Empowering Children and Families with Food Allergies: An Innovative Role for Occupational Therapy

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Abstract
Food allergies (FAs) have far-reaching implications regarding occupational participation. Children with food allergies and their families experience impacts on their daily life activities. The current standard of care for FAs fails to adequately address the wide-ranging barriers to participation in home, school, and community environments. This study used a mixed-method design to examine the impacts of FA on the needs of children and families affected by FA. Eighteen parents of children with FAs and six health care providers of children with FAs were interviewed; the parents also completed two questionnaires to identify the level of impact of FA on areas of daily living. The results indicated that parents perceive FA as a significant barrier to several aspects of daily life, and parents and health care providers recognized the need for additional supports for families of children with FA. Occupational therapists can intervene to help families with FA improve their participation in daily life activities while managing and limiting exposure to FAs. Expanding the role of occupational therapists to address the needs of families with FAs and recommendations for supporting this population are discussed.

Comments
The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords
food allergy, occupational therapy, participation, daily living

Credentials Display
Salma H. Bachelani, OTD, OTR/L; Meredith P. Gronski, OTD, OTR/L, CLA, FAOTA; Kelly A. Carlson, BS, MSOT/S

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The prevalence of food allergy (FA) has rapidly increased in recent years and affects over 26 million Americans (Gupta et al., 2019). FA affects children more frequently than adults, with FA affecting one in every thirteen children under eighteen years of age (Gupta et al., 2018). FAs occur when a person’s immune system has an adverse reaction to stimuli, referred to as allergens. There are over 170 foods that may elicit allergic reactions in people, though eight food allergens in particular account for the majority of food-allergic reactions: shellfish, dairy, peanut, tree nuts, egg, fish, wheat, and soy (Sicherer et al., 2020).

Exposure, contact, and/or ingestion of allergens can prompt symptoms of allergic reactions. Symptoms can be mild and include reactions such as sneezing, stomach pain, or rashes to more severe reactions such as difficulty breathing, altered heart rate, loss of consciousness, and anaphylactic shock (Broome-Stone, 2012). The high-risk reactions associated with FA emphasize the critical nature of managing FA. FAs are primarily controlled by avoidance of allergens, early recognition of reactions, and immediate treatment of symptoms of reactions. These methods of controlling FA require a high degree of lifestyle modification, self-awareness, and advocacy skills. They also place substantial psychological distress on those affected and their family members (Bollinger et al., 2006; Broome-Stone, 2012). Because of these abundant implications on daily life activities, it is clear that FAs pose barriers to participation.

Occupational therapy (OT) is a unique profession well-suited to address barriers to participation, such as those caused by FAs. The domain of OT includes occupations, environmental contexts, performance patterns, performance skills, and specific client factors. More specifically, occupations refer to daily tasks and life activities. Outcomes of OT interventions facilitate improved occupational performance and participation (American Occupational Therapy Association, 2020).

Impacts of FAs on Daily Life

The omnipresent role of food in our daily activities and society makes it vital to provide support for those at risk of life-threatening reactions to foods. Monitoring FAs can contribute to decreased quality of life because it requires constant vigilance, which yields high levels of anxiety and stress in those affected (Broome-Stone, 2012). Having a FA impacts psychological well-being and many aspects of daily living (Bollinger et al., 2006). FAs influence dietary intake, social engagement, and participation in the community; both physical and mental well-being are affected (Broome-Stone, 2012). Participation in daily activities is crucial for social relationships, skill development, and overall health (Law et al., 2006).

While individuals with FA are directly impacted by their allergies, parents, caregivers, and family members also experience barriers to engagement and participation. Families impacted by FA must diligently avoid allergens (Bollinger et al., 2006). To optimize growth, development, participation, and quality of life for children with FA, accurate diagnosis, dietary management, family education, and ongoing support are necessary (Denton et al., 2014).

Current Standard of Care

Allergy specialists and primary care physicians provide diagnosis and general follow-up for symptom management to patients with FA, but consistent provision of resources and strategies tends to be lacking (Sicherer et al., 2012). In some settings, specialists, such as nurse educators and dietitians, provide additional support to children and families impacted by FAs. However, these services are an extra benefit in certain practices rather than the standard of care. The health care practitioners that most commonly work with people with FA primarily focus on allergen avoidance and education regarding the management of physical symptoms of reactions rather than the impacts of FA on daily life. Educational
materials do not fully encompass the array of day-to-day concerns of children with FAs and their families (Goossens et al., 2013; Vargas et al., 2011).

Time constraints and the scope of the medical model often inhibit providers’ ability to address all of the day-to-day implications of FAs. To date, interventions that address daily life participation for individuals with FA are uncommon, and the few that exist focus on one specific element of coping with FA, such as nutritional counseling or epinephrine auto-injector use (Denton et al., 2014; Vargas et al., 2011). The lack of consistency and standardization in the content of existing resources and their dissemination is a critical issue that warrants innovative health promotion interventions and health management (Sicherer et al., 2012). In addition, FA can be considered a chronic disease because those who experience FA in early life often experience disease persistence (Protudjer et al., 2019). However, FA is not typically addressed by chronic disease self-management programming (Grover & Joshi, 2019). The complex nature of FA indicates the need for a multi-disciplinary, team-based approach to care (Sicherer et al., 2020). Occupational therapists are well-equipped to fill this gap. Health management is an important occupation in the domain of OT, which includes symptom and condition management, communication with the health care system, medication management, and nutrition management (American Occupational Therapy Association, 2020).

Overall, medical providers see the importance of helping patients and families address the depth of the barriers they experience, but there remains a gap in making this a reality (Vargas et al., 2011). Further information is needed to better determine how medical practitioners, and potentially occupational therapists, can better address the barriers to daily life participation in families impacted by FA.

**Method**

An exploratory, cross-sectional study design with mixed-methods data collection was used to gain an improved understanding of the daily-life impacts of FA on children with FA and their families. In partnership with a large metropolitan hospital in a Midwestern city, the research team members recruited two groups of participants through purposive convenience sampling (see Table 1). Group 1 included parents of children 18 years of age and under with physician-diagnosed FA. Group 2 included health care providers of children with FA, including licensed physicians, nurses, or nurse practitioners with at least 2 years of work experience working with children with FA. The research team obtained institutional review board approval for the study, and all participants provided informed consent. Quantitative survey data were analyzed with descriptive statistics, and qualitative interview data were analyzed through thematic analysis.

<table>
<thead>
<tr>
<th>Group</th>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
<th>Method</th>
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<tbody>
<tr>
<td>Group 1</td>
<td>Parents of children (0–18 years of age) with a physician-diagnosed FA</td>
<td>Non-English speaking Child with confounding diagnosis</td>
<td>Informant interviews Questionnaires</td>
</tr>
<tr>
<td>Group 2</td>
<td>Licensed physicians, nurses, or nurse practitioners with 2+ years of FA work experience</td>
<td>Non-English speaking</td>
<td>Informant interviews</td>
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The participants from Group 1 and Group 2 participated in informant interviews over the phone. The researchers designed the interview questions and format to maintain consistency across each interview to enhance the data’s integrity while collecting data that correlated with topics from quantitative survey data. One researcher conducted all of the interviews to support the quality of the data. During data
collection, the participants answered open-ended questions regarding the facilitators and barriers to FA management. Questions from the interview are presented in the Appendix. Interview calls were recorded via smartphone native software and transcribed by hand. Analysis and coding were guided by principles of grounded theory (Corbin & Strauss, 1990; Krueger & Casey, 2000). The primary researcher reviewed the interview transcripts and identified initial broad themes. The researchers developed a coding structure that was applied to the interview transcripts and adjusted based on data and a review of background literature. Similar concepts and codes were consolidated, diagramed, and grouped around central themes. Transcribed interview excerpts were selected to highlight and illustrate the identified themes.

In addition to the informant interviews, the Group 1 participants also completed two questionnaires: the Food Allergy Quality of Life – Parental Burden (FAQoL – PB) and the Scale of Psychosocial Factors in Food Allergy (PSF – FA) (Knibb et al., 2016; Knibb & Stalker, 2013). The FAQoL – PB is a 17-item questionnaire that assesses the impact of FA on quality of life by analyzing family and social activities, school, time for meal preparation, health concerns, and emotional issues. It is shown to have strong internal validity and good correlation with existing quality-of-life measures. The FAQoL – PB asks parents to rate how much their child’s FA troubles them across different situations. It uses a 7-point Likert Scale where 0 is not troubled at all and 7 is extremely troubled. The Scale of PSF – FA is a 9-item questionnaire examining the impact of FA on psychosocial aspects and quality of life.

Results, Emergent Themes, and Findings

Results from Questionnaires (Group 1)

On the PSF – FA, 40%–50% of the respondents indicated that they have felt discriminated against because of their child’s FA, that FA has impacted social interactions with family and friends, and that FA has impacted their family budget. Over 50% of the respondents indicated their child’s allergy symptoms affected their mood and affected them psychologically.

The items on the FAQoL – PB with the highest response rates identified specific areas of daily living affected by FA. The results indicated that parents of children with FAs are most concerned with going out to eat, going to social activities involving food, taking their children to group activities, and leaving their children in the care of others (see Figure 1).

Figure 1
Parents’ Level of Concern for Food Allergy in Areas of Daily Life
Emerging Themes from Informant Interviews (Group 1 and Group 2)

Three main themes emerged from the parent (Group 1) and health care provider (Group 2) interviews. The first theme captured the barriers to daily living experienced by children and families with FA. The second theme identified beneficial resources, supports, and policies already in place. Finally, the third theme identified additional resources and supports that would be beneficial in the future.

**Theme 1: Barriers in Daily Life – Home, Community, and School**

The parent and health care provider respondents noted impacts in contexts of daily life. It was reported that families must be cautious to keep their homes free of certain foods (allergens) and frequently need to adapt recipes, which impacts routines. In regard to eating out, the parents noted that even though restaurants may claim to have certain foods that are allergen-free, fears of cross-contamination decrease the desire to eat out and lead to a preference for cooking and eating at home. One parent shared:

I have an older son that’s five and isn’t allergic. We used to do breakfast for dinner, where we would have pancakes, eggs, and bacon, but we just don’t do that near as much. We don’t go to IHOP because he loves pancakes, but they have such a high dose of eggs. We avoid it so he doesn’t have a fit because [his] brother can have it, but he can’t. It’s got to be something that works for both of them.

The parent and health care provider participants noted that home routines and meal rotations needed adjustment as a result of FA. In addition, the respondents indicated concerns about living situations, such as apartment buildings or areas with frequent neighborhood cookouts.

The parent and health care provider participants also noted disruption to community activities. For example, the parents noted concerns with church attendance, where barriers to participation for those with FA occur in regard to services or religious education where food is served. Sports events were also noted to be a concern, as there are impacts for those with FA, whether they are playing on sports teams or observing sporting events, because of aspects such as snacking in an open environment. The respondents also indicated significant barriers to participation in social events, such as birthday parties, fairs, festivals, and other community events.

Some families coping with FA reported avoidance of public gatherings where foods are freshly prepared by being fried or roasted on open flames. There was also noted concern with birthday parties because birthday treats have a high likelihood of containing allergens. Finally, families experience challenges using public transportation, such as airplanes, buses, and trains. The small shared spaces of public transport can present risks, particularly airplanes, when airlines cannot guarantee nut-free flights or may even serve mixed nuts.

In the school setting, reported barriers included lunchtime, snack time, interactions with peers, and classroom roles and responsibilities involving food. The participants from the health care provider group and parent group identified school as a source of stress and challenges for families impacted by FA. The health care providers noted inconsistencies among the aptitude various schools demonstrate for managing FA. Some schools are well-versed in how to support children with FA, while others need further support to sufficiently ensure safety. One parent shared that her child was unable to attend school if the food he was allergic to was being prepared. She explained:
In elementary school, it was really bad. Sometimes fish was cooked in the school. It was bad to the point where they were like, “OK, he just can’t come to school on that day [when we serve fish] because you walk in the front door, you smell the fish!”

**Theme 2: Supportive Resources and Policies**

The second theme was there are certain resources, supports, and policies that are helpful for families with FAs. The health care providers and parents reported value in resources ranging from pamphlets, brochures, books, websites, and customized FA action plans. Some of the parents reported receiving resources, while others reported receiving insufficient or no resources.

The health care providers described the average appointment time to be 10–20 min. While some of the health care providers felt this was enough time, all of them noted that they anticipated parents would like more time and attention. All of the parent participants expressed a desire for more time and attention from practitioners as a supportive resource.

A commonly favored support that the parents identified was the ability to look online for resources. However, the parents communicated that they felt unsure about which resources were most credible. The health care providers indicated that parents would find information about FA online and mention this information to them, but often the information the parents found was false or inaccurate.

**Theme 3: Identified Needs and Requests for Resources**

The third theme was there are additional resources and supports that families of children with FA want and from which they would benefit. The parents identified a desire for supports for themselves and resources for their children with FA. All of the parents who participated in the interviews reported a desire for more time and attention from practitioners. The parents reported interest in resources that help them better understand background information about FA, strategies for identifying and avoiding foods with allergens, recipes, and alternative food options. A parent noted that existing resources are not always the most reliable: “Unfortunately, there are a lot of websites that are not really based on data, and I guess they give a lot of advice that’s not really consistent with what is actually shown in research.” For children with FA, the parents wanted resources that could help children better understand their FA. They reported a desire for their children to develop coping skills and understand how to deal with accidental ingestion of allergens. Both the parent and health care providers participant groups reported children with FA and their parents would benefit from support groups. Both groups also reported a need for more people in the general public to have a better understanding of FA and the related safety and inclusion considerations.

**Discussion**

Overall, the qualitative and quantitative results provided insight into the pervasive effects of FA on daily life. The quantitative results indicated that families with FA experience impacts on psychosocial factors and quality of life. The qualitative results illuminated specific barriers to daily life activities encountered by families with FA, ranging from home routines to school and community participation. The parents identified the ability to use online resources as a helpful support; however, they reported difficulty verifying the accuracy of online resources. Notably, this parallels concerns raised by the health care providers who reported their patients’ families would share information they learned online that was false or inaccurate. This indicates a need for trustworthy and reliable resources to be consistently provided to families impacted by FA.
The Role of Occupational Therapists

Through this study, many specific implications of FA on daily routine, as well as ideas for innovative, supportive resources for families, were identified. Occupational therapists could fill a health promotion role, provide parent education, help children gain self-management skills, facilitate support groups, and advocate for children with FA in school settings.

Through the informant interviews, the parents indicated they would benefit from resources that facilitate an improved understanding of FAs. Occupational therapists can intervene to help families impacted by FA find ways to continue and expand participation in daily life activities while managing and limiting exposure to food allergens. The parents identified concerns about exposure in community settings, such as social events, community gatherings, public transportation, restaurants, sports, church, and more. Interventions that help parents consider modification of their habits and routines to address awareness of cross-contamination risks and promotion of strategies for daily self-management would decrease the likelihood of accidental allergen exposure, thus decreasing hospitalizations for patients with FA and subsequent health care costs. This is notable because pediatric FA has a staggering economic cost of $25 billion per year, $1.9 billion of which are from hospitalizations because of reactions to allergens (Gupta et al., 2013).

Occupational therapists have the unique training and expertise to play a critical role in helping patients with FA engage and participate without being limited by FA. The parents and health care providers who participated in the informant interviews identified a desire for children to gain self-management skills related to their FA. Occupational therapists could expand the supports available for patients with FA to help them better understand and self-manage their FA. Therapeutic services and supports offering a variety of specific strategies to cope with FA could increase self-efficacy in the management of FA as a chronic condition, with the ultimate goal of decreasing levels of stress and anxiety, reducing exposures and anaphylactic events, and improving the quality of life (Denton et al., 2014). Individualized self-management and advocacy skills training may contribute to better health outcomes in children affected by FA.

In addition, support groups are another resource that may be beneficial for those impacted by FA. For individuals with FA, participating in support groups can provide a range of benefits, including increased accessibility to support, reduced feelings of isolation, improved emotional support, and introduction of new coping strategies (Coulson & Knibb, 2007). For parents of children with FA, support groups can impart valuable advice on FA risks and safety procedures, provide help in managing and coping with FA, decrease anxiety about FA, increase comfort in communicating with their child’s allergist, and improve their child’s quality of life (Sharma et al., 2011). Occupational therapists consider how an individual’s participation in their daily life is impacted by the interaction between their environment (for example, their social, natural, and built environments) and their person-factors (including, but not limited to, their health conditions, knowledge, and emotions). Support groups complement this holistic approach to intervention by providing opportunities to develop both person factors, such as an individual’s knowledge and feelings about their FA, and environmental factors, such as social connections, that impact individuals with FA and their families. In this way, the facilitation of support groups is one way that occupational therapists can expand their services to meet the expressed needs of children and families affected by FA.

Many of the participants identified schools as an area of concern for children and families impacted by FA. In the school setting, the role of OT services could extend to a consultative role with school staff
to help foster inclusive and accommodating environments so that children with FAs do not feel ostracized and excluded. Occupational therapists could hold in-services for teachers and administrators to ensure staff awareness of the impacts of FA on participation in school routines. Children without FA would also benefit from introductory information regarding FA and its impacts on daily life. Students with FAs experience impacts on participation in occupational roles, such as being lunch box helpers, stacking cafeteria chairs, enjoying birthday treats, and participating in field trips. Students with FAs who cannot participate in these occupations may feel left out, be treated differently, and, as a result, may be more prone to bullying. Occupational therapists are uniquely equipped to be part of multi-tiered systems of supports in schools, where they can address and decrease bullying as well as promote health and wellness and safe environments (Njelesani, 2020).

The Occupational Therapy Practice Framework identifies the purpose of OT services to enhance or enable engagement in “roles, habits and routines in the home, school, workplace, community and other settings” (American Occupational Therapy Association, 2020, p. 12). It is the distinct and core value of occupational therapy to address the daily routine implications of health conditions. Research has identified that occupational therapists are well-suited to address primary care roles, such as health promotion, prevention, and wellness (Jordan, 2019). Similarly, it is in the OT scope of practice to fill this important role of supporting children and families impacted by FA in addressing the identified needs.

Conclusion

The development of a unique and innovative OT role in working with patients with FA could improve the standard of care for patients with FA across medical, community, and educational models of care. Children with FA would be empowered to better understand and manage their condition, they would have policies in place in their schools, and their families would receive additional resources and supports to help cope with all the daily-life impacts of FA. An effective, innovative OT intervention for people with FA could greatly improve overall health and quality of life for those affected. In addition, expanding the role of occupational therapists would help enable participation for all those who may benefit; occupational therapists should strive to promote efforts for any individuals who experience barriers in day-to-day life.

References


## Appendix

### Interview Questions for Groups

<table>
<thead>
<tr>
<th>Questions for Group 1 (Parents of children with FA)</th>
<th>Questions for Group 2 (Health care providers for children with FA)</th>
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</thead>
<tbody>
<tr>
<td>Tell us about your child’s FA diagnosis; how old was s/he, and with what was s/he diagnosed?</td>
<td>What are some resources you give to families that have just been diagnosed with FA?</td>
</tr>
<tr>
<td>Do you recall if you were given any resources or supports by any health care providers when your child was diagnosed? Which of these resources was helpful? Which were not helpful?</td>
<td>Do you follow a standard protocol for following up with food allergy patients? How many follow-up appointments?</td>
</tr>
<tr>
<td>What kinds of resources or support would you have liked that you were not given?</td>
<td>On average, how much time do you spend with a food allergy patient and/or their family members per visit?</td>
</tr>
<tr>
<td>Do you have any other children? If yes, do you feel that they are affected by your other child’s FA?</td>
<td>What have you observed to be the biggest difficulties faced by children/families that have FA?</td>
</tr>
<tr>
<td>What are the biggest difficulties you and your family face in the home environment related to your child’s FA?</td>
<td>What have you observed to be the most helpful supports for children/families affected by FA?</td>
</tr>
<tr>
<td>What is your experience supporting your child in the school setting related to his/her FA?</td>
<td>Do you feel that you have enough time to fulfill the needs of children/families with FA?</td>
</tr>
<tr>
<td>What are the biggest difficulties you and your family face in the community environment related to your child’s FA?</td>
<td>What kinds of resources do you think kids/families with FA could benefit from?</td>
</tr>
<tr>
<td>What is your understanding of occupational therapy?</td>
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<tr>
<td>In the context of occupational therapy, “occupations” are any of a person’s daily tasks. For a child, this includes going to school, playing, doing chores, etcetera. Do you feel that food allergies can affect a child’s ability to participate in their occupations?</td>
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</tr>
<tr>
<td>Based on your understanding of occupational therapy and occupations, can you describe a potential role occupational therapists would have in working with children with FA?</td>
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