

Psychosocial Aspects of Food Allergy

Resiliency, Challenges and Opportunities



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KEYWORDS

• Food allergy • Quality of life • Psychosocial • Resilience • Development • Anxiety

KEY POINTS

- Food allergy has many psychosocial impacts and can worsen quality of life in affected patients and their families.
- The psychosocial impacts of food allergy vary by age group and developmental stage.
- Resilience may improve quality of life in food allergy. Allergists can promote resilience through encouraging education, problem-solving, self-efficacy, enhancing social support, engagement in school, and meaning making.

Food allergy (FA) is a public health concern, affecting approximately 8% of US children and 10.8% of adults, and has been growing in prevalence.^{1,2} The constant vigilance to avoid allergen exposure can lead to distress and decreased quality of life (QOL).³ In addition, specific FA treatment, such as oral food challenges and allergen immunotherapy (eg, OIT), which may promote QOL and adjustment in the long-run, are often anxiety-producing while occurring.⁴⁻⁶ Certainly, the experience of anaphylaxis and the prospect of epinephrine administration by autoinjection (EAI) is often accompanied by heightened anxiety, impacting patients and caregivers.^{6,7} Research in other chronic medical diseases has found that a focus on resilience can decrease the burden and improve the experience of living with chronic medical conditions.⁸ This article highlights recent (within the past 10 years) research on psychosocial aspects related to FA within a developmental framework. Clinical recommendations are provided, contextualized within the construct of resilience.

DEVELOPMENT AND RESILIENCE

Contextual changes and evolving performance demands interact with brain and hormonal changes to move children through development.⁹ Developmental tasks vary

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greatly by age, but involve growth and maturation in broad areas, such as emotion-behavioral regulation, social connection, and executive functioning.⁹ Key microsystem contexts influencing child development include families, early care settings, schools, and peers, whereas macrosystem factors include poverty and racism.⁹

Resilience is characterized by the ability to maintain a positive developmental trajectory, or even flourish, in the face of adversity,^{10,11} and has been studied in other chronic pediatric conditions (**Box 1**).⁸ A limited view of resilience as a character trait that resides in an individual undervalues the power of systemic processes in promoting healthy outcomes; thus, resilience reflects the systemic influences that an individual accesses across time when managing adversity.¹⁰ Adversity is, of course, not uniformly bad for children; with proper support, navigating challenges can set the stage for the development of adaptive skills,¹⁰ and adaptations in one context can be transferred to other contexts.⁹ Factors that are frequently associated with childhood resilience across cultures include family factors (eg, nurturing caregivers), problem-solving skills, self-efficacy, emotion regulation, belief systems (eg, optimism, meaning making), positive engagement in school, and connection within communities.¹⁰ The construct of resilience has been extended to the family itself; key family resilience factors include belief systems, organizational processes (connectedness, flexibility), and communication/problem-solving (eg, open and positive emotional sharing, collaborative problem-solving, clear and consistent information).¹¹ Importantly, resilience is bolstered by boosting resources or assets and mobilizing systems. Allergists working with individuals with an FA are in an optimal position to enhance resilience by identifying individual and family strengths and providing resources to bolster important resiliency variables.

FOOD ALLERGY THROUGHOUT THE LIFESPAN

Infancy, Toddlerhood, and Preschoolers

Early childhood is marked by the development of interpersonal attachment, executive function, and cognitive-emotional and behavioral integration, setting the stage for later successful self-regulation.⁹ These skills are largely dependent on a child's ability to actively engage with their environment. This age group has the highest prevalence of FA¹ and management of FA differs from older developmental stages in that the burden of responsibility falls solely on parents and caregivers.^{12,13} Young children, such as toddlers, may require extra oversight because they may independently grab food or introduce oral exposure through thumb sucking or putting toys in their mouths.^{14,15} Identifying a food-allergic reaction is particularly difficult because language skills are still being acquired through infancy and toddlerhood, and the child may not be able to communicate a reaction.¹³ Parents must balance the difficult FA-related tasks with encouragement of typical development and exploration; constant monitoring of the child may decrease the child's sense of autonomy and increase the risk of separation anxiety.^{12,16} As point of fact, mothers of preschool children with FA are more likely to intervene needlessly with general tasks (eg, puzzle solving) than mothers of children without FA.¹⁶

Box 1

Definition of resilience

Resilience is the ability to maintain a positive developmental trajectory in the face of adversity. The quality of life of children with food allergy and their caregivers is optimized by health care providers bolstering resiliency factors during routine clinical care.

Childcare (eg, day care facilities, babysitters, and/or extended family) may be among the first instances where the child is fed outside the home.¹³ One study in anaphylaxis in infants less than 12 months old found that anaphylaxis occurred in the care of the mother 65.2% of the time; the babysitter was present in 30.4% of cases, and the grandmother in 4.3% of cases.¹⁷ Parents with allergic children report worry surrounding the choice of a safe day care, even electing to forgo out-of-home employment,¹⁸ and may limit participation in social activities, such as eating at restaurants, attending preschool, or having playdates.¹²

School-Age Children

Middle childhood is characterized by increasing independence, developing self-regulation, academic knowledge acquisition and deepening interpersonal skills, with relationships to caregivers moving from proximity to availability.⁹ FA in school-age children in the United States is common, affecting an estimated 8% of 6- to 10-year-old children, and 7.5% of 11- to 13-year-old children.¹ As children with FA age, their growing awareness of the FA may coincide with a growing sense of uncertainty on how to manage it.¹⁹

FA may pose challenges for increasing the breadth and depth of interpersonal relationships, critical developmental tasks for school-aged children. Honing social skills and expanding social networks often involve activities outside the home, such as dining at restaurants, participation in sports, and sleeping over at friends' houses. Many of these social activities involve eating without parental oversight; children aged 7 to 12 have worse parent-reported FA-related QOL compared with younger children, which has been related to the perception of a higher risk of accidental ingestion while away from family.²⁰ The self-reported psychosocial experience of school-aged children with FA has not been well-studied, but existing research suggests generally similar levels of anxiety between children with and without FA,²¹ although children with FA may be at increased risk for post-traumatic stress symptoms, particularly if they have experienced an anaphylaxis episode.²²

One transition that is particularly important for this age group is the increased time spent at school. School is a place where children spend a significant amount of time, and consume meals; several recent reviews highlight important FA school-related considerations, guidelines, and legislation.^{23,24} Nearly 40% of schools reported having at least one food-allergic reaction within the past 2 years.²⁴ Nearly half of all children with FA report the experience of being bullied, which can include teasing, criticism, and even being threatened with the allergen.^{3,25}

Adolescents

Adolescence is a period of dramatic brain growth, intentional skill development, emotion intensity, expanding decision-making skills, social cognition, autonomy, self-awareness, and identity formation.⁹ It is marked by reliance on the peer group. It is also the developmental stage where the impact of FA is notably potent; adolescents have the highest risk of anaphylactic reactions from FA and the highest risk of death.^{26,27} Although there are conflicting results as to whether adolescents with FA have a higher incidence of psychological difficulties compared with healthy peers, some studies do note increased risk of mental health concerns^{28,29}; risk factors include gender (eg, boys with FA may be at particular risk for social anxiety) and maternal anxiety.³⁰ Youth with FA also report greater dating anxiety and fear of negative peer evaluation.³¹

The increased autonomy in adolescence sets the stage for a pivotal transition in FA: the transition of management from the parent to the patient.¹² This increased

responsibility has been shown to also increase anxiety for some adolescents with FA.^{26,32} Because most fatal food-allergic reactions during adolescence occur when away from home,¹² supporting adolescents in safely navigating new situations and relationships is imperative. Adolescent FA risk-taking behaviors include decreased adherence to carrying epinephrine, eating foods that may contain an allergen, and not speaking up if a reaction is suspected.^{19,33} In one study, only 42% of adolescents with FA asked about food ingredients at restaurants, and only 35% asked at friends' houses.³² Supportive family, peers, and teachers have been shown to be related to less risk-taking behavior, as has having a school 504 plan.²⁶ Although decreasing risky behaviors is important for successful FA management, there is a downside: youth with FA with less risky behavior also report greater barriers to normal socialization (eg, going to restaurants or to other people's homes) than do youth with more risky behavior, which may put them at risk for greater isolation.²⁶

Adults

Developmental tasks of emerging adulthood may include navigating a period of notable instability (eg, multiple job changes, series of intimate relationships), whereas established adulthood often includes commitments in romantic relationships and careers, and the stressors associated with parenthood.³⁴ Adults with FA have previously been a topic of little attention, with few published studies; however, the prevalence of FA in adults is increasing, estimated to affect approximately 1 in 10 adults.^{2,35} One in four adults with FA report developing the allergy as an adult.³⁶ Only a few psychosocial areas related to adulthood have been studied in FA (eg, college, work); many important areas, such as the experience of pregnancy for a person with FA, cohabitating with friends, the impact on significant partners, or parenting as an adult with FA, remain unexamined.

Literature pertaining specifically to the young adult population with FA is sparse, and young adult samples are often integrated with adolescent samples. Many studies in this age range center on college experiences. Twenty-five percent of FA-related deaths occur in 18 to 22 year olds; approximately 50% of these deaths occurred on college campuses.^{37,38} Among students who have had a reaction while at college, 62% of reactions occurred on campus, and 21% occurred at restaurants.³⁹ College students with FA report generally avoiding foods with known allergens and paying attention to posted ingredients of foods prepared on campus.⁴⁰ However, they often do not specifically ask about ingredients in foods prepared by others. Other risky behavior of college students with FA includes inappropriate use of an EAI: 16.4% of college students with an EAI always carry it; 17.9% report never carrying it.⁴⁰ There are a variety of factors that contribute to the decision on whether to carry epinephrine, including the concern of informing peers about the FA.^{19,41,42} The psychological health of young adults with FA has been understudied, but a greater risk for anxiety or depression has been associated with FA in college students.⁴³ However, in a study using the National Health and Nutrition Examination Survey data to examine the mental health of adolescents and adults with FA, no association between mental health and FA was found for adults.²⁹ This may indicate that patients develop their own coping strategies with their FA with time.

Studies examining the daily experience of FA in adults highlight the significant burden associated with FA. In a study collecting daily reports of the experience of more than 100 adults with FA (average age, 40.2 years; range, 18–87), participants reported experiencing an FA-issue on nearly 50% of days, with incidence of FA-issue associated with heightened stress; most common issues were related to availability and cost of allergen-free food, allergic reactions, and the stress of navigating social

situations.⁴⁴ Studies of FA-specific QOL in adults highlight the negative impact of allergen restriction, fear of FA worsening, uncertainty and anxiety about the diagnosis, and anxiety about an allergic reaction.^{45,46}

Because adults are generally autonomous in their management of FA, they also carry the tremendous economic burden of FA,⁴⁷ which can include direct (eg, food, medical care) and indirect costs (eg, lost labor productivity, time spent information seeking, time spent on FA-related household tasks).^{48,49} More than 25% of adolescents and young adults with FA reported FA as a barrier to obtaining employment.²⁶ Costs may be one of the contributors to the low rate of EAI access in adults.³⁶ Only one in three adults with FA have one at age 50, and even less by age 60.^{2,14} In addition to life-saving, having an EAI may improve FA QOL.³⁶

FAMILY ADJUSTMENT

Parents experience significant challenges caring for a child with FA, including maintaining vigilance and managing uncertainty related to accidental exposures, advocating for their child across systems (eg, school, camps), and managing treatment tasks (eg, OIT or EAI use). Parents must provide ongoing FA education (at the appropriate developmental level), navigate the tension of allowing their child increasing autonomy while maintaining appropriate supervision, and provide emotional support to their child.^{6,50} This burden has been found to increase parental anxiety surrounding FA.¹² Mothers specifically have been found to have increased stress and anxiety compared with other family members.³ Child FA can also exert a financial toll on families, with parents reporting diminished work productivity or job loss related to managing their child's FA.⁴⁸ Not surprisingly, parents of children with FA report higher levels of stress, anxiety, and depression compared with parents of healthy children, and fluctuating patterns of parental distress have been found, such as anxiety worsening after an anaphylaxis event.^{6,50} Parental distress is related to the psychosocial functioning of their child with the FA.³⁰ Parenting practices are impacted by FA, with youth who have experienced anaphylaxis reporting greater parental protection,⁵¹ and parents who report high levels of parental overprotection note poorer child functioning.⁵² Of course, with FA in particular, families must balance the need for vigilance with promoting child autonomy. In a recent study of family coping patterns, about half of the families fell into the "Balanced Responder" category, characterized by appropriate vigilance, moderate anxiety, the ability to integrate the FA into daily lives, and children with FA having good FA management skills.⁵³ In addition to impacting child psychosocial functioning, parent anxiety may impact FA knowledge acquisition or retention.⁵⁴ Although understudied, siblings of children with FA also report considerable worry about FA, and involvement in FA management, including anaphylaxis events.⁵⁵

PSYCHOSOCIAL TREATMENT

There is a dearth of outcome studies examining the impact of psychosocial interventions for patients with FA. A study of an FA sleep-away camp for 11- to 12-year-old children that focused on education and confidence-boosting physical activities reported improvements in several aspects of anxiety and QOL at 6-month follow-up.⁵⁶ A group-based half-day workshop for children 5 to 7 years old that involved medical play, social, and emotion-based activities was rated positively by children (pre and post psychosocial variables were not assessed).⁵⁷ Two studies have targeted specific FA anxieties. A prospective randomized trial targeted anxiety about casual allergen exposure in youth 9 to 17.5 years of age; everyone received education about the minimal risk of casual allergen contact, and youth randomized to the intervention were asked

to hold a cup with a nut kernel then instructed to touch the nut in a step-wise fashion (followed by hand-washing). All participants reported decreased worry 1 month later.⁵⁸ Another randomized trial targeted EAI-related anxiety. Thirty adolescents were coached in the self-injection of a sterile 25-gauge needle, whereas the control group were provided education and demonstration of self-injection on a dummy. All youth in the intervention were able to self-inject, and the group reported improved comfort with self-injection relative to the control subjects.⁵⁹

More research has investigated psychosocial interventions developed to support caregivers. A systematic review conducted in 2020 identified 15 interventions (involving 6511 participants).⁵⁰ Of note, only two studies were randomized controlled trials, and most studies scored poorly on the standardized quality assessment tool used for the review. Educational interventions were most common (in 7/15 studies), involved face-to-face and online delivery of material, and consistently improved FA knowledge and caregiver confidence in managing FA. Psychological interventions included components, such as psychoeducation, self-regulation, problem-solving, and cognitive-behavioral therapy, and corresponded with improvements in psychosocial outcomes. Of note, dose of intervention varied widely (eg, one session cognitive behavioral therapy, 12 sessions cognitive behavioral therapy, three 25-minute telephone calls). Two parent support groups were reviewed, with reported decreases in social isolation and anxiety and increased confidence in talking with allergy providers (in a support group including an allergist).

CLINICAL IMPLICATIONS

Pediatric psychosocial preventive health models highlight the importance of assessing risk and resiliency factors, and providing preventive and intervention efforts to optimize child and family biopsychosocial outcomes.⁶⁰ Some patients with an FA present with obvious and significant risk factors that require referral to appropriate psychosocial or community services. Signs of significant risk may include (but are not limited to) significant economic hardship; heightened and/or persistent psychological distress; patient struggling to meet developmental milestones; and patient/family inadequately managing FA, such as evidenced by heightened risk of allergen exposure or inability to complete FA treatment tasks (eg, OIT, EAI use). However, all patients with FA benefit from interventions that enhance known resiliency factors. Resiliency factors that dovetail closely with the experience and demands of FA include education, problem-solving, self-efficacy, enhancing social support, engagement in school, and meaning making (eg, coming to understand one’s life events in a way that fosters positive adjustment, such as enhancing a personal sense of purpose or growth). FA provides opportunities to the treating clinician to enhance these factors across the developmental span (Box 2).

Box 2
Resilience-building clinic activities

Activities that can occur during clinic visits to strengthen resiliency include:

- Education
- Problem-solving
- Enhancing self-efficacy
- Social support
- Meaning making

Education

Education is the cornerstone of successful navigation of any health condition. Families deserve up-to-date information about the true risks related to allergen exposure. FAs, by definition, are restrictive; when people overestimate the risk of exposure and subsequently narrow their experiences beyond what is reasonable or necessary, QOL suffers. Education related to symptoms of allergen exposure should be initiated early; by age 9 to 11, children should be able to recognize signs of anaphylaxis.⁶¹ Education on appropriate use of EAI is also essential, and is life-saving, yet many FA sufferers identify problems with the training that was provided.^{36,49} The mandate for high-quality information provided by knowledgeable health care providers is clear; a recent review of the quality of FA publicly available videos (on YouTube) demonstrated poor-quality information, including blatantly misleading information.⁶²

Problem-Solving

Problem-solving is a skill set characterized by active engagement in addressing challenges, delineating a challenge into concrete and actionable goals, generation of ideas, selecting a possible solution, and evaluating the result after implementation; training in these skills has been shown to enhance positive adjustment in health conditions.^{63,64} Clinicians should regularly ask patients and families the problems they encounter in managing the FA, and can be framed in terms of important activities not occurring (“What are the things you wish you could do but do not, because of your FA”), or lapses in management (“I know it is important to you to not have an allergic reaction – what got in the way of you asking about the ingredients?”). Brainstorming solutions means generating a variety of ideas for addressing the problem; clinicians can offer possible solutions from their expertise and experience talking to hundreds of patients/families, but eliciting ideas from the patient/family themselves is critical because these ideas are generated within their own context and values. Importantly, individuals and families may choose a solution that is okay, but not optimal from the perspective of the clinician; a solution that is grounded in a family’s values and context is most likely to be used.

A critical caveat that clinicians must be sensitive to is that real health disparities exist among patients and families with FA (discussed elsewhere in this issue). Families should not feel the burden of solving systemic barriers to managing health; allergists must be knowledgeable of community resources available to address disparities, and consider their own role in advocating for equitable health care.

Self-Efficacy

Self-efficacy involves the belief a person has about their ability to perform specific tasks, and their belief that performing the task will have a positive outcome. A person’s self-efficacy is enhanced by mastery experiences (personal and observing others) and by the assurances of others that the person can be successful, and has been associated with improved health outcomes, positive psychological adjustment, and improved QOL.⁶⁵ Parents with greater self-efficacy in managing FA reported better QOL, particularly in social settings.⁶⁶ For young children, general self-efficacy is promoted by parents allowing exploration and highlighting successes in skill acquisition; allergists can discuss with even young children the positive ways they take care of their bodies (“You are learning to brush your teeth! Good for you!”). As children age, allergists can encourage increasingly shared FA responsibilities between the parent and child, such as informing adults about their allergy and symptoms of a reaction, avoidance of sharing food, reading ingredient labels, informing

restaurant staff of the allergy, and carriage of medications.¹⁴ For instance, allergists can encourage children to describe their FA during the clinic visit, and reinforce positive communication. Innovative technologies can be used to improve FA self-concept. For example, a mobile application specific to FA anaphylaxis management has been found to improve teenagers' belief in their ability to manage their FA, thereby increasing self-efficacy.⁶⁷ In addition, behavioral practice of important skills (eg, self-injection for EAls) can be conducted within the clinic setting to provide mastery experiences.⁵⁹ To build self-efficacy during transition into greater independence as a young adult, allergists can work with patients in mastering important transition steps, such as establishing care with a physician or allergist, becoming familiar with the school clinic, gathering information regarding dining options, and creating an FA action plan.^{12,40}

Social Support

Enhancing social support involves optimizing peer and family support for the person with FA. Allergists can promote opportunities for children and adolescents to engage in age-appropriate social activities. In addition, adolescents and young adults with FA would prefer their peers and the public be educated on FA^{41,42,68}; allergists can provide this information to their patients for distribution among their social networks to decrease isolation and facilitate engagement. Given that children with FA who reported bullying at school had improved QOL after disclosing the bullying to their parents,⁵⁹ allergists can also model for families how to have supportive, nonreactive conversations with youth about their social relationships to enhance the family's ability to provide support.

Safe School Environment

Ensuring a safe school environment for the child with FA involves having clear communication between families and schools.²⁴ These conversations may also include the allergist, teacher, and school nurse. A written emergency plan should be developed and given to the school, including symptoms of a reaction and instructions of treatment, and should be updated at least every school year.²⁴ People of all ages with FA must be able to advocate for themselves, whether it is primary or secondary school, higher education, or at work; these conversations can be practiced at the clinic to increase self-efficacy. Certainly, allergists should ask about FA-related victimization, and provide support in enhancing safety.

Meaning-Making

Finally, engaging patients and families in conversations about their strengths and values promotes adaptive meaning-making. A curious, patient/family-centered approach about the experience of managing FA may initially elicit discussion of FA challenges and struggles. Noting adaptive responses that families have made and asking about the strengths and values that are accessed during successful navigation of challenges can shift the conversation toward an affirming and invigorating dialogue about what is most important to patients/families and how their positive responses to FA challenges reflect these attributes. Both adolescents and young adults with FA have reported that their FA made them more responsible, better advocates for themselves and others, and more likely to offer help to those with special needs.²⁶ Allergists can and should acknowledge the significant adversity that FA poses, and allergists can and should drive conversations that highlight the positive growth and strengths that rising to the challenge of FA has afforded for the patients they serve.

CLINICS CARE POINTS

- Education for patients and families should be developmentally appropriate, and should include accurate estimates of risk for allergen exposure.
- To enhance self-efficacy, have patients and caregivers practice in clinic critical allergy-related health behaviors, such as anaphylactic symptom communication, assertiveness about allergen-avoidance, and use of autoinjector (if it includes a practice device).
- Assess for social concerns, including any incidence of bullying by peers or minimizing of risk by adults who may be involved in gatekeeping patient's food. If these are present, problem-solve with patients and families and provide written or verbal communication to escalate concerns.
- Intentionally assess for barriers to full engagement in developmentally important activities and problem-solve with families to determine solutions.
- Solicit from and reflect to patients and families the strengths that help them navigate the challenges of food allergy.

DISCLOSURE

The authors have nothing to disclose.

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