OIT). Anxiety following an anaphylactic reaction may be brief or persistent, and can interfere with everyday functioning. An allergist noted, "there is no protocol for treating issues from OIT. As their primary allergist, I am responsible for the fallout." Although allergic reactions and epinephrine use can be scary and disruptive, these experiences are often opportunities for positive coping as successfully using epinephrine can bring a sense of relief after the unknown is faced. Following a reaction, allergists review what happened and "stress the importance of either reinforcing what they already did or encouraging them to do it differently next time." Allergists remarked that those who self-administered epinephrine are "certainly more likely to administer epinephrine in the future" because "they realize it wasn't the worst thing in the world, we have that experience in our food challenges too." This allergist again reiterated that food challenges are an opportunity for families to mitigate their fear of the unknown.

With regard to other positive coping patterns, major themes that emerged from the interviews included thoughtful and balanced communication (within the family and between the physician and family) and having credible health information to share with children. Allergists

described a feedback loop between parents and children; children take cues from their parents, and thus their level of anxiety often reflects their parents' level of anxiety. One allergist commented on the importance of parents recognizing their own anxiety and coping skills, stating, "parents should be encouraged to transfer their knowledge to children, not all of their worries.". An allergist also expressed that healthy coping is promoted when parents communicate using reassuring dialogue ("we'll get through this") rather than expressing their own anxiety and fear. Allergists can encourage this by asking questions such as "What's your greatest fear?" and "What do you actually think will happen?" With this in mind, when high stress and social isolation are present, a mental health referral may be warranted, concluded some allergists.

Allergists universally emphasized that, for many families, coping is impeded by misinformation regarding FA. As one physician remarked, "people with misinformation have a harder time coping." Allergists provide psychoeducation, consistent messaging, and counseling to help families cope with FA, but because a diagnosis can trigger strong emotions, it is important that accurate information is repeated to families. An allergist described this, saying, "it takes more than one time to build rapport and have things sink in." Some allergists routinely have parents come in for counseling without the child, noting, "you are taking care of the kid, but you are [also] managing the family unit, as you should be."

In summary, these allergists characterize patients' psychosocial adjustment to FA as occurring across a developmental spectrum, and consequently, their care and counsel varies. However, one piece that remains important across the developmental spectrum is the need for open communication and consistent education. To this end, the development of educational materials (such as brochures, apps, virtual groups, etc.) that offer scientifically informed

resources for the psychosocial management of FA would be helpful in supplementing the counseling allergists already provide to families. Additionally, training that outlines and supports when allergists should refer patients to mental health professionals would be beneficial, and could create a team that serves the psychosocial needs of patients.

While this study is limited by the small convenience sample, these interviews were conducted to act as a catalyst for further discussion and study on this need in care. Future research in this population should include a larger and more diverse sample of allergists with varying backgrounds, experiences, and patient populations, so that appropriate and comprehensive psychosocial treatment for FA patients and families nationwide can be better understood and designed.

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Table 1: Allergist Demographics

Variable	N= 6
Years in Practice	
15 years	2
16 years	1
17 years	1
18 years	2
Hours Spent in Patient Care per Week	
15- 25 hours per week	2
26- 35 hours per week	3
36- 45 hours per week	1
Location of Practice	
Urban	3
Suburban	2
Rural	1
Region	
Midwest	2
West Coast	1
Northeast	3
Type of Practice	
Private Practice: Group practice	3
Academic Medical Center Practice or Clinic	1
Hospital Owned Practice or Clinic	2
Practice Affiliated with a University or Academic Institution	

Yes	3
No	3
Percentage of Medicaid Patients	
0-25%	2
26-50%	2
51-75%	2