

ORIGINAL RESEARCH

Living with and Caring for People with Multiple Food Allergies: A Qualitative Study

Christina Ciaccio [6], Jessica Dunne [62], Andrea Bever², Karissa Johnston², Stacey Kowal [63], Arpamas Seetasith [63], Andrew Lloyd [64], Alexis Mickle [62]

¹The University of Chicago, Chicago, IL, USA; ²Broadstreet Health Economics & Outcomes Research, Vancouver, British Columbia, Canada; ³Genentech, Inc., South San Francisco, CA, USA; ⁴Acaster Lloyd Consulting Ltd, London, UK

Correspondence: Christina Ciaccio, Department of Pediatrics and Medicine, The University of Chicago, 5841 South Maryland Avenue, Chicago, IL, 60637, USA, Tel +1-773-834-4010, Email cciaccio@bsd.uchicago.edu

Purpose: The quality of life (QoL) impact of food allergies extends beyond severe allergic reactions, as food avoidance can permeate the daily lives of individuals with food allergies and their caregivers. People with multiple food allergies may experience a greater impact on QoL than people with a single food allergy, but there is limited evidence available. The aim of the study was to provide insight into the lived experiences of adults, teenagers, children, and caregivers of children with multiple food allergies.

Methods: Semi-structured interviews were conducted of people with multiple food allergies and their caregivers (n = 20) in the United States, including 10 adults, 5 teenagers, and 5 caregivers of children. Patterns in responses were explored using reflexive thematic analysis.

Results: Four themes were developed by the researchers to convey the experiences of people with food allergies and QoL impact: preparedness and allergen avoidance results in a loss of spontaneity; emotional impact varies by person and for each person; participating in society involves speaking up and trusting others; and food is more than nutrition. In addition, 3 themes were identified that convey the experiences of caregivers: looking out for your child's safety is an emotional balancing act; limitations on what you can do on your own and as a family; and creating a safe and fulfilling environment can be time-consuming and costly.

Conclusion: These findings highlight that people with multiple food allergies experience social limitations, stress about food safety and allergen avoidance, and restrictions on freedom. Caregiver QoL is impacted by the need to navigate social, emotional, and practical implications of caring for a child with multiple food allergies.

Plain Language Summary: People with food allergies must constantly make an effort to avoid the foods they are allergic to. Having an allergy to more than 1 type of food (for example, peanuts, eggs, or milk) can be even more difficult. In this study, we interviewed adults and teenagers with food allergies, as well as parents of children with food allergies, about how having an allergy to more than 1 type of food affects their daily lives. We found that people with more than 1 food allergy often had stress and anxiety. They also had to change the way they traveled or socialized. Parents caring for a child with food allergies were also impacted. Parents had to look out for their child's safety and made changes to family plans and activities. The lives of people with food allergies and their families may be improved by treatments or interventions that can lower the risk of allergic reactions.

Keywords: food hypersensitivity, quality of life, patients, caregivers, multiple food allergies

Introduction

Food allergies affect 1 in 9 adults and 1 in 13 children in the United States, ^{1,2} and can cause severe reactions, including anaphylaxis. One survey found that 38% of adults with food allergies visited the emergency room for an allergic reaction in their lifetime. ¹ However, the impact of food allergies on quality of life (QoL) extends beyond severe reactions. ³ The standard of care is primarily food avoidance, which permeates the daily lives of people living with food allergies, as well as their caregivers and families.

1949

Qualitative studies have highlighted the burden of food allergies among people with food allergies and their caregivers. 4-11 However, there is limited research specifically focusing on the burden of multiple food allergies, which may occur in up to 48% of people with food allergies. 1,2,12,13 Of note, individuals with multiple food allergies may have higher rates of atopic comorbidities, health care resource use, and a greater perceived psychosocial burden than individuals with a single food allergy. With new treatments emerging for food allergies, understanding the impact of multiple food allergies on daily activities and OoL is important.

The objective of this qualitative study was to provide insight into the burden experienced by a group of adults, teenagers, and caregivers of children with multiple food allergies, by exploring impacts on daily activities and QoL. This qualitative study provides in-depth knowledge about people's day-to-day experiences of their food allergies, allowing a greater understanding of why people with food allergies make certain choices in terms of food avoidance, and providing insight to the heterogenous accounts of impact on QoL.

Methods

Study Design and Participant Recruitment

Qualitative interviews were conducted to collect data on the lived experiences of people with multiple food allergies and their caregivers. Development of the interview guide was informed by a targeted review of literature that described the impact of food allergies on QoL. The interview guide was subsequently reviewed by all members of the study team, which included a food allergy specialist physician and a researcher with lived experience of multiple food allergies. The study sample was recruited through a patient recruitment agency (Pinpoint Patient Recruiting, Cary, North Carolina, United States). The sampling strategy was informed by both findings from the literature review and clinical expert input and considered key determinants of health and QoL outcomes among individuals with food allergies. A purposive sampling approach using social media, patient advocacy groups, and patient panels was implemented.

The inclusion criteria for participants were physician diagnosis of 2 or more food allergies and a history of allergic reactions (based on self/caregiver report), United States residency, fluency in English, and ability to provide informed consent. An allergy to multiple tree nuts was considered 1 food allergy. The exclusion criteria for participants were cognitive impairment that could interfere with meaningful participation in the interview, and multiple food allergies not diagnosed by an allergist, immunologist, or primary care physician.

Adults (≥18 years of age), teenagers (13–17 years of age), and caregivers of children (≤12 years of age) with multiple food allergies were all included in the study (n = 20). The inclusion of teenagers allowed for exploration of how people with multiple food allergies transition from childhood to adulthood, in which they become more responsible for their own food choices and health decisions. Caregivers were interviewed on behalf of their child as they were primarily responsible for making food choices and health decisions. Caregivers provided insight into the life of children with multiple food allergies and shared their own lived experiences.

Recruitment quotas were used to help achieve diversity in a variety of sociodemographic and clinical characteristics, including household income, race, peanut allergy status, number of allergies (2 or ≥3 allergies), and history of a severe reaction. In this study, a severe reaction was defined as a reaction resulting in the use of an epinephrine autoinjector and/ or a hospital/emergency room visit.

The study received ethical approval from the Western-Copernicus Group Institutional Review Board (#20220251) and was conducted in accordance with the Declaration of Helsinki. Participants were compensated for their time and expertise.

Data Collection

Participants were recruited and semi-structured interviews were conducted over teleconference from March to April 2022. The interviews were approximately 1 hour in length and were audio-recorded. Each interview was conducted by a single health researcher with training and experience in qualitative methods (either author AB or JD). The interview guide (see eSupplement) consisted of open-ended questions about experiences of living with multiple food allergies and impact on social and emotional aspects of QoL. The guide was used to outline the interview approach and questions were

https://doi.org/10.2147/PPA.S466749 Patient Preference and Adherence 2024:18

selected depending upon the participants' responses to previous questions. The guide included probes throughout for the interviewer to clarify which food allergen the participant was referring to. In the interview, participants were asked about their experience taking preventative or desensitization treatment. These data were not used in this analysis and will be reported elsewhere.

One version was developed for use in people with multiple food allergies, and another for caregivers of a child with multiple food allergies. Clinical and demographic information was collected to characterize the study sample and to contextualize participant responses.

Analysis

Participant demographic and clinical characteristics were summarized. Audio recordings were transcribed, and patterns in responses were explored using reflexive thematic analysis ^{14,15} within a critical realist framework, which views meaning and experience as subjective and attends to the social and cultural context in which they are produced. ¹⁶ In reflexive thematic analysis, themes are actively created by the researcher and are produced not only from the data, but from the researchers' theoretical assumptions and qualitative analysis skill. ¹⁴ The researchers strived to thoughtfully engage with the data, practiced reflecting throughout the analytic process, and worked collaboratively to develop a more nuanced understanding of the data.

An iterative, 6-phase approach was used to code the data and develop themes:

Phase 1: Data Familiarization: Two researchers, who were also the interviewers, met regularly to discuss initial thoughts from conducting interviews and reading through transcripts, and making notes of any insights.

Phase 2: Coding: Coding was conducted using Taguette, an open-source computer-assisted qualitative data analysis program.¹⁷ A mostly semantic, inductive approach was chosen to code the data and develop themes; this approach was driven by the information shared by the study participants and reflects their experiences and perspectives. Notes/memos were taken throughout coding. The researchers separately coded 5 initial transcripts of interviews with adult participants and then met to discuss and compare their codes. Codes were applied to any aspect of the data that was relevant to the research objectives. One researcher coded the remaining 5 transcripts from adult interviewees and the 5 transcripts from teenage interviewees, and the other researcher coded the 5 transcripts from caregiver interviewees. Codes were refined, reorganized (ie merged or split), and new codes were added, as needed, throughout the coding process.

Phase 3: Generating Initial Themes: The researchers continued to meet and discuss potential themes throughout the data familiarization and coding process. After coding was complete, codes were organized into broader categories of meaning based on initial ideas for themes. The experiences of people with food allergies and caregivers were considered separately when developing themes to ensure that the study findings reflected caregiver insights with respect to their child's experience as well as their own unique experience as a parent.

Phase 4: Developing and Reviewing Themes: Categories of meaning were reviewed against coded data extracts to determine how well they conveyed participant experiences and perspectives, and how well they collectively addressed the research question. Categories were revised based on discussion with the research team.

Phase 5: Refining, Defining, and Naming Themes: Categories of meaning were further developed into a set of themes, with each theme given a name and description. Subthemes were developed as needed to convey any key nuances of the overarching themes.

Phase 6: Writing Up the Study Findings: The study findings were documented. This analysis explicitly reflects the content of the data. However, after identified data patterns were organized and summarized, the analyst interpreted and theorized the significance of the patterns and their broader meaning and implications.¹⁵

Results

Participant Characteristics

This study included 10 adults, 5 teenagers, and 5 caregivers (mothers) of children ≤12 years of age (participant demographics and characteristics are reported in Table 1). Overall, 70% of participants with multiple food allergies

Table I Participant Characteristics

Characteristic, n (%) ^a	Participants (n = 20)		
Participant			
Adult (≥18 y)	10 (50)		
Teenager (13–17 y)	5 (25)		
Caregiver of child aged ≤12 y	5 (25)		
Age at interview ^b , y, mean (median)	24.0 (21.5)		
Age at diagnosis ^b , y, mean (median)	9.4 (2.5)		
Caregiver age ^c , y, mean (median)	38.8 (38.0)		
Female	17 (85)		
Race and ethnicity			
White	14 (70)		
Hispanic, Latino, Spanish origin or any race	I (5)		
Black, African, Caribbean, or African American	I (5)		
Asian or Asian American	2 (10)		
Two or more races	2 (10)		
Household income			
Less than \$25,000	2 (10)		
\$25,000 to <\$50,000	0		
\$50,000 to <\$100,000	5 (25)		
More than \$100,000	9 (45)		
Prefer not to answer	I (5)		
Do not know	3 (15)		
Allergic to peanuts	15 (75)		
Allergic to ≥3 foods	14 (70)		
Severe reaction	13 (65)		
Use of epinephrine autoinjector	11 (55)		
Visit to the hospital/emergency room	10 (50)		

Notes: aUnless stated. BAge of individuals with food allergies. Caregiver age at diagnosis of child with food allergies (n = 5).

Abbreviation: y, years.

reported allergies to 3 or more foods (14/20), while 30% reported allergies to 2 foods (6/20). Many participants (65%) had previously experienced a severe allergic reaction (13/20).

The Experience of People with Food Allergies

Four themes were developed to describe the experiences of people with multiple food allergies and impact on QoL (Figure 1).

Preparedness and Allergen Avoidance Results in a Loss of Spontaneity

Many individuals with multiple food allergies conveyed the need to always be prepared for a reaction, and to plan ahead to avoid exposures. Participants described how they cannot spontaneously try new places or foods, making it difficult to eat "on the go", and spoke of the time spent on taking steps to avoid allergens and prepare to eat safely, including reading labels of all packaged foods, researching new foods and restaurants, always preparing their own food, and frequent cleaning at home. Participant 9 stated:

"I can't just go. I have to slow down. I have to read labels. I have to do all these other tasks just so I can eat".

Family, friends, colleagues, and housemates may also have to avoid food allergens. Participant 7 explained:

"My husband was... I mean, he gave up all of his favorite foods just to be with me..."

Caregivers expressed that children with multiple food allergies must assume responsibility for their own safety from a young age; for example, a caregiver of a child with multiple food allergies (Participant 19) said:

https://doi.org/10.2147/PPA.S466749 1952

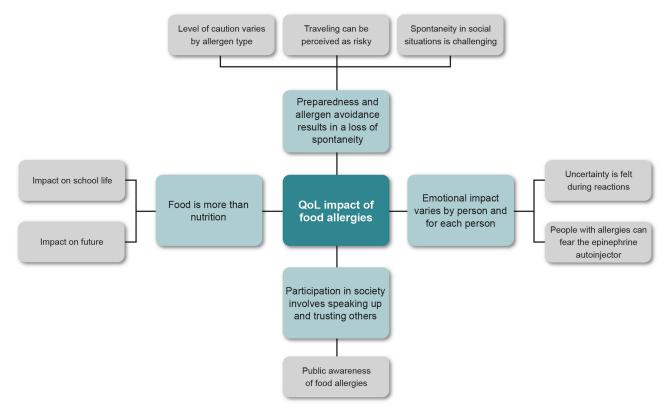


Figure 1 Map of themes resulting from analysis of the lived experiences of people with food allergies (n = 20). Four key themes (teal) and subthemes (gray) were developed by the research team on the impact of food allergies on quality of life (QoL).

"She knows how to prepare. She knows how to look out for her reactions if an accident happens. She knows the steps to take. She's like a little old lady".

Three subthemes were identified by the research team (Figure 1 and Table 2): level of caution varies by allergen type, traveling can be perceived as risky, and spontaneity in social situations is challenging. The steps taken to avoid allergen

Table 2 The Experience of People with Food Allergies: Subthemes and Illustrative Quotations

Theme	Subtheme	Illustrative quotations
Preparedness and allergen avoidance results in a loss of spontaneity	Level of caution varies by allergen type	"I stick to totally peanut-free foods. If it says 'May contain egg' or 'Manufactured in a facility with eggs',I will eat that, but only because it's not an anaphylactic reaction like peanuts". Participant 2, adult "For me, eating outside, fish is usually the biggest issue because there's just always contamination, especially with fish. But the nuts allergy scares me more because I am more severely allergic to it But then most foods will say, 'We have this nut,' but they will not really say exactly what fish or things like that". Participant 15, teenager
	Traveling can be perceived as risky	"So, there's an event next week that's a training in Las Vegas that I am just not going to attend because last year I could not eat anything at the training seminars. It's just a lot to go there, find a grocery store, find pre-packaged food that's healthy I can eat, and then being around nuts and having to sit in a room with nuts. I end up just not eating anyway because I am scared I am going to touch something and then eat something". <i>Participant 7, adult</i> "We can't go on any airplanes or flights anymore because [of] my allergies, because of people eating on the plane. So can't go cross-country or travel outside of the country really. We have to go on road trips exclusively, so that takes a long time". <i>Participant 11, teenager</i>
	Spontaneity in social situations is challenging	"because COVID, it was easy because everything was here from our kitchen. But I think times when he's gone on overnight field trips or where we do not know he's going to be traveling on a bus with a group of people and they are going to stop somewhere but they do not tell you where, those times have been more difficult". Participant 12, teen's caregiver "If I'm just with my friends, sometimes we have a habit of just ending up somewhere. So, sometimes that is worrisome because I never know where my day's going to go". Participant 7, adult

(Continued)

Table 2 (Continued).

Theme	Subtheme	Illustrative quotations
Emotional impact varies by person and for each person	Uncertainty is felt during reactions	"We immediately got the check and got in the car to go to the hospital. So we were sitting there, debating, like I am having a reaction and I am like, 'I don't know if I should use the EpiPen. Should I? Should I? So I ended up using it on the way to the hospital". Participant 6, adult "I was confused about when I should be using my EpiPen, because if the hospital, the doctors, the ones who are the professionals thought I did not need it, how am I supposed to know if I need it? But my direction was always 'Administer the EpiPen in case. You don't want to be too late.' So I am just trying to convince myself that that is still the right way to go about it and just say that it's a weird, rare occasion that the hospital did not give me my EpiPen when I was very much clearly in anaphylactic shock, and just try to convince myself that that was just a one-off situation". Participant 10, adult
	People with allergies can fear the epinephrine autoinjector	"I've never used it before, so I just don't like needles in general, so and I just, I would not want to use it. So that's why just I'm always extra alert". <i>Participant 13</i> , teenager "I know that they say to Epi immediately. You know, 'better to be safe than sorry,' but I do find that to be a little bit – I do not know I think I find that to be it could be a little traumatizing because if you do not need that severe of a [intervention]" <i>Participant 4</i> , adult
Participating in society involves speaking up and trusting others	Public awareness of food allergies	"I think it's just easier because of the more global acceptance that's there and the more offering and understanding". <i>Participant 8, adult</i> "I think it honestly depends on the people, not society but there's a lot of people who just do not believe allergies exist or they do not believe in the severity of it. Then I know a lot of restaurants do not take it as seriously as some people do. So, I feel like, nowadays, I definitely see more labeling and more just ingredient lists being more detailed, especially places where we eat". <i>Participant 15,</i> teenager
Food is more than nutrition	Impact on school life	"even the school system. I mean, they were like, "Well, he needs to pack her food," and put her at a separate table I mean, that's no way to treat a child, not even a person". Participant 19, caregiver "Like sometimes when I am eating lunch at school or something, I'd have to sit away from people who are eating peanut butter sandwiches. And when I was little, I had to eat at a peanut-free table by myself because I just had to be really safe. And that, it just really sucked". Participant 14, teenager
	Impact on future	"Then just because I am going to college next year, so I am just worried about when I am in college and meeting all of these new people, how am I going to because food is a big part of interaction. So, I worry about eating with other people. How am I going to just go out normally?" <i>Participant 15</i> , teenager "Relationship-wise, cannot really go on any food dates, cannot have anything related with food. I cannot have certain jobs. Like office jobs, people are eating. I have to work from home or find something. Cannot do anything where I have to travel or be in active service". <i>Participant 11</i> , teenager

exposure may vary for different food allergens for people with multiple food allergies; for example, Participant 2 explained how they exercise more caution when avoiding allergens that cause anaphylaxis than allergens that cause less severe reactions. Participants described how food allergies can be especially difficult to manage for allergens that are commonly consumed by people close to them and for which public awareness is poor. In addition, uncertainty and risk of allergen exposure may increase when traveling, eating at new places, or trying new foods. Some individuals with multiple food allergies were better able to manage their food allergies during the COVID-19 pandemic, when socializing was limited.

Emotional Impact Varies by Person and for Each Person

Food allergy-specific anxiety and resulting level of caution can vary among people with multiple food allergies, based on age, personality, and experiences. Anxiety can also vary for each person at different events/places and at different times in life. Some people described being at peace with their food allergies, whereas others experienced distress during daily life. However, feelings of panic and uncertainty during allergic reactions were shared by all participants, regardless of the severity of previous allergic reactions. Participant 5 recounted:

"I couldn't swallow and started to get panicky. Kind of like, 'Why is my throat closing and I cannot swallow and I'm having a hard time getting air in?""

In addition, teenagers and children often felt self-conscious about being different from their peers, and expressed feelings of embarrassment and guilt. For example, Participant 14 shared:

"I feel really bad for waiters and waitresses who have to deal with my allergies, because I feel bad that they have to go and check everything that I eat to make sure that there's nothing I'm allergic to".

Two subthemes were identified (Figure 1 and Table 2): uncertainty is felt during reactions, and people with allergies can fear the epinephrine autoinjector. Some people with multiple food allergies can experience uncertainty about reaction severity and the need for epinephrine, which may be accompanied by fear of the pain associated with epinephrine autoinjector use.

Participating in Society Involves Speaking Up and Trusting Others

Individuals with multiple food allergies often rely on others to be conscientious when preparing their food. Participants conveyed a lack of trust in others who do not fully understand the severity of food allergies. Participant 7 recounted a situation where restaurant staff were negligent:

"I ate a salad one time that had peanuts in it. It came with peanuts. I told them no peanuts, sent it back, and I guess they just took the peanuts off the salad that I ended up eating. I just [had] full-blown anaphylaxis in the middle of the restaurant".

There is a need to speak up and advocate for yourself, which can deter people with multiple food allergies from fully participating in society. Participant 9 explained:

"Sometimes it makes me not want to go do things – like, especially if it's eating or going out to a restaurant, or even if it's just traveling. Sometimes it makes me not want to do those things because I have to think about, 'Oh, I have to talk to people, and I have to ask them about allergies.' ... So, sometimes I'll just cancel and be like, 'Oh, I can't go,' or, 'Oh, I have something else to do.' I really don't. Just because I don't want to deal with it".

One subtheme was developed: public awareness of food allergies (Figure 1 and Table 2). Most people with multiple food allergies believe that the public awareness of food allergies has improved over time, including improved food labeling and provision of safe food. However, participants also conveyed that others may conflate food allergies and sensitivities.

Food is More Than Nutrition

Food is cultural and enjoyable, and allergen avoidance creates challenges for fully engaging in social situations. Individuals with multiple food allergies may avoid going to social events altogether or choose not to eat at social events. One teenager (Participant 15) said:

"... if we have family or friends over, I usually can't eat anything that they bring because there's almost always nuts in it. So, it's like discomfort when I'm eating with other people because I want to eat... It's like a social thing. If you're not eating anything that everyone else is eating, it's a little awkward, sort of'.

Food allergies can impact quality time with loved ones and strain relationships when their allergies are not taken seriously. Participant 6 shared:

"Well, I definitely had friends who don't take my allergy seriously, which is surprising and quite frustrating. I have a friend who doesn't... like literally for years forgets that I have an allergy, and I don't even know how that's possible. So, I honestly have chosen probably not to socialize with them as much".

In addition, a caregiver (Participant 16) said:

"I mean I think it impacts in that you have to be choosy about the people that you hang out with, and if we go to their house and whatnot".

Two subthemes were developed (Figure 1 and Table 2): impact on school life and impact on future. Children and teenagers recalled experiencing loneliness at lunchtime, as well as missed school days due to allergic reactions. Teenagers expressed concerns about the potential future impact of their food allergies on friendships, relationships, and careers. One teenager shared that they cannot pursue their dream of working in aviation due to their food allergies because of the higher risk of an allergic reaction.

The Caregiver Experience

Three themes were developed by the research team to convey the experiences of caregivers looking after their child with multiple food allergies and the impact on QoL (Figure 2).

Looking Out for Your Child's Safety is an Emotional Balancing Act

Caregivers experience stress and anxiety over trying to prevent accidental exposures to allergens, especially through cross contamination which can be difficult to control. The "right" level of caution is often subjective and there is a lack of feedback to know whether one is being overly cautious. Parents must learn to trust others to protect their child when they are not present, and as their child grows older, this involves teaching them to advocate for themselves and trusting that they will make good decisions about food safety. A caregiver of a child with multiple food allergies (Participant 20) said:

"It's just always in the back of your mind as a parent. Especially as your child gets to be older and she's almost a teenager, she's going to be away from me more often, and you just hope that you have equipped your kid with those tools where they can make the decisions they need to make and continue to ask and not be embarrassed and protect their health and advocate for themselves. And that's a scary idea, really".

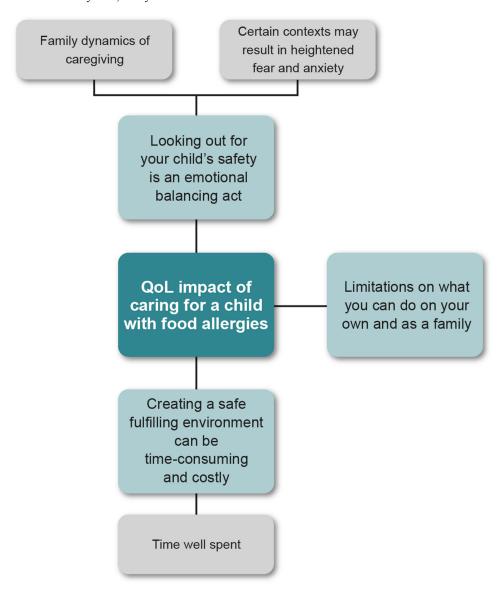


Figure 2 Map of themes resulting from analysis of caregivers' experiences of looking after a child with food allergies (n = 5). Three key themes (teal) and subthemes (gray) were developed by the research team on the impact of food allergies on caregivers' quality of life (QoL).

Two subthemes were developed to convey additional nuances of the caregiver experience (Figure 2 and Table 3): family dynamics of caregiving, and certain contexts may result in heightened fear and anxiety. Primary caregivers (all of whom were mothers in this study) may experience a greater emotional burden related to protecting their child, particularly if they take on greater responsibility than their spouse for daily prevention of allergen exposures. Differences in perceptions of the "right" level of caution can create a challenge between spouses. Other factors related to the characteristics of the child and the nature of their allergy may contribute to heightened fear and anxiety for caregivers, such as age of the child, type of food allergy, sensitivity, and prior experience with severe reactions.

Limitations on What You Can Do on Your Own and as a Family

Caregivers described ways in which their participation in independent and family activities was limited as a result of precautions they took related to their child's food allergies. One mother described how she gave up her job to manage her child's food allergies, which were deemed too risky for the child to attend preschool. Family meals, social gatherings, and travel are all affected. Parents may also be less likely to go out and socialize without their children, because this involves trusting others with their child. Participant 17 explained:

"She can [go] to my parent's house, for example, but I wouldn't necessarily let her go anywhere else because I don't feel that other people realize how serious it is... We don't just go and hire a babysitter... so, it's very limited".

In contrast, another caregiver (Participant 20) described few limitations to her family's social participation and focused on encouraging her daughter to adapt to different social situations.

"I think because we downplayed it in that way a lot – 'Hey, we'll figure it out. You'll be fine. There's other things for you to eat,' I think my husband and I kind of... we never really wanted to make it a huge deal – she's really, really chill about it".

However, this participant also described her daughter's food allergies as less severe.

Table 3 The Caregiver Experience: Subthemes and Illustrative Quotations

Theme	Subtheme	Illustrative quotations
Looking out for your child's safety is an emotional balancing act	Family dynamics of caregiving	"I am definitely hyperaware of it. And I think my husband's a lot calmer, but I am more aware of it and I think in tune [with] it, and I am more paranoid for sure, but also I have been able to identify every time there's hives, every time there's something. I have sort of like 'supersonic mom' vision where pre-emptively I can tell this little dot, and the rest of my family's like, 'How do you know that's a hive?' 'I just know, it is.' So I feel like I carry a lot of the burden of it because I am the one to research all this and provide the safe environment, and I am also the one that is mostly likely to notice that something is amiss". <i>Participant 16, caregiver</i>
	Certain contexts may result in heightened fear and anxiety	"That's one of the hardest things we deal with is everything will be everything-free that she's allergic to, and then you get to that one thing that's got some kind of corn in it — corn starch, corn juice, vegetable, corn oil. Like, oh my God. I think they need to bump that up on the list as a main allergen". <i>Participant 19, caregiver</i> "It was really, really hard to just even give him things even things that were just changing to another brand or things like that. And so it really provoked a lot of stress for me and anxiety for me that's been difficult to recover from. I mean anytime you see your kid go to the hospital is pretty terrifying". <i>Participant 16, caregiver</i>
Creating a safe and fulfilling environment can be time-consuming and costly	Time well spent	"Now that she's older, we just use it as bonding time, whether it's doing a grocery order or making a meal list or just cooking together. So, it's enjoyable now". <i>Participant 19, caregiver</i> "It gives me something to stay focused on and centered on". <i>Participant 19, caregiver</i>

Creating a Safe and Fulfilling Environment Can Be Time-Consuming and Costly

Caregivers spend a lot of time researching safe foods, shopping, cooking, and cleaning to prevent cross contamination at home. Most parents wanted to prevent their child from missing out on family meals, holidays, and celebrations, which required additional planning. For example, 1 caregiver (Participant 17) said:

"We've protected her so much about it. If we have like a family pizza night, we have regular pizza and then I make her a special pizza sort of, and she has her pizza. And if we do an Easter Egg hunt, we will change out the chocolate for either chocolate that she can have or stickers or something".

In addition, sourcing specialty foods that are labeled as being prepared in allergen-free facilities was described as very expensive, and having to throw away food that may have been contaminated could further increase costs. Participant 18 explained:

"We do prepare 100% of things at home from scratch. The budget is higher than what we would like because the food is more expensive that's safe. It's just it does take more time than I probably would otherwise as a parent. If we're running tight on time, it's not a possibility for us to stop at McDonald's or fast food. It's just not a possibility".

One subtheme was developed (Figure 2 and Table 3): time well spent. The time taken to avoid allergens was not always considered a burden. One caregiver described that the extra steps to prepare safe foods provided valuable bonding time with their child.

Discussion

This study highlights the impact of multiple food allergies on daily activities and QoL of people living in the United States. Our findings suggest that people with multiple food allergies experience social limitations, stress about food safety and allergen avoidance, and restrictions on freedom. Furthermore, teenagers and children must learn to take responsibility and navigate challenges around food allergies at a young age, and the impact of food allergies also extends to family members. These findings build upon previous qualitative literature on food allergies and add new insights into the burdens faced by people with multiple food allergies and their caregivers.

Participants with multiple food allergies in this study reported similar lived experiences to people with a single food allergy (including peanut allergy) in other qualitative studies. For example, many studies report that people with food allergies may experience exclusion from social situations, negative impacts on close relationships, and restrictions in daily life (including school, work, and travel). 4,8,9 In addition, the uncertainty of allergen exposure, caution when eating out, and label reading, may all have an impact on the QoL of people with food allergies and their families. 5,18,19 Furthermore, caregivers of children with food allergies are often tasked with daily allergen avoidance and supporting their child's independence while controlling their own anxiety and isolation. 6,10 Although we show that the impacts of living with multiple food allergies may be similar to other qualitative studies on single food allergies, these impacts may be compounded in people with multiple food allergies. This incremental burden could be estimated in the future using quantitative research methods.

The results of this study highlight the varying narratives on the impact of multiple food allergies, which are currently underrepresented in the literature. This is consistent with previous research suggesting that individuals with food allergies have differing QoL and impressions of key events, which may be associated with sociodemographic and clinical factors (for example, number of allergies and allergic reaction history). Experiences may also be shaped by allergen type, ^{18,20} different food-related mental health concerns, 21 and comorbidities such as atopic dermatitis and asthma, which are prevalent in people with multiple food allergies. 13 Caregivers may also respond differently to looking after their child with food allergies; for example, our findings indicate that caring for a child with food allergies is not always considered a burden. Our results support previous findings that suggest people's unique personalities and outlooks in life have a part to play in shaping internal coping strategies for living with food allergies, which may contribute to diversity in experiences.²²

A key strength of the study is that qualitative interviews provide in-depth knowledge of the lived experiences of people with multiple food allergies, among whom the daily life implications of food avoidance may be compounded. Adults, teenagers, and caregivers of children were included in the study to provide varied perspectives on the

1958 Patient Preference and Adherence 2024:18

experiences of living with multiple food allergies. The purposive sampling strategy was developed to address potential socioeconomic disparities among individuals with multiple food allergies, and to reflect diversity in certain characteristics.²³ We understand that our findings may not be generalizable for all people with multiple food allergies, and that generalizability is not a goal of qualitative research. The main limitation of the study was the lack of diversity in gender, as only three participants identified as male, and all caregivers of children were mothers. This could have impacted the breadth of lived experiences in caregivers of children with multiple food allergies, and subsequent identification of themes by the researchers. In addition, we relied on participants to self-report their multiple food allergy diagnoses, and although this is typical in qualitative research, this may have impacted the reliability of our findings.

In conclusion, this study highlights the unmet needs of people with multiple food allergies and provides evidence that the burden of food allergies may also extend to their family members. As management of food allergies is primarily centered on food avoidance, treatment strategies that minimize the risk of severe reactions have the potential to improve QoL in both people with food allergies and their caregivers as they may enhance social participation and relieve daily stress and anxiety.

Ethics Approval

The study received ethical approval from the Western-Copernicus Group institutional review board (#20220251). All study participants (patients and legal guardians of minors) provided informed consent prior to the interviews, which included publication of deidentified responses and quotes.

Acknowledgments

The authors would like to thank the study participants.

Author Contributions

CC, JD, AB, KJ, and AM developed and/or reviewed the qualitative interview guide. JD and AB conducted the interviews, coded data, and interpreted themes. All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Funding

This study was funded by Genentech, Inc., a member of the Roche Group. Medical writing assistance was provided by Nilisha Fernando, PhD, of Envision Pharma Group, and funded by Genentech, Inc., a member of the Roche Group. Envision Pharma Group's services complied with international guidelines for Good Publication Practice (GPP 2022).

Disclosure

CC: research support from the Duchossois Family Foundation, FARE, NIH, and Paul and Mary Yovovich; advisory board for ClostraBio, Genentech, Inc., Novartis, and Síolta. JD, AB, KJ, and AM: employees of Broadstreet HEOR, a vendor paid by Genentech, Inc. involved in the study design and data analysis. SK and AS: employees of Genentech, Inc.; stockholders in Roche. AL: employee and stockholder of Acaster Lloyd Consulting Ltd. The authors report no other conflicts of interest in this work.

References

- 1. Gupta RS, Warren CM, Smith BM, et al. Prevalence and severity of food allergies among US adults. *JAMA Network Open.* 2019;2(1):e185630. doi:10.1001/jamanetworkopen.2018.5630
- 2. Gupta RS, Warren CM, Smith BM, et al. The public health impact of parent-reported childhood food allergies in the United States. *Pediatrics*. 2018;142(6):e20181235. doi:10.1542/peds.2018-1235

3. Greenhawt M. Food allergy quality of life and living with food allergy. Curr Opin Allergy Clin Immunol. 2016;16(3):284–290. doi:10.1097/ ACI.00000000000000271

- 4. Couratier P, Montagne R, Acaster S, et al. Allergy to Peanuts imPacting Emotions And Life (APPEAL): the impact of peanut allergy on children, adolescents, adults and caregivers in France. Allergy Asthma Clin Immunol. 2020;16:86. doi:10.1186/s13223-020-00481-7
- 5. Stensgaard A, Bindslev-Jensen C, Nielsen D. Peanut allergy as a family project: social relations and transitions in adolescence. J Clin Nurs. 2017;26(21-22):3371-3381. doi:10.1111/jocn.13696
- 6. Abrams EM, Simons E, Roos L, Hurst K, Protudjer JLP. Qualitative analysis of perceived impacts on childhood food allergy on caregiver mental health and lifestyle. Ann Allergy Asthma Immunol. 2020;124(6):594-599. doi:10.1016/j.anai.2020.02.016
- 7. DunnGalvin A, Gallop K, Acaster S, et al. APPEAL-2: a pan-European qualitative study to explore the burden of peanut-allergic children, teenagers and their caregivers. Clin Exp Allergy. 2020;50(11):1238-1248. doi:10.1111/cea.13719
- 8. Tsoumani M, Regent L, Warner A, et al. Allergy to Peanuts imPacting Emotions And Life (APPEAL): the impact of peanut allergy on children, teenagers, adults and caregivers in the UK and Ireland. PLoS One. 2022;17(2):e0262851. doi:10.1371/journal.pone.0262851
- 9. Barnett J, Botting N, Gowland MH, Lucas JS. The strategies that peanut and nut-allergic consumers employ to remain safe when travelling abroad. Clin Transl Allergy. 2012;2(1):12. doi:10.1186/2045-7022-2-12
- 10. Chooniedass R, Soller L, Hsu E, To S, Cameron SB, Chan ES. Parents of children with food allergy: a qualitative study describing needs and identifying solutions. Ann Allergy Asthma Immunol. 2020;125(6):674-679. doi:10.1016/j.anai.2020.05.014
- 11. Golding MA, Gunnarsson NV, Middelveld R, Ahlstedt S, Protudjer JLP. A scoping review of the caregiver burden of pediatric food allergy. Ann Allergy Asthma Immunol. 2021;127(5):536-547.e3. doi:10.1016/j.anai.2021.04.034
- 12. Gupta RS, Springston EE, Warrier MR, et al. The prevalence, severity, and distribution of childhood food allergy in the United States. *Pediatrics*. 2011;128(1):e9-17. doi:10.1542/peds.2011-0204
- 13. Warren CM, Aktas ON, Manalo LJ, Bartell TR, Gupta RS. The epidemiology of multifood allergy in the United States: a population-based study. Ann Allergy Asthma Immunol. 2023;130(5):637-648.e5. doi:10.1016/j.anai.2022.12.031
- 14. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health. 2019;11(4):589-597. doi:10.1080/ 2159676X.2019.1628806
- 15. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
- 16. Madill A, Jordan A, Shirley C. Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies. Br J Psychol. 2000;91(Pt 1):1-20. doi:10.1348/000712600161646
- 17. Rampin R, Rampin V. Taguette: open-source qualitative data analysis. J Open Source Softw. 2021;6(68):3522. doi:10.21105/joss.03522
- 18. Antolín-Amérigo D, Manso L, Caminati M, et al. Quality of life in patients with food allergy. Clin Mol Allergy. 2016;14:4. doi:10.1186/s12948-016-0041-4
- 19. MacKenzie H, Roberts G, van Laar D, Dean T. Teenagers' experiences of living with food hypersensitivity: a qualitative study. Pediatr Allergy Immunol. 2010;21(4 Pt 1):595-602. doi:10.1111/j.1399-3038.2009.00938.x
- 20. Saleh-Langenberg J, Goossens NJ, Flokstra-de Blok BM, et al. Predictors of health-related quality of life of European food-allergic patients. Allergy. 2015;70(6):616-624. doi:10.1111/all.12582
- 21. Feng C, Kim J-H. Beyond avoidance: the psychosocial impact of food allergies. Clin Rev Allergy Immunol. 2019;57(1):74–82. doi:10.1007/s12016-018-8708-x
- 22. Conner TS, Mirosa M, Bremer P, Peniamina R. The role of personality in daily food allergy experiences. Front Psychol. 2018;9:29. doi:10.3389/ fpsyg.2018.00029
- 23. Tracy SJ. Qualitative Research Methods: Collecting Evidence, Crafting Analysis, Communicating Impact. John Wiley & Sons; 2019.

Patient Preference and Adherence

Dovepress

Publish your work in this journal

Patient Preference and Adherence is an international, peer-reviewed, open access journal that focusing on the growing importance of patient preference and adherence throughout the therapeutic continuum. Patient satisfaction, acceptability, quality of life, compliance, persistence and their role in developing new therapeutic modalities and compounds to optimize clinical outcomes for existing disease states are major areas of interest for the journal. This journal has been accepted for indexing on PubMed Central. The manuscript management system is completely online and includes a very quick and fair peer-review system, which is all easy to use. Visit http://www.dovepress.com/testimonials.php to read real quotes from published authors

Submit your manuscript here: https://www.dovepress.com/patient-preference-and-adherence-journal

