



Parents of children with food allergy

A qualitative study describing needs and identifying solutions

Rishma Chooniedass, RN, MN^{*}; Lianne Soller, PhD[†]; Elaine Hsu, MPH[†];
Sharon To, PhD^{‡,§}; Scott B. Cameron, MD[†]; Edmond S. Chan, MD^{†,§}

^{*} Faculty of Health and Social Development, School of Nursing, University of British Columbia, British Columbia, Canada

[†] Faculty of Medicine, Department of Pediatrics, University of British Columbia, British Columbia, Canada

[‡] BC Children's Hospital, Vancouver, Canada

[§] Department of Psychology, University of British Columbia, British Columbia, Canada



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ABSTRACT

Background: Parents experience a wide range of emotions, specifically stress and anxiety, when their child receives a diagnosis of a food allergy. Managing this health condition and coping with emotions require professional and peer support. Currently, there is a lack of resources and a lack of awareness of the resources that are required to help assist parents in managing their child's food allergy.

Objective: To describe parental experiences when caring for a child with food allergy and to review the resources parents need to manage living with a child with food allergy and more specifically how they would want these resources delivered.

Methods: A total of 7 semistructured focus groups were conducted in British Columbia, Canada. Parents were asked to describe their experiences with managing their child's food allergy and identify helpful resources.

Results: A total of 40 parents (33 females) participated in the focus groups. Participant demographics were collected. The following 3 main themes emerged: (1) anxiety (an emotional roller coaster); (2) a transformational journey (the waiting game, loss of normalcy, strained relationships and mistrust, and financial challenges); and (3) the need for resources (day to day management, ages and stages, mental health supports, and "the dream").

Conclusion: An in-person allied health care team is needed to provide an integrated, patient-centered approach for how families can live and manage food allergies. Credible information and resources, such as medically reviewed websites, support groups, and counseling services, with a goal of reducing child and parental anxiety, should be provided by health care professionals.

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Introduction

When parents are told that their child has a life-threatening immunoglobulin E (IgE)-mediated food allergy, the unpredictability of allergic reactions and the steep learning curve required to manage this condition can cause considerable worry and difficulty coping. Attempts have been made to provide resources to families with a food allergy diagnosis using multiple methods, but not all resources have been well received. Some studies found in-person support groups with other parents enhanced learning and

decreased anxiety.^{1,2} Other studies identified the use of social media platforms and websites to share information and learn more about food allergies.^{3,4}

When a person receives a diagnosis of an illness, it is expected that they will receive information from health care practitioners about how to live with their medical condition. For instance, with a diabetes diagnosis, patients are taught how to monitor their blood glucose levels and manage their diabetes with proper nutrition and exercise, and, if needed, they are given medications to control their blood glucose levels. There are community and hospital-based diabetes educators who meet in groups and individually to offer personal education and support. However, when it comes to food allergy, no standardized education for health care professionals is available in North America, and training courses for patients are sparse around the world; those who do not know how to access them often fall through the cracks. Chooniedass et al¹ stated that

Reprints: Rishma Chooniedass, RN, MN, Faculty of Health and Social Development, University of British Columbia, ARTS 161-1147 Research Rd, Kelowna, British Columbia V1V 1V7, Canada; E-mail: rishma.chooniedass@ubc.ca.

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“in a system where healthcare can be delivered by several different professionals, it is imperative that consistent information and treatment is given to all patients.” Currently, no standardized education is available for health care practitioners to become certified allergy educators. Having a structured educational program designed for allied health care professionals would provide consistent information that parents need.

To date, no Canadian studies have explored parent preferences about who should deliver food allergy educational information and in what learning style. What parents consider helpful needs to be better understood to best support them with resources.

The aim of this article is to describe parental experiences when coping with a child with food allergy. In addition, the article explores the types of resources parents would prefer to help them cope with having a child with food allergy and more specifically how they would want these resources delivered.

Methods

Parents of a child with diagnosed food allergy were recruited to participate in focus groups in Vancouver, Victoria, and Kelowna, British Columbia, Canada. Advertising material was displayed in local allergists' offices and circulated to British Columbia members of Food Allergy Canada. Inclusion criteria included the ability to effectively communicate in English. The study was approved by the University of British Columbia Research Ethics Board.

A total of 7 semistructured focus groups were conducted (4 in Vancouver with a total of 18 participants, 1 in Victoria with 8 participants, and 2 in Kelowna with a total of 14 participants). All participants signed informed consent and completed a demographic survey before the start of the focus group. Sessions were held in a semistructured format, and participants were instructed to individually respond to each question before sharing with other participants (Table 1). Focus group sessions lasted 50 to 90 minutes. All focus groups were audio-recorded and transcribed. Transcripts were initially read to understand content and then analyzed line by line to identify codes that accurately represented the narrative. Codes were categorized into themes. Data sources included transcripts, field notes, and memos, which were imported into the software (Nvivo software, version 12; QSR International Pty Ltd, Doncaster, Australia). For verification, 3 researchers (RC, LS and EH) reviewed transcripts to ensure accuracy of coding. Recruitment ceased when data saturation was achieved. Researchers identified codes and collapsed them into themes and subthemes. Participant quotes were identified to represent the themes.

Results

A total of 40 parents (33 females) participated in the focus groups. Children ranged from 8 months to 15 years of age, with almost 60% males. Approximately one-third of the children had 1 or 2 food allergies, another third had 3 to 6 food allergies, and the remainder had 7 or more food allergies. Sample demographics are detailed in Table 2. The findings from this study supported the following 3 main themes: (1) anxiety (an emotional roller coaster), (2) a transformational journey, and (3) the need for resources (Table 3).

Theme 1: Anxiety

Many parents spoke about the range of emotions experienced initially when their child received a diagnosis of a life-threatening food allergy and as new challenges arose. For many, reliving the first reaction was traumatic. The quote below illustrated that this parent reminisced about that initial period of confusion and how overwhelmed she felt. She described feeling unprepared for what she saw unfolding.

When we were taking him to the hospital . . . his voice went hoarse, um, and so we knew that there was more to it than just hives (crying). And I think, then I knew that, you know, things weren't gonna be the same, and I don't know that you can really grasp it from the beginning because you have no idea what it really entails to avoid allergens. . . . Just sort of keeps you accumulating.

Feeling safe came with time and familiarity in a new environment. This mother explained that her anxiety comes from new and uncontrolled environments. The uncertainty with transitions to new schools and new policies with new teachers created angst. In attempts not to add to her daughter's previous history of anxiety, this mother desperately tried to conceal her fears.

I've had my own anxiety over the years as well, but I think my anxiety has definitely increased, and the whole school thing . . . I was asking her to do something that I wasn't even comfortable with and we had gone through therapy previously like because of she's also got phobias and um in other areas of her life, so the peanut thing is just another. . . . I would say that my anxiety built along with hers, and I probably, although I was remaining calm on the surface, I'm sure that she sensed that

In the world of social media, any person around the world can post regardless of expertise or knowledge on a topic. Although social media was a source of support, it was also a source of anxiety. Reading about other children and their severe reactions made parents more anxious, expecting the worse.

And I think um the Facebook pages um are great, but I think they can also um be like invoke a lot of anxiety, when you know, I'd be in a good place and I'd read stuff and be like 'oh my God we need to do this and control this.'

Theme 2: A Transformational Journey

A child diagnosis of food allergy started a transformational journey. The immediate path looked rough, but parents quickly learned to navigate the challenges necessary to keep their child safe. This theme was separated into the following 4 subthemes: (1) the waiting game (a period of the unknown), (2) a loss of normalcy, (3) strained relationships and mistrust, and (4) financial challenges.

The Waiting Game: A Period of the Unknown

Experiencing an anaphylactic reaction is scary for parents and their child, and whether the family is treated at the emergency

Table 1
Focus Group Questions

At the time of diagnosis:
1. How did you feel when your child was first diagnosed with food allergy?
2. What resources were you given to help you cope with the diagnosis? Were the resources helpful? Why or why not?
3. What additional resources, if any, would you have liked to receive to help you cope with the diagnosis?
Assessing a change over time:
4. Since diagnosis, how have your experiences around coping with having a child with food allergy changed?
5. Thinking back to those difficult moments you mentioned in the previous question, what resources did you have at your disposal which helped you cope during these difficult moments? What would you have liked to have that you didn't have?

Table 2
Allergic Child and Parent Information

Variable	Finding ^a
Allergic child information	
Age of children, mean (range), y	6.6 (8 mo to 15 y)
Sex of children	
Female	13/40 (32.5)
Male	27/40 (67.5)
Allergens	
Peanut	31/40 (77.5)
Tree nut	17/40 (42.5)
Fish	3/40 (7.5)
Shellfish	2/40 (5)
Sesame	1/40 (2.5)
Milk	18/40 (45.0)
Egg	19/40 (47.5)
Wheat	0/40
Soy	3/40 (7.5)
Other (mustard, beef, peas, chickpeas, lentils, split peas, and green peas)	5/40 (12.5)
No. of allergens	
0–2	13/40 (32.5)
3–6	15/40 (37.5)
7–10	5/40 (12.5)
≥10	7/40 (17.5)
Report child's allergies are severe	39/39 (100)
Child has had anaphylaxis	30/39 (76.9)
Child has been to the ED for reaction	36/39 (92.3)
Parent information	
Age, mean, y	39.1
Sex	
Female	33/40 (82.5)
Male	7/40 (17.5)
History of mental health issues or concerns in self or family	13/40 (32.5)
History of anxiety in self or family	14/36 (38.9)
Postsecondary education	32/36 (88.9)
Health care professional	6/35 (17.1) (3 nurses and 3 other)
Married or living with partner	35/35 (34 married and 1 living with partner)
Annual income >\$100,000	26/35 (78.8%)

Abbreviation: ED, emergency department.

^aData are presented as number/total number (percentage) of participants. Not all participants responded.

department or a clinic, a wait time is required before seeing an allergist after getting a referral. Depending on the family's location, the wait time to see an allergist can be many months. During this confusing and stressful period, parents are left on their own to learn about their child's food allergy while trying to keep their child safe.

We were told we would get a referral to an allergist but that took a few months so it was like navigating on our own for a few months like with a baby who crawls around and eats everything that it can find on the floor.

During the waiting times, parents resorted to searching for any information they could find, often from the Internet or from other people who have experience with food allergy.

A Loss of Normalcy

People stated that their lives changed after having their first child, but parents of children with food allergy live with the additional responsibility of keeping their child safe while living with a life-threatening medical condition. This additional burden weighed heavily on them. Many parents described that their lifestyle changed after their child received a diagnosis of a food allergy.

Events that were previously easy required great amounts of pre-planning, such as school activities or family gatherings. Some described that they believed that others saw them as obstructive parents, but they felt they needed to become these types of parents to keep their child safe.

It changed me as a human being. I'm like, I'm a different person. . . . I used to be really easygoing, and just kind of really carefree and we just did things on a whim and that is just not life anymore, so, yeah that's changed. And, and anxiety too, like I wasn't really an anxious person before, I don't think, um and yeah, every single moment has to be calculated now. Every moment!

Strained Relationships and Mistrust

Many parents described the strain on relationships, especially with family members. Close family members who were expected to be a source of support did not always understand the severity of the situation and the additional stress they created. Parents needed to know that their family understood the importance of allergen avoidance and how to treat a reaction. Mistrust can occur if parents feel other family members have not learned these skills. It also became very difficult when one parent was not supported by their partner or if the parent felt like their partner was not taking their child's medical condition seriously. It put additional pressure on the one parent to be solely responsible for their child's safety and well-being, which was overwhelming and extremely stressful.

We're on high alert all the time. Especially with my in-laws, I get anxious . . . going to their house. . . . And I was kinda saying to my mother-in-law 'you need to tell her to like clean her house, cause they eat eggs and peanuts in her house', and um and then she's like 'oh, there might be like egg protein on the driveway', and I was like physically anxious, and we ended up not going and it ended up being this huge thing cause the thing was cancelled.

Parents expressed that when their children were young it was easy to keep a closer eye on them. As they grew older and new activities arose, children would want to attend events without parents. Parents acknowledged that not all people understand food allergy, and only when parents felt like their child was in a safe environment could they attend the activity without a parent.

I can't expect um you know one of her friends' parents to necessarily understand the severity or the seriousness or to keep an eye on her, so it's gonna be tough that way kind of vetting who she's hanging out with, at least in an unsupervised setting you know. At least it's gotta be somebody I trust that uh understands and acknowledges all these things that you know can be a concern.

Trusting people was a challenge for parents. Often it is family and friends who are expected to be supportive and ultimately protect one another. However, many parents experienced frustration when family members and friends did not understand the challenges of having a child with a food allergy. Despite the education and explanations, parents felt that no one understood the extent of their daily responsibility to keep their child safe.

Financial Challenges

Most parents in the focus groups described that having a child with food allergy affected them financially because it affected their work schedules. Deciding what to do when a child became school-aged and was no longer under parent supervision at all times created anxiety. Parents described the need for flexible jobs so that they were present for school activities when there was a higher possibility of an accidental reaction. Taking time off work to

Table 3
Themes, Subthemes, and Quotes

Theme	Subtheme	Quotes
Anxiety (an emotional roller coaster)		<p>We were on a Westjet flight and right behind me, [whispering] I, I go, [to her husband] there's a lady with a bag of peanuts like open, like a Costco sized bag of peanuts, just munchin' away and I was like, [sighs] I was like so stressed out.</p> <p>I am anxious, but I'm also realistic, and it really does happen, it just takes a second. Like it's scary and it's absolutely, your life is forever changed, and you're never gonna be able to just be like ughhh let's just relax and have a birthday party.</p> <p>We had friends in Australia who were there when he was diagnosed and we felt safe around those people, but then we moved here and now I feel like we have to explain it to everybody again and it's, it's pretty devastating.</p>
A transformational journey	The waiting game: a period of the unknown	It took us about a year, or, about 6 months to a year to actually get in, once our doctor made the referral.
	A loss of normalcy	<p>Even just going to the playground and worrying every time somebody brings food out, like what is in that food? Like other people just don't get it, and it's hard to explain, cause you just look like a nag and you're just that annoying person who you know wants to know what you're eating and [others laugh] you're just the fun ruiner for everybody.</p> <p>It's just part of our reality now and we have to plan for it, and I think you told me when I was a bit of a jerk when I said that, but I was trying to be blunt in the sense that, you know, you know it sucks but this is what it is, we have to deal with it.</p>
	Strained relationships and mistrust	<p>Dealing with family, and in-laws, and stuff—um like I've yelled at my mother in law, um, because she wasn't willing to use a cell phone to call 911.</p> <p>And then even like yeah like parties, like my brother-in-law the other day was, like made an offhand comment like, 'oh you never see us anymore cause you can't eat peanuts'. People just don't understand! He [spouse] doesn't know what I go through every day to keep my kids safe, right, and that's my full-time job is just making sure you know all these flying eggs and milk are staying away from my kids.</p>
	Financial challenges	Every single one of us in the room can say that something has impacted our workplace because of this [food allergy].
The need for resources	Day to day management	<p>There definitely needs to be more uh logistical support about known safe products, how do we interpret label information for those you know random ingredients that are so you know chemical sounding like calcium chloride or whatever it is, and what do those mean.</p> <p>More information on restaurants, and what's safe, and what, what um, like menus I find are very helpful looking through, we always go through um a restaurant menu just to make sure, because it's not just the nut, or, it's peanut oil, like fish and chips, you wouldn't think to ask, like you know things like that.</p>
	Ages and stages	I think it would be more like a parent, just because through the stages, you just kinda want to know what's coming up, or what to look for, what you know you could do to prevent certain things.
	Mental health support	And so that's where I really think having a counselor with a specialization in managing food allergies within the family would be amazing.
	"The dream"	<p>I've actually like asked my allergist to refer me to a psychologist because I need I need I need resources. A hotline. Like you can call 811, why can't there be one for an allergy. Like so if you have a question you can just call somebody, that would be very nice.</p> <p>I feel that, there's nothing local, no group where I can just go and talk and vent, or just be like or have you tried this it just came out. See I need you guys.</p>

support and monitor their child and for physician visits reduced income. Some parents even left their jobs to homeschool their child because they believed it was the only safe option.

And I go on the fields trips and I need to have a flexible schedule—there was a financial cost to that, it's very expensive.

So, we've chosen to homeschool, because of our allergies.

Theme 3: The Need for Resources

All families unanimously agreed that they were not given sufficient information at the time of their child's diagnosis. Most parents accessed the Internet, social media, HealthLinkBC (a government-funded telehealth support line), and friends or family to learn more about food allergies. They felt that better resources would have helped their anxiety. This theme is separated into the following 4 subthemes: (1) day to day management, (2) ages and stages, (3) mental health supports, and (4) "the dream."

Day to Day Management

Parents stated that receiving helpful resources on diagnosis was of paramount importance. One family felt too much information at

the time of diagnosis was overwhelming, but most parents said they needed credible information as soon as the diagnosis was made. They said that any information led to additional questions for future allergist appointments.

What may seem a simple diagnosis of one food allergy can be very difficult to manage when trying to decipher a confusing food label. Some allergens go by several different names. Getting relevant and credible information about the different names of the allergen is vital. Parents need to have access to this information to keep their child safe.

. . . it's not just milk, [laughs] it's dairy, everything, it's in everything, and I didn't really grasp that until I had to do it myself and look it up myself.

The simple act of talking to people became a concern, specifically, how parents approached the topic of food allergy in a restaurant, school, or even a social group. Parents wanted guidance on how to initiate this type of dialogue.

how do you deal with certain things or how do you approach this, or what's a better way to maybe speak with somebody that you're having a hard time with you know, getting that information across.

Ages and Stages

As children grew, each developmental stage had its own challenges. For parents of children with food allergies, each stage presented new complications. Infants and toddlers often put items they find randomly into their mouths, and school-age children often share food. Parents said that they needed support for these new life stages. Hearing about real-life experiences from a parent whose child had similar food allergies or who recently passed through a developmental stage provided reassurance and encouragement for parents who were preparing for a new stage. Parents wanted information and advice that helped them for the uncertainties with upcoming transitions. First-hand information was considered ideal in these situations.

And there's some really amazing websites and those are really helpful, but even if the, the initial group that you get the education from, there can be, sort of like, you know, 'now that your child's a tween', 'now that your child's a teenager', 'now that your child's'—and then of course, the kids are starting to access these and so. 'Now that you're stepping into adulthood', um, what can we do. So, resources along the way.

Mental Health Supports

Parents realized that even if they received resources with pertinent information on allergy avoidance and management, much more information was required when living with food allergy. The mental health component that accompanied food allergy was often left out of resources.

Parents did not feel that they had the tools necessary to help their child cope with the mental health effects of living with food allergy. Providing care for a child in this area was often not clear or concrete.

It's one thing to control your environment and the food, it's completely different when it hits the mental. And then you're like well now I'm, I'm out of my league.

Parents wanted help with coping mentally with food allergies not only for their child but also for themselves. The complicated emotions that families went through require understanding and guidance by those trained in mental health. This parent went as far as asking the child's allergist for a referral to a psychologist to help them better cope.

I think another thing that would have been nice is some mental health or counseling resources um just to be able to I guess talk things through.

Health care professionals, especially those with knowledge of food allergy, can be an excellent resource because they understand the medical condition and have experience dealing with possible concerns; they can also provide validation, emotional support, and strategies.

"The Dream"

All parents gave examples of resources that would have been more helpful at the time of their child's diagnosis. They spoke about the need for credible sources of information, a variety of delivery methods, and who would be the best to provide this information. One parent suggested a 24-hour helpline to provide immediate support and answers to food allergy questions. Parents stated that a program designed to provide support and education from health care professionals that offered solutions to common food allergy-related concerns, including daily management and dealing with social relationships, would have been beneficial.

I think initially, people should have a nurse or a counselor and a care plan for everybody who gets a diagnosis. I think that definitely there should be some sort of follow-up . . . you should have somebody who sits down and who's qualified and do some therapeutic communication who can find you your resources, whether its counseling or a dietitian or whatever, and a plan, and a follow-up and some like, and get all your basics, like here's your epipen practice kit, here's your little video to watch, here's papers to give out to your family.

In a perfect world, parents explained that there would be a multidisciplinary clinic dedicated to food allergy that consisted of an allergist, nurse educator, dietitian, counselor, social worker, and psychologist. Local peer supports groups that would meet monthly would also complement this healing approach. This integrated health care team would continually educate and support families on daily management skills as their child grows.

The dream would be having a clinic where you have access to a dietitian, a social worker, a parent, you know preferably somebody who knows about how you need to read labels and somebody who has food allergy experience.

Discussion

This qualitative study describes anxiety and coping of parents in the context of food allergy and explores the resources that parents would find helpful at different stages of their food allergy journey. Few parents in this study reported receiving information or resources to appropriately care for their child while waiting to see an allergist. No patient should need to navigate the medical system on their own and sift through multiple sources of information to determine which ones are credible. Under the health care umbrella, there is a need for a systematic approach when a patient has an allergic reaction to a food. For example, when patients are first seen in the emergency department or in a primary care practice for a confirmed diagnosis of anaphylaxis, they must be given a prescription for an epinephrine autoinjector and standardized educational material about management and treatment. Patients could be given information on how to access local food allergy education groups, which would provide credible resources, such as medically reviewed websites, support groups, and counseling services. In particular, designing such educational resources with a goal of reducing child and parental anxiety would have considerable benefits.

Every parent in this study expressed some form of anxiety when managing a child with food allergy. When a child receives a diagnosis of a food allergy, parents experience an array of emotions, including guilt, frustration, isolation, grief, and anxiety.^{1,5} Caring for a child with food allergy places an additional burden on parents who must ensure that their child is not exposed to foods that could cause a potentially fatal reaction.⁶ This added responsibility can lead to increased stress and poor coping of the caregivers.⁵ Some parents report a diminishing sense of distress over time, but others report feeling more distress when new life challenges arise.⁷ The health care team needs to take a more active role in helping parents understand the diagnosis and implications of food allergy so that the entire family can lead a normal life.⁸ Parents need support to cope with the emotional and behavioral responses when living with a child with food allergy.¹ These parents stated the importance of hearing other parents' experiences. The parents in this study wanted local peer support groups to meet regularly to share stories, offer advice, and even vent. They explained that they enjoyed contributing to the research and, more importantly, meeting other parents living with a similar problem. Parents chose to stay

connected after the focus group and planned play dates with their children who had similar food allergies.

Parents in this study expressed that physicians can be too casual with a first-time diagnosis of a life-threatening food allergy, which potentially contributes to a false sense of security for the patient and family. The initial diagnosis of food allergy should not be taken lightly because it is a life-threatening condition that warrants close attention to management and treatment. Physicians should take the time to emphasize the importance of allergen avoidance, the possible severity of a reaction, and the treatment of a reaction to every new patient. Monga and Manassis⁹ stated that “children who present with allergies and secondary anxiety require a comprehensive assessment” because there are multiple anxiety conditions associated with allergies in children. Children with food allergy face numerous challenges with understanding management and treatment, and they also must deal with complicated associated emotions. Discussions with an allergist can uncover whether a child will benefit from a referral to a psychologist or other mental health professionals.

This study only recruited parents who spoke English. It is possible that families speaking other languages would have other needs, including services to translate educational information. Most of the research participants were white, university educated, and middle- to high-income earners; lower socioeconomic status families may have different needs, including the way they access information or use funds to purchase epinephrine autoinjectors and specialty foods.

Parents experience a wide range of emotions, specifically stress and anxiety, when their child receives a diagnosis of a food allergy. Managing this health care condition and coping with these emotions require professional and peer support. There is currently a lack of resources and a lack of awareness of the resources that are available. This article highlights the need for a structured health care plan and a path for ongoing management for patients and their

families. Although parents like accessing online information at their convenience, credible information and resources for support should be provided by their health care practitioner at diagnosis and follow-up appointments. An in-person allied health care team to provide an integrated, patient-centered approach for these families to live with and manage food allergies would be beneficial.

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