

The Unmet Needs of Patients with Food Allergies



Melissa L. Engel, MA^a, Bryan J. Bunning, MS(c)^{b,*}

KEYWORDS

- Food allergy • Anxiety • Developmental psychology • Adolescence • PRO
- Oral immunotherapy

KEY POINTS

- Food allergy–related anxiety is prevalent among pediatric patients and their caregivers.
- The current treatment paradigm, involving only strict allergen avoidance, is associated with anxiety-related symptoms. An appropriate level of anxiety is protective to the patient. However, in excess, anxiety may decrease quality of life.
- As pediatric patients transition into adolescence and adulthood, responsibility of care must shift from caregiver to patient. The anxiety that often co-occurs with food allergies among both patients and caregivers may make this transition difficult.
- A great deal of uncertainty surrounds daily self-management, leaving patients and caregivers to frequently crowdsource guidance, which is of variable utility.
- Managing treatment expectations and addressing psychological concerns regarding exposure will be increasingly important as various forms of allergen immunotherapy become available.

Food allergies present patients with a unique set of psychosocial challenges. As others have reviewed, many of these challenges involve elements of anxiety, which can be defined as anticipation of future threat.^{1–3} From a psychological perspective, this is expected. As a protective measure, individuals with food allergies have been conditioned, often from a very young age, to associate their allergens with danger. They have learned through experiencing an allergic reaction, or, in the case of a young child, through parental modeling, that exposure to their allergens is a severe threat to bodily integrity. Although variants of immunotherapy are on the clinical horizon, only peanut-specific oral immunotherapy has approval in the United States; thus, allergen avoidance and emergency epinephrine administration remain the current food allergy treatment for most of the allergic population.⁴ Patients have been explicitly directed by physicians to strictly avoid their allergens. Although such allergen avoidance is critical,

^a Department of Psychology, Emory University, 36 Eagle Row, Atlanta, GA 30322, USA;

^b Department of Biostatistics, Mailman School of Public Health, Columbia University, 722 West 168th Street, FL R6, New York, NY 10032, USA

* Corresponding author.

E-mail address: Bjb2178@columbia.edu

from a cognitive-behavioral perspective, avoidance is precisely what may fuel anxiety. Others have argued that a certain level of anxiety is adaptive for individuals living with food allergies.⁵ The authors take this 1 step further, suggesting that anxiety should be considered a side effect of the recommended food allergy management strategy of avoidance.

This article reviews psychosocial challenges faced by individuals with food allergies through both daily self-management and through treatment (Box 1). Next, it addresses the allergy-anxiety relationship as an unmet need for the patients or their caregivers, in part because of a lack of clear guidance and the heterogeneity of food allergy severity and management. Then, it highlights the dearth of research on the transition to adulthood and calls for an increased focus on the psychosocial needs of individuals with food allergies across children’s development. As more and more pediatric food-allergic patients become adult food-allergic patients, this is a critical direction for future research. In addition, this article highlights the conflict that may arise as patients switch from the previous paradigm of avoidance to one involving avoidance, including a therapy with constant and measured exposure. With an increasing number of exposure-based food allergy therapies on the horizon, this will be a growing issue.

THE ANXIETY OF DAILY MANAGEMENT: ARE THERE PEANUTS ON THE PREMISES?

Traditionally, to be labeled clinically significant, anxious thoughts and/or avoidant behaviors must be deemed out of proportion to the degree of threat.³ Cognitive-behavior therapy to treat anxiety may generally focus on altering cognitive misappraisals of danger and preventing avoidant behaviors.⁶ This focus presents a challenge when it comes to food allergies, in which allergen exposure may be life threatening and allergen avoidance is paramount. Furthermore, many behaviors that are associated with anxiety and are considered maladaptive, such as perfectionism, repeated checking, leaving social situations, and hypervigilance, may be adaptive in the context of food allergies.^{6,7} Interestingly, longitudinal epidemiologic research has identified that youth with food allergies are at increased risk for symptoms of anxiety, as well as depression and anorexia nervosa, but not actual psychiatric disorders.^{1,8} These anxious symptoms tend to be specific to food allergies, as opposed to general fear or anxiety. Although such symptoms may be subthreshold from a psychiatric perspective and reflect reasonable adaptations to living with food allergies, they may also negatively affect quality of life.⁹ For instance, youth with food allergies report increased rates of anxious coping, as well as symptoms of separation anxiety, social anxiety, and panic disorder.¹⁰

It is easy to see how anxiety is an inherent part of food allergy management; fear of allergen exposure is what motivates allergen avoidance and prevents potentially life-threatening risky behavior. Patterns of increased anxiety and reduced quality of life are

Box 1
Summary of unmet needs in food-allergic patients discussed in this article

- Establishing and promoting practices for the safe transition of care from caregiver to patient
- Understanding the impact of transition of allergy-related care on a family unit
- Creating and disseminating patient-centered psychoeducational information
- Psychosocial difficulties in adults with food allergies
- Preventing and treating patient and parent anxiety related to desensitization treatments

common among families of children with food allergies.¹¹ However, it is difficult to determine what level of avoidance constitutes adaptive versus excessive. Allergen avoidance can range from simply not eating buckets of peanuts to approaching every life activity by first detecting whether there is even the slightest chance that there have been any peanuts on the premises. Although the latter approach may reduce reaction risk, such paralyzing fear may also lead to an overly restricted diet and avoidance of social situations, which have serious consequences for child and adolescent growth and development.¹² Furthermore, 1 study of children with seafood allergy found that parental over-restriction of children's diet was not associated with decreased risk of accidental reactions. In fact, over-restriction was associated with increased anxiety and decreased quality of life.¹³ Thus, at a certain level, heightened anxiety, avoidance, and restriction may exert significant psychosocial cost with little physical benefit. It has been suggested that pediatric allergists are not well prepared to identify clinically significant anxiety among patients.¹⁴ Perhaps this is because there is little consensus as to what an appropriate so-called Goldilocks, or just-right, level of anxiety looks like.⁵ At what point should food allergy worries, checking, restrictions, and avoidance be considered excessive? Patients with food allergies, and perhaps allergists as well, need guidance as to what constitutes helpful versus harmful anxiety. Without such guidance, overly anxious individuals may simply be labeled adherent, with no detection of anxious distress or opportunities for behavioral interventions.

Importantly, how food allergy-related anxiety manifests changes across development. Younger children show fear of going places without their primary caregivers, whereas older children and adolescents experience fear surrounding uncertain social situations, negative social evaluation, and bullying.^{15,16} Beyond adolescence, there is remarkably little research on anxiety in adults with food allergies,² perhaps because the food allergy epidemic has increased only in the past few decades, mostly affecting children.¹⁷ Given that many children currently with food allergies will become adults with food allergies, prospective longitudinal research following allergy-related anxiety across development is critical.

The limited existing research suggests that adults with food allergies indeed experience anxiety. Adults with food allergies have reported experiencing anxiety related to food safety and social situations, and young adults with food allergies who rated themselves high in health competence reported experiencing anxiety from maintaining constant vigilance.¹⁸ Although this research is in its infancy, there is far more literature devoted to the psychosocial issues faced by adults in relation to parenting a child with food allergies. Mothers of children with food allergies experience greater rates of stress, anxiety, and depression, and these symptoms have each been linked to children's food-related anxiety, emotional functioning, and social limitations.¹⁹ However, little is known about exactly how these dynamics shift across development.

ALL GROWN UP?

Throughout childhood, food allergy management is often in the hands of the primary caregivers. As mentioned earlier, caring for a child with a life-threatening condition is an enormous responsibility and thus often comes with a burden of stress and anxiety.¹⁹ In addition to keeping a child with food allergies physically safe, caregivers carry the additional responsibility of teaching the child skills to manage the allergies autonomously and develop independence before reaching adulthood. Across medical conditions, health care transitions from pediatric, parent-supervised care to adult, patient-centered care are rife with vulnerability, and transitions in food allergy management are no exception.²⁰ Caregivers who teach too much vigilance set the stage

for anxiety, whereas those who do not teach enough vigilance predispose the risky behavior that is already common in adolescence, resulting in an increased potential for life-threatening reactions.⁵ However, caregivers have insufficient guidance when it comes to scaffolding children through such developmental transitions. Clarity and guidance are made difficult by the vast heterogeneity, at both the individual and population levels, that characterizes food allergens as well as the degree of severity of the reactions they provoke.²¹ However, patients with food allergies and their families are in need of more structured developmental recommendations. Although individual circumstances call for unique timelines, creating a centralized, vetted template of food allergy-specific developmental milestones may be a worthwhile endeavor. At what age should the average child with food allergies be reading labels, speaking with a chef on their own, or independently carrying their epinephrine? Creating such guidelines may instill caregiver confidence and alleviate stress while simultaneously giving allergists developmental benchmarks to routinely assess.

Pediatric patients with food allergy and their caregivers need assistance in navigating this transition safely while maximizing quality of life, especially given that mental health disorders, such as anxiety and depression, are highly prevalent and persistent among adolescents, with less favorable trajectories among those with chronic illness.^{22,23} As previously discussed, there is little research examining the long-term outcomes of youth who experience food allergy-related anxiety. However, the developmental psychopathology literature suggests that there is reason for concern. Child and adolescent anxiety may not be a transient phenomenon that disappears over time but may be the root of psychological distress across the lifespan. Children and adolescents who experience anxiety are more likely to experience anxiety, depression, and substance use as adults.²⁴ Developmental psychologists have argued that properly managing child anxiety may prevent a future of diverse mental health problems, and this advice may be applicable to youth with food allergy-related anxiety.²⁴ Developmental psychologists have also highlighted the intergenerational transmission of anxiety from parents to children, and research indicates that such anxiety is directly transmitted through the environment, rather than genetically.²⁵ When applied to food allergies, this suggests that some young patients may model their parents' anxious behaviors and subsequently grow to experience psychological distress themselves. Thus, in order to prevent young people with food allergies from developing future psychological challenges, routine screening and monitoring of anxiety among children and adolescents with food allergies is warranted. This monitoring may be especially important when transitioning the responsibility of care from caregiver to patient, an ambiguous and highly variable period of time that may be fertile ground for anxiety. As others have reported, the lack of availability of mental health services for patients with food allergies is a major unmet need, and integrating mental health professionals into allergy clinics is a priority.²⁶

IN SEARCH OF CERTAINTY

Regardless of who holds the burden of responsibility, stress among patients and caregivers with food allergies remains high. Perceived stress generally depends on how unpredictable or uncontrollable individuals interpret their circumstances to be.²⁷ Given that uncertainty is a core feature of allergic reactions, and that intolerance of uncertainty is a key component of emotional distress, it is rational that individuals with food allergies, or their caregivers, feel a high degree of stress and a need to reduce this distress by feeling in control.^{6,21} As Feng and Kim¹ (2019) have asserted, "the stress from having a food allergy may be more burdensome than the food allergy itself"

(p. 77). Qualitative research suggests that parents of children with food allergies sense that they are perpetually on guard and feel a strong need to control every aspect of their children's daily lives.^{2,28,29} Such need for control may explain why many parents of children with food allergies have been found to avoid dining out or to repeatedly visit the same safe restaurant; limit travel based on perceived risk of airplanes and overnight stays; and restrict children's participation in play dates, sports teams, camp, birthday parties, and even school.^{1,7,28,30,31} Likewise, it may explain why stakeholders in the food allergy community place a high priority on the area of product labeling, rating it far more important than researchers perceive.³² Current precautionary allergen labeling is inconsistent, and patients with food allergy and their parents report a need for greater clarity.³³ In the absence of such clarity, patients and caregivers need tools to manage the stress associated with daily uncertainties.

A dearth of clear information with regard to food allergy management, aside from allergen avoidance and epinephrine administration, leads many patients and parents to make decisions rooted in fear rather than facts.³⁴ For instance, despite little evidence supporting the efficacy of peanut-free schools, tables, or airplanes, such policies often give parents a greater perception of control.³⁴ Likewise, despite little evidence of the smell of peanut butter, aerosolizing peanut dust on airplanes, or minor skin contact with peanut butter causing a reaction in most patients with peanut allergy, many individuals endorse these beliefs and mold their behaviors around these potential situations.^{34–38} Messages delivered by the media, as well as by providers, tend to emphasize worst-case scenarios, such as fatality, setting the stage for anxiety-driven thoughts, feelings, and behaviors, which some patients describe as paralyzing.^{34,39}

Clarity, education, and support are major unmet needs in the food allergy community, leaving many to find this information through whatever means necessary. Many patients and caregivers now turn to the Internet, where they may find supplemental information from large food allergy organizations and local support groups.⁴⁰ In addition, individuals managing food allergies may also look to crowdsourcing for lifestyle guidelines or advice. This tendency is evident by quickly searching through the preponderance of Facebook groups, Instagram pages, and apps geared toward individuals with food allergies and their families. In addition, individuals who were recently diagnosed with food allergy have been shown to be more likely to use social media for allergy-related purposes.⁴¹ As of September 2020, membership in the Dining Out With Food Allergies Facebook group exceeded 29,000, the No Nuts Moms Group exceeded 32,000, and the Food Allergy Adventurers Club: Managing Food Allergies at Disney exceeded 12,000. That patients and caregivers with food allergies are seeking help is undeniable; however, less known is the effectiveness of such unvetted crowdsourced information. One study noted that individuals generally report finding online resources and social media helpful, and another study found that the top reasons for online engagement included searching for information about food allergies, asking questions, and looking for safe restaurants.^{40,41} It is important to recognize that the Internet is full of misinformation, including when it comes to food allergies.¹ Although parents have reported valuing information offered by consumer organizations, certain aspects have been found to be unhelpful, such as advice that was not applicable to their unique experiences, and anxiety contagion from interaction with anxious parents.⁴² The potential for an iatrogenic effect from online resources, such as social media groups for parents of children with food allergies, is further supported by a study identifying new information regarding potential risk as a key contributor to renewed parental anxiety.⁵ It is possible that frequent exposure to anxiety from other parents of children with food allergies, whether it be through articles about severe allergic reactions or posts about excessive social restrictions, may serve to increase parental

anxiety rather than provide reputable, evidence-based information. This area is important for future research to explore.

To complement this crowdsourced information, the authors suggest that allergy researchers, clinicians, and educators continue to create and promote patient-centered psychoeducational materials. To reduce anxiety and improve quality of life, patients and families need practical guidance for navigating daily life and the development process while managing food allergies. Research suggests that a food allergy management curriculum may simultaneously educate parents, model adaptive coping, and empower them with a sense of control.⁴³ Furthermore, many parents have identified lack of knowledge among other parents and the school system as major contributors to anxiety, suggesting that allergy education efforts on a population level are critical.^{2,28,29} Education in schools has also been suggested as a method to decrease social anxiety among children.⁴⁴ Such education may simultaneously decrease stigma and bullying while increasing safety in the event of an emergency.

THE ANXIETY OF TREATMENT: YOU ARE EXPOSING ME TO MY KILLER?

As clinicians move toward the next generation of therapy, it is important to remember where patients are coming from psychologically. Patients' were taught strict avoidance and have developed a framework to manage it and then suddenly have an option for a desensitization-based therapy. Some may have trouble adapting to the therapy at a psychological level. Anxiety and stress are heterogeneous between patients and their caregivers.¹¹ Adapting and helping high-stress-level families will only become more important as desensitization treatments become more widely available. It is important to provide support and acknowledge the confusing situations treatment may put pediatric patients and/or their caregivers in. The patient's and caregiver's mental state is one of many factors that should be taken into account on an individual basis. The first iteration of oral immunotherapy is not a 1-treatment-fits-all situation. It is well established that immunotherapy is not a therapy for everyone, because it requires strict compliance and high time investment.⁴⁵ Further, it is a treatment with both benefits and risks, including adverse events associated with therapy.⁴⁵⁻⁴⁷ Although research into sustained unresponsiveness is ongoing, compliance is essential for the up-dosing and maintenance phases of oral immunotherapy.⁴⁵ Looking ahead, there is hope that combination therapies, including those using biologics, may lessen the burden of desensitization-based therapies on the patients and their families.⁴⁸

When initiating immunotherapy, allergists may consider drawing from the child anxiety literature on exposure therapy. Exposure therapy for anxiety disorders such as specific phobia, obsessive-compulsive disorder, or posttraumatic stress disorder is conducted in a graded fashion. Rather than taking children who cannot swim and throwing them into the ocean, psychologists aim to get in the pool with the children and give them floaties.²⁴ In collaboration with the children, psychologists often create a fear hierarchy, in which patients may gradually work up to exposing themselves to feared stimuli. Each exposure is preceded by extensive preparation and followed by thoughtful processing. Adapted for patients with food allergies, this may begin with imaginal exposures, such as simply asking a patient to imagine seeing or touching a peanut, followed by looking at pictures of peanuts, smelling peanuts, and touching peanuts, all before ingestion. After ingestion, patients discuss how this experience made them feel, not only physically but also emotionally.

Acknowledging the anxiety and mental state of the patient and the caregivers, and further managing expectations, can remove uncertainty for the patient and family,

reducing overall stress. This approach is especially relevant for pediatric patients and may have potential to improve outcomes and quality of life. A study by Howe and colleagues,⁴⁹ sought to use a mental framework as a method to improve patient quality of life during immunotherapy. In this randomized, blinded controlled trial, patients (n = 50) and their caregivers were randomized 1:1 and informed that non-life-threatening symptoms were either (1) unfortunate side effects of treatment or (2) a potential signal of the desensitization process. Those who were informed that symptoms signaled the desensitization process were significantly less likely to report being anxious and report experiencing a non-life-threatening adverse event.⁴⁹ Fostering and acknowledging the mindset of patients and using psychological tools to help them has potential to improve not only experiences and overall stress but potentially clinical outcomes as well.

SUMMARY

Patients with food allergies often experience anxiety because of the daily self-management and potential new desensitization treatments for food allergies. On one hand, anxiety can be seen as a necessary adaptation to remain vigilant and physically safe. In excess, however, anxiety can lead to significant psychological distress and impairments in quality of life. Little is known about food allergy anxiety across the lifespan, and patients and caregivers could benefit from guidance in developmental milestones, transitioning from parent to patient responsibility, and managing anxiety throughout this vulnerable period. In the absence of clear guidelines, patients and caregivers have turned to crowdsourced information with varying levels of utility. Patients are in need of reviewed guidelines from established knowledge sources. As more pediatric patients reach adulthood, this will be a critical target. Furthermore, as advanced therapeutic options become available, it will be important to provide individualized recommendations, considering and minimizing children's and caregivers' levels of anxiety, and draw from psychological research to best support the transition from a paradigm of avoidance to one of exposure through desensitization. Although improved therapeutics give hope for reduced overall patient and caregiver burden, it is important to ensure that the psychological burden of disease is acknowledged and minimized in the process.

CLINICS CARE POINTS

- An understanding of the psychosocial nature of food allergy and the relationship between allergic child and caregiver can improve outcomes.

DISCLOSURE

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