Psychosocial issues and quality of life associated with food allergy

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ABSTRACT

The day-to-day challenges involved in caring for a child with food allergies can be a significant stress within a family. As the child with a food allergy grows up, developmental changes as well as external influences such as bullying and peer pressure can further influence these stressors. When the child with a food allergy is young, the family may be limited on where they can vacation or go out to restaurants, which can cause tension and frustration within the family. Hypervigilance and fear of accidental exposure to the allergen takes an emotional and physical toll on the child with a food allergy and the child's family. Socially, children with a food allergy may have to limit participation in school events, parties, or camps. These limitations can cause feelings of isolation for the child and feelings of guilt for the parents. As the child becomes an adolescent and young adult (AYA), increased autonomy of dining options and a desire to fit in with peers can trigger higher risk-taking behavior, which can be a source of anxiety for the AYA as well as the caregivers. The aim of this review was to describe potential negative psychosocial impacts of having a food allergy for the family. Data were reviewed from a literature search of medical literature data bases between 2010 and 2020 by using the search terms "food allergy," "psychosocial," "anxiety," and" quality of life." As we better recognize the psychosocial issues associated with food allergies, we will have a better ability to develop effective interventions to improve the quality of life for these families.

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The prevalence of food allergies in the United States is ~8%.[1] The primary management strategy continues to be strict avoidance. Vigilance at every meal to ensure an allergen-free environment is a daily reality for families with a food allergy. Despite these measures, unintentional exposures invariably occur, with food-related anaphylaxis being the most common cause of anaphylaxis in children in the United States. Gupta *et al.*[1] found that, among children with a food allergy who were surveyed between 2015 and 2016, >42% reported more than one lifetime food allergy–related emergency department visit. Daily activities such as shopping for groceries, preparing meals, and eating at restaurants can place an emotional strain on parents with children with a food allergy.[2] The maintenance of an allergen-free environment has consistently been shown to have a negative impact on daily living and food allergy quality of life (FAQOL) for families.

The World Health Organization defines quality of life (QOL) as "the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."[3] FAQOL focuses on the burden that food allergies place on families and patients.[4] Cummings *et al.*[5] found that influences such as gender, age, disease severity, coexisting allergies, and external perceptions can impact FAQOL. Even the caregiver's perception of the severity of an allergic reaction can alter the caregiver's FAQOL. Greenhawt[4] surveyed 305 caregivers of patients with a food allergy and found that caregivers with an inaccurate perception of the severity of the allergic reaction were significantly more worried about their ability to treat a future reaction. In addition, the caregivers were concerned that others were not appreciating the seriousness of their child's food allergy.[6] The impact that these influences have on the FAQOL within a family can further be affected by the developmental age of the child and family dynamics. The aim of this review was to highlight potential stressors present at different stages of a child's life and how they affect the child with a food allergy as well as the family.

PSYCHOSOCIAL IMPACT OF FOOD ALLERGY IN THE YOUNG CHILD

Most early childhood experts agree that a sense of autonomy is crucial in a child's growth and personal confidence. Sleeping over at a friend's home, attending

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extracurricular activities, or going to parties promote self-reliance by allowing the child to develop a sense of independence. The only known successful management strategy for food allergies is strict allergen avoidance to decrease the risk of anaphylaxis. Because most food-associated anaphylaxis occurs outside of the home, parents are educated to always carry emergency medications with them, including an epinephrine autoinjector. Gupta *et al.*[7] found that the fear of allergen exposure outside the home or away from the parents most significantly impaired parental FAQOL, despite high levels of parent-reported empowerment related to their children's food allergies. The limitation of early autonomy in the development can affect socialization skills and foster feelings of isolation, which can become a source of anxiety, especially when being away from home.

This feeling of isolation for the child with a food allergy can be further propagated in the school setting. Many schools have adopted allergen-free lunch tables, which limit the child from appropriately socializing at school. Another source of distress in the school setting is bullying and teasing because of food allergies. Lieberman *et al.*[8] reported that 24% of children with a food allergy who had filled out a questionnaire survey reported having been teased or harassed as a result of their food allergy. Of these children, 57% reported that the teasing included physical provocation, such as being touched by the food allergen or having it waved in front of them.[8] Even more alarming, was that, in 21% of the cases, the harassment came from teachers or administrators at the school.[8]

Fedele *et al.*[9] examined patterns of adaptation to food allergies across families. Mothers with high food allergy anxiety scores were found to have children with comparable food allergy anxiety.[9] Parental modeling of anxious behavior may play a factor in increasing anxiety in the child with a food allergy. Corner *et al.*[10] reported that children with a food allergy and between ages of 5 and 7 years were particularly vulnerable to the maternal stress from autoinjector use in predicting food allergy–related anxiety in the child. They also found that maternal overprotection, irrespective of food allergy severity, was negatively associated with their child's functioning.[10] Most anxiety in childhood is observed between the ages of 6 and 11 years, when children are starting to better comprehend their allergy and the real risks associated with it. Some anxiety could be interpreted as protective if encouraging the child with an allergy or the family to comply with avoidance measures. However, excessive anxiety may cause unnecessary avoidance of activities or excessive clinginess with parents.[11] This anxiety has a negative effect on QOL for these children and their families.

Feeding disorders are frequently seen in children with food allergies. These difficulties often start in early childhood. The inability of the young child to effectively communicate his or her anxiety about eating a food allergen can present as crying, tantrums, or refusal to eat food.[12] This can lead to altered mealtime dynamics as parents become permissive with the behavior because of uncertainty to whether the child is having an allergic reaction. Sharma *et al.*[13] found that parents of young children with food allergies had significantly more mealtime behavior issues than typically developing peers and comparable with young children with type 1 diabetes.

PSYCHOSOCIAL IMPACT OF FOOD ALLERGY IN ADOLESCENCE AND YOUNG ADULT

Developmentally, adolescents and young adults (AYA) want more independence, which puts them in situations in which they have to make their own risk assessments of what is safe to eat. This burden of having to take more responsibility in maintaining a food allergy–free environment can become a significant source of anxiety. As they become more independent, the AYAs have to also take the burden of becoming their own advocate. However, they tend to be reluctant to notify their peers, teachers, or a social network of their food allergies.[14] Previous feelings of isolation as a young child because of the child's food allergies and desire to "fit in" can influence the decisions to not inform peers. Gupta *et al.*[15] reports that this continues to be a challenge as AYAs transition to living on college campuses, often feeling uncomfortable when discussing their food allergies with new acquaintances.

The desire to "fit in" with their peers can lead to noncompliance with management strategies (not carrying an epinephrine autoinjector) and put them at a higher risk for a more severe outcome if exposed to their food allergen. Miller *et al.*[16] reported that 26% of adolescents felt that carrying their epinephrine actually caused them more anxiety. Possible reasons for this include concerns about how to recognize anaphylaxis, uncertainty on how and when to use the epinephrine, or fear of using an autoinjector on their own.[17] Disease denial is another issue often seen in AYAs. This could be partially explained by the fact that the AYAs may not remember the anaphylactic reaction.[18] Adolescents may also be more aware of parental anxiety about their food allergies. Miller *et al.*[17] found that adolescents reported worse QOL than younger children. A hurdle in diagnosing anxiety in adolescents with food allergies is that they have greater internalization; so care has to be made to not miss clues of anxiety or depression.[19]

PSYCHOSOCIAL IMPACT OF FOOD ALLERGY IN THE FAMILY

As the child's first social group, the family unit is crucial for the development of values; skills; socialization;

and basic needs, such as food, shelter, and clothing. In families with a child with a food allergy, the ability to perform these duties becomes a source of anxiety not only for the child but for siblings, caregivers, and extended family. To maintain a "safe" diet for the child with a food allergy, simple tasks such as grocery shopping and meal preparation can be time consuming and expensive. Even activities that are perceived as relaxing, such as going to a friend's home can become a source of anxiety in making sure that "safe" food is available. Gupta *et al.*[20] analyzed data from 1126 caregivers of children with a food allergy and found that the caregivers were most troubled by limitations on social interactions. In the same study, Gupta *et al.*[20] noted that poor QOL was significantly more likely in caregivers who were more knowledgeable about food allergy, whose children had been seen in the emergency department for a food-related allergic reaction in the past year, had multiple food allergies, and were allergic to certain foods, *viz.* milk, wheat, or egg. Abrams *et al.*[21] also found multiple food allergies had a significant impact on the mental health of caregivers, with many parents feeling "overwhelmed and alone." Another potential source of anxiety for the caregiver is in balancing the relationship between the child with a food allergy and siblings. The time and extra attention required by the child with a food allergy can cause sibling rivalry, which can further increase the stress in the family.

CONCLUSION

The hypervigilance required to manage food allergies, along with the unpredictable nature of allergic reactions, is a constant source of anxiety and stress for the entire family. As a young child, the burden of the management usually falls on the caregiver. However, the young child feels the psychosocial impact of having a food allergy in how it affects social interactions and activities. Young children with food allergies can be further influenced by the effects of their caregivers' anxiety. AYAs take on more of the stressors associated with managing their food allergies: making sure they are eating "safe" food, always carrying emergency medications, knowing how and when to use their emergency medications, and having to decide whether to inform their peers of their allergies. The psychosocial impact of having food allergies on a caregiver is influenced by many factors: developmental age of the child with a food allergy, timing of last allergic reaction, perception of the severity of allergic reaction, type of food, and whether a caregiver feels emotionally supported.

It is crucial for anyone who interacts with families with food allergies to recognize potential triggers for food-related anxiety in young children, AYAs, and caregivers. Effective interventions to help reduce anxiety in families with a food allergy have to include international, local, and individualized efforts. Education and advocacy measures to improve safety within schools, colleges, airplanes, and restaurants will help alleviate many of these stressors. The development of individualized support systems (psychologists, dieticians, social workers, counselors) for each family, based on their ever-changing psychosocial needs, is essential to ensure that families with food allergies have the coping skills to effectively manage their food allergies and improve their overall FAQOL.

CLINICAL PEARLS

- Children with food allergies are at risk for anxiety, feelings of isolation, and fear of situations, all of which negatively affect their FAQOL.
- Parental anxiety can influence the child with a food allergy's level of anxiety and how the child perceives his or her FAQOL.
- Symptoms of anxiety in the young child can present as crying, tantrums, food aversions, and excessive clinginess to parents.
- AYAs report worse QOL than younger children.
- Care has to be taken to not miss signs of anxiety or depression in this group because they can internalize their feelings.
- Caregivers, particularly mothers, of children with food allergies are at risk for high levels of anxiety and stress in carrying the burdens of managing food allergies.

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