

The perceived impact of pediatric food allergy on mental health care needs and supports: A pilot study



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Background: Evidence suggests a mental health impact of food allergy on affected children and their families; however, little is known about health care professionals' understanding of these impacts and the resources available to patients and their families. **Objective:** Our aim was to conduct a pilot study examining health care professionals' perceptions of the psychosocial and financial burden of food allergy to identify gaps in education and resources and thus better support families with food allergy moving forward.

Methods: Between February 20 and November 19, 2020, we conducted audiorecorded interviews (n = 6) and profession-specific focus groups (n = 2 [representing 7 individuals]). The participants included pediatric allergists, allergy nurse educators, and clinical dietitians who were directly involved in pediatric food allergy care. The interviews were recorded and transcribed verbatim. Thematic analysis was subsequently applied to identify the main themes.

Results: Our study consisted of an interdisciplinary group of Manitoban health care providers (N = 13) who were directly involved with pediatric food allergy care. We identified 3 main themes from these interviews: anxiety among families with food allergy, which is a common comorbidity; limited resources available within current public infrastructure; and empowerment through education. These themes describe issues surrounding access to information and resources and how this can affect anxiety and parenting styles among families with food allergy.

Conclusions: Health care professionals perceive that many families experience anxiety as a result of their child's food allergy. They further advocate that access to information and suitability of public resources be considered when planning for related programs. (*J Allergy Clin Immunol Global* 2022;1:67-72.)

Key words: Children, pediatric food allergy, allergist, food allergy education, food allergy supports, dietitian, allergy nurse, anxiety

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For the 6% to 8% of Canadian children living with food allergy, selecting what and where to eat can be challenging, and in the event of an accidental exposure, it can be potentially fatal.¹ Given the absence of curative treatments, individuals with food allergy are advised to avoid any known allergens and to continuously carry an epinephrine autoinjector (EAI) to be used in case of anaphylaxis.² Although these measures are typically effective in preventing acute symptoms and treating serious reactions, they pose a significant burden for both patients and their families.

Research suggests that children and teens with food allergy tend to have a lower quality of life and higher levels of psychological distress than their peers without food allergy do.^{3,4} Among children with food allergy who are aged 0 to 17 years, the impact of food allergy on health-related quality of life appears to differ by age.^{5,6} Families with school-aged children with food allergy have quantitatively reported increased maternal distress and being overly protective,⁷ whereas adolescents (aged 13-17 years) are more commonly bullied than school-aged children (aged 5-12 years) are—simply because of their food allergy.⁸ Despite a higher risk among adolescents, peer bullying is common in both age groups.⁸ Not surprisingly, parents also appear to be burdened by managing a pediatric food allergy, as a recent review found lower levels of quality of life and higher financial costs among families raising a child with food allergy.⁹

At the same time, allergists and allergy fellows struggle to collectively determine their role in advising on food allergy risks.¹⁰ How health care professionals manage psychological challenges in their patients is also unclear. To this end, we

Abbreviation used

EAI: Epinephrine autoinjector

performed a qualitative pilot study to assess their perceptions of food allergy–related mental health issues and needs for families with children with food allergy.

METHODS**Study design and participant recruitment**

Between February 20 and November 19, 2020, we conducted a combination of 3 in-person and 5 virtual interviews and focus groups with various health care professionals, including pediatric allergists, allergy nurses, and dietitians. Purposive sampling was used to recruit participants, all of whom worked in the same metropolitan center.¹¹ In total, we conducted 6 interviews with pediatric allergists and dietitians, as well as 2 profession-specific focus groups consisting of pediatric allergists and allergy nurses. In total, we spoke with 13 health care professionals. Health care professionals were asked not to reveal information that might lead to the identification of patients or their families. All data were collected by 2 experienced research assistants. A semistructured interview guide (Table I) was supplemented with follow-up questions for clarification.¹² The interviews and focus groups averaged 34 minutes (range 28–65 minutes) and 60 minutes (range 52–68 minutes), respectively, and they were recorded and transcribed verbatim.

Data analysis

Data were thematically analyzed independently but concurrently by 2 analysts (initials blinded for review, T.M., M.G.).¹² First, transcripts were read for surface descriptive content and organized by like-with-like ideas. Second, transcripts were reread for latent meaning. At that time, each analyst independently generated and systematically applied themes across all transcripts. Semantic validity checks were performed to ensure that different words and phrases within a category had similar meanings. Constructs were considered to be saturated when no new or additional constructs were identified, consensus was reached on all overarching themes, and no alternative explanations were found with subsequent interviews. This study was approved by the University of Manitoba Health Research Ethics Board (HS22242 [H2018:405]).

TABLE I. Interview guide

| Introductory question |
|---|
| Would you please tell us a bit about your role and background in working with families with a child with food allergy? |
| Content questions |
| Please tell us about your experiences and perceptions when diagnosing a child with a potentially life-threatening food allergy (medical doctors only). When talking to families with a child with food allergy, what concerns do they raise? Please describe your interactions with families with a newly diagnosed allergy versus with those families who have lived with food allergy for a while. Likewise, please describe interactions between families with very young children and families with school-aged children. What do you perceive as the major burden faced by these families and why? What kinds of supports do you feel are necessary for these families? Please talk about whether and how these supports would fit in the current scope of practice. How have current circumstances with regard to COVID-19 changed your scope of practice? What are some positive outcomes related to these changes? What are some of the negative outcomes? Do you have any further recommendations on how the system can improve during this time and for future pandemics? |
| Closing question |
| We've talked a lot today about working with a child with food allergy. Is there anything that I should have asked but did not? |

RESULTS

Our sample consisted of 13 participants: 4 pediatric allergists, 5 allergy nurses, and 4 clinical dietitians, all practicing in Manitoba, Canada. Among the participants, individual clinical experience in pediatric allergy ranged from 1 to 15 years. We identified 3 main themes that provide insight into common challenges faced by families with food allergy (Table II), as well as gaps in food allergy–related resources and education.

**Anxiety among families with food allergy:
A common comorbidity**

The first theme that we identified, namely, that anxiety among families with food allergy is a common comorbidity, speaks to the prevalence of anxiety among affected families. Throughout the interviews and focus groups, allergists, nurses, and dietitians all emphasized the ubiquity of anxiety among families with food allergy. One allergist put it succinctly, “the biggest morbidity associated with food allergy is actually the concern around the diagnosis [of food allergy] as opposed to the actual risk.” Many of the health care professionals interviewed were of the belief that parental anxieties were often rooted in concerns surrounding fatal accidental exposures outside of the home, particularly at school. Participating health professionals also described how the uncertainty surrounding proper use of EAIs was another common source of anxiety for families with food allergy. Although worries centered on accidental exposures and EAI use were commonly reported by each group of health care professionals interviewed, dietitians were unique in that they often fielded concerns surrounding nutrition. Dietitians commented that the biggest concern with which parents of their patients struggled was finding nutritionally adequate alternatives to the foods that they were omitting. Not surprisingly, these concerns were heightened among families raising a child with multiple food allergies.

**Limited resources within the current public
infrastructure**

The second theme, limited resources within the current infrastructure, highlights perceived gaps in the ability to support

TABLE II. Qualitative themes and supporting quotations from healthcare professionals

| Themes | Supporting quotations | | |
|---|--|---|--|
| | Dietitians | Allergists/immunologists | Allergy nurse educators |
| 1. Anxiety among families with food allergy, a common comorbidity | “They are scared to feed their infants and toddlers.” | “The biggest morbidity associated with food allergy is actually the concern around the diagnosis as opposed to the actual risk.” | “I feel like families get [a food allergy] diagnosis and they might get like an anxiety disorder with it.” |
| 2. Limited resources available within the current public infrastructure | “Another [concern] is the financial burden. I have a lot of parents express, you know, concerns with choosing allergy-free foods and the expense of some of these products.” | “If you do not have private insurance, [we] can refer to psychology through the hospital, but the wait list is enormous. You can access a psychologist easily in the community, but you need private insurance and it is incredibly expensive.” | “Definitely the [need for] financial support for some families. For some families, the financial thing is a big thing, because often these kids don’t only have food allergy, they also have asthma or eczema, and also the cost is not just for the [EAI] for some of these families, it is many other things. They need to prioritize what is the most urgent [medicine].” |
| 3. Empowerment through education | “Community dietitians, they were afraid, they did not know what to do, they did not even know like how to communicate or talk with families [with food allergy].” | “I find that one of the big problems with misinformation is they come back avoiding many more foods than what had been counseled, and the issue with the food avoidance these days is that we know that eating early protects against allergy.” | “More specific education in schools regarding cross-contamination of allergens [is needed].” |

the psychosocial and financial needs of families with children with food allergy. Unfortunately, a number of allergists interviewed for the current study noted that although anxiety was a problem for some families with food allergy, addressing psychosocial issues during clinic visits was often not practical owing to a lack of time and resources. Briefly put, “dealing with the psychosocial aspects, anxiety, etc, is very time-consuming, and although it is incredibly important,” doing so is “not feasible in [the] current scope of my practice” (an allergist). Although addressing all the psychosocial consequences of food allergy was not perceived to fall within the allergist’s scope of practice, 1 allergist did note that allergists could adopt a greater role in screening for

psychological distress, albeit through use of a standardized screening tool. Another allergist suggested the possibility of opening further dialogue with the referring pediatrician, who could assist in monitoring families for mental health disorders. Interviewees also discussed the lack of financial support available for families with food allergy. It was mentioned that “a lot of parents express concerns with choosing allergy-free products and the expense of these products.” Expanding on the high cost of specialty food items, a number of dietitians noted an absence of government funding for those who live above the poverty line yet still struggle financially. In addition, several health care professionals reported that allergic comorbidities could exacerbate the financial

TABLE III. Summary box: Gaps and implications for clinical practice

| Gaps in patient support | Implications for clinical practice |
|---|--|
| Lack of adequate infrastructure to support the psychosocial and financial needs of families with children with food allergy | <ul style="list-style-type: none"> ● Using standardized screening tools in allergy clinics to assess patient and family mental health status ● Enlisting general care pediatricians to assist with regular psychosocial screening ● Dedicating social workers and psychologists (specialized in cognitive behavior therapy) to the pediatric food allergy team ● Increasing nutrition support initiatives for families with food allergy (eg, dietitian-led grocery tours, food preparation classes, and meal planning sessions) |
| Food allergy knowledge gaps among clinical dietitians | <ul style="list-style-type: none"> ● Incorporating food allergy-specific training for dietitians outside of clinical practice (eg, community dietitians) |
| Basic dietary care knowledge gaps among pediatric allergists | <ul style="list-style-type: none"> ● Increasing the availability of continuing educational courses on basic nutritional counseling for allergists and allergy nurses |
| A lack of consistent food allergy education for school-aged children with and without food allergies | <ul style="list-style-type: none"> ● Integrating standardized food allergy education into the school curriculum to raise food allergy awareness and reduce the risk of anaphylaxis in school settings |

strain of families with food allergy, given the need for multiple medications. In fact, some families with multiple comorbidities were described as having to prioritize medications because of their high costs.

Participants also spoke about barriers to accessing mental health services as a problem faced by families. In particular, 1 allergist acknowledged long wait times for public psychological services and high costs for privatized care.

Empowerment through education

The last theme, empowerment through education, focuses on knowledge gaps among health professionals and in the larger community. Consistent with this theme, a number of the dietitians indicated that there is a lack of knowledge regarding food allergy among those who work outside of specialty settings. In fact, 1 dietitian, in recounting his experiences in a training role, noted that community dietitians often expressed feeling inadequately prepared to care for families with food allergy. Given that these families were described as having concerns surrounding their child's nutrition, this lack of food allergy-related knowledge among community dietitians may prevent them from confidentially providing families with food allergy with the nutritional support they desire. Dietitians were not, however, the only health care professionals who emphasized the need for more education. In fact, one of the allergists interviewed indicated that basic dietary care should be a part of allergists' ongoing mandatory learning.

Aside from their own knowledge gaps, a number of allergists also expressed concerns over food allergy misinformation, much of which originates from unverified online sources (eg, social media posts). Examples included misinformation on the routes of allergen exposure that can induce anaphylaxis and the unnecessary avoidance of foods. As consequence of misinformation, patients could "come back avoiding many more foods than what had been counseled, and the issue with the food avoidance these days is that we know that eating early protects against allergy." To combat this misinformation, many of the allergy nurses we interviewed indicated a need for food allergy education in schools, specifically regarding the recognition and treatment of anaphylaxis, as well as the mitigation of risks surrounding cross contamination.

The participating allergy nurses also recognized the importance of early food allergy education in child care centers and schools. As children are often required to assume more responsibility for their allergy management and personal safety once they enter the school system, such training was described as a means to ensure that all children with food allergy have the knowledge and skills to manage their allergy appropriately before or shortly after entering elementary school. Interestingly, although many of the dietitians echoed the recommendations of the allergy nurses for greater education, they differed slightly in their approach and target audience. In particular, a number of interviewees recommended holding dietitian-led grocery tours, food preparation classes, and meal planning sessions aimed at helping families with food allergy find safe and nutritious foods. They explained that such initiatives may help alleviate anxiety experienced by some families with food allergy, particularly those with allergies to staple foods, surrounding their ability to not only identify allergens in food products but also to find foods that meet their families' multifaceted needs.

DISCUSSION

Through this pilot study, we sought to better understand how various health care professionals perceive the psychosocial issues and needs of families that include children with food allergy. Our findings revealed that although health care professionals perceive anxiety to be a significant problem among families with children with food allergy, they often lack the time and resources to address it fully. Our results also emphasized how a lack of public programs and support geared toward food allergy can impede timely access to care and, in some cases, access to medication. Lastly, the current study highlighted knowledge gaps among allied health professionals and the community at large while also noting the detrimental effect that misinformation surrounding food allergy can have on affected families (Table III). The information collected from this research will go on to inform a larger study that will include pediatric allergy centers across Canada so as to assess transferability in other contexts.

In the present study, health care professionals noted that they often encounter anxiety among families with food allergy. This finding is consistent with the results of patient-oriented research, which has found anxiety to be pervasive among affected families.⁵⁻⁸ From the perspective of the health care professionals interviewed in our study and elsewhere, this anxiety appears to stem from the threat of accidental exposure and the adverse consequences that exposure entails.⁷

Despite frequently encountering anxiety among their patients, the allergists in our study noted that limited time and resources prevented them from fully addressing the psychosocial aspects of food allergy. As a result, families struggling with food allergy-related anxiety often go undiagnosed or are required to wait a considerable amount of time to receive psychological services. Participants suggested incorporating a mental health screening tool into their practice and opening communication with primary care physicians to discuss the mental health needs of patients and their families. Although the use of screening tools appears to be a sensible solution for identifying psychological distress among families with food allergy, more research is needed to better understand how to identify and support these families with their mental health needs.^{13,14}

Improvements to mental health care can also be achieved through partnerships with other allied health professionals, such as social workers and psychologists. Social workers can both counsel and help guide families through public programming, although psychologists who are trained in cognitive behavior therapy and are food allergy-knowledgeable can play a key role in the management of related anxiety disorders.^{15,16}

Additionally, participating health care professionals indicated that out-of-pocket expenses related to food allergy can be quite high, especially when families are without private health insurance. Recent research has shown that on average, families with food allergy spend more money on food, transportation, and medications than their counterparts without food allergy do, which may act to exacerbate stress and anxiety.^{15,17} Dietitians in the current study expressed concern over the high cost of specialty food items with little to no government support to offset this burden. Beyond the cost of specialty food, medications were also cited as a source of financial strain, a finding that is consistent with past research.¹⁸

The last theme centers around the need for quality food allergy education, not only for affected families but also for health care professionals and in schools. Herein, health care professionals perceived that parental anxiety increased when children entered the school system. This increased anxiety is likely due, in part, to a loss of control and fear of accidental exposure to food allergens.^{19,20} To combat concern, allergists and allergy nurses in the current study recommended enlisting the community as active management partners by providing food allergy education in childcare centers and schools. When combined with early education aimed at helping children manage their food allergy independently, these additional safeguards could help alleviate parental anxiety as children enter the school system.²¹ A recent Portuguese study by Pádua et al looked at the impact of a web-based program to improve food allergy knowledge in community settings.²² The educational program included information on basic food allergy definitions, recognition of an adverse reaction, prevention, and treatment. Results from the study showed a significant increase in the participants' food allergy knowledge scores after completion of the program. Although further research is needed to better understand whether online programs such as that examined by Pádua et al ultimately enhance safety and/or reduce stigma, online learning tools do appear to provide a potentially scalable means for the enhancing collective food allergy knowledge, especially in light of the current Covid-19–related restrictions on in-person gatherings.

Allergists also explained how misinformation, typically gathered from social media, could lead to unnecessary avoidance of food among parents of children with a suspected allergy. Given the importance of early exposure in preventing food allergy, unnecessary avoidance of food may increase a child's likelihood of developing additional allergies.²³ In light of this finding, it would appear as though the provision of accurate information regarding food allergy has the potential to reduce not only parental anxiety but also additional allergies for some families. Although differing from allergists in their approach, a number of dietitians interviewed for the current study also stressed the importance of education and recommended the provision of grocery store tours, cooking classes, and meal preparation sessions for families with food allergy. Although experiential learning programs, such as those suggested by the interviewees, appear to hold potential as an innovative means to help families with food allergies find products that are safe, affordable, and nutritious, the uptake and success of such programs may be constrained by a lack of food allergy knowledge among community dietitians. In particular, several of the dietitians interviewed in the current study perceived a lack of training and consequent lack of knowledge surrounding the management of food allergy among their colleagues in community dietetics. Although this knowledge gap has received some attention in the academic literature²⁴ and has inspired nonprofits aimed at educating health professionals on food allergy,²⁵ the findings from the current study suggest there is still a need for greater food allergy education among dietitians.

Conclusion

The health care professionals interviewed for the current study described families with food allergy as experiencing high levels of anxiety due to fears surrounding accidental exposures and dietary constraints. Although many health care professionals

described the need for greater mental health support and education for families with food allergy, few believed that increased support was feasible within the current health care system owing to constraints on time and resources and gaps in training. Consequently, future researchers should strive to find innovative solutions to address these deficits so as to ensure that the psychosocial needs of families with food allergy are met.

Key messages

- Clinicians have described the psychosocial burden of food allergy and identified barriers that may interfere with patient care.
- Recommendations included improving education and incorporating a multidisciplinary food allergy team.

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