

Preliminary Development of the Food Allergy Coping and Emotions Questionnaires for Children, Adolescents, and Young People: Qualitative Analysis of Data on IgE-Mediated Food Allergy from Five Countries



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What is already known about this topic? Early-life experiences provide the foundation for later cognitions and behaviors. Adolescents and young people with food allergy are at increased risk of psychological problems, compared with their peers.

What does this article add to our knowledge? The Food Allergy Coping and Emotions model shows how food allergy impacts experiences and emotions and mediators of coping style. The data generated will also be used for 3 age-appropriate questionnaires to assess emotions and coping in food allergy.

How does this study impact current management guidelines? Understanding the key emotional and coping factors that result from growing up with food allergy may guide individualized patient management strategies and interventions and ultimately improve patient outcomes in safety and well-being.

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BACKGROUND: We have previously developed a food allergy-specific developmental model, that explained emotions and coping styles, among children aged 6 to 15 years in Ireland. **OBJECTIVE:** The objective of this study was to investigate the usefulness of the developmental model in a large multicountry data set, including any mediators of coping style, and to use the findings to generate an item pool that will form the basis for 3 age-appropriate self-report questionnaires to measure coping and emotions.

METHODS: We conducted deductive thematic analysis on secondary data from interviews with 274 participants aged 6 to 23 years, and 119 parents from Australia, Ireland, Italy, the UK, and the USA. Analysis was undertaken across the entire data set. **RESULTS:** The Food Allergy Coping and Emotions (FACE) model has 5 major themes: (1) experiences and emotions, (2) search for normality, (3) management and coping, (4) "external mediators," and (5) "internal mediators" (between emotions and coping). These themes were present across countries, but differed according to age.

CONCLUSIONS: Early-life experiences provide the foundation for later cognitions and behaviors. The expanded FACE developmental model is useful in explaining emotions and coping styles across different age groups and countries. These data will also be used to generate an age-specific bank of items

for the development of 3 (age-specific self-report, and parent proxy) questionnaires to assess emotions and coping in food allergy. Findings provide insight into how particular styles of coping develop and vary from patient to patient and may also guide clinician-patient communication and the development of individualized management strategies. © 2018 Published by Elsevier Inc. on behalf of the American Academy of Allergy, Asthma & Immunology (J Allergy Clin Immunol Pract 2018;6:506-13)

Key words: Qualitative; Development; Model; Item generation; Management

Abbreviations used

FA- Food allergy

FACE- Food Allergy Coping and Emotions

Definitions

Biopsychosocial approach- explains human development as a result of an interaction between biological, psychological, and social forces.

Developmental model- a conceptual framework devised to be used as a guide to understanding a developmental process, and forming a prognosis for continued development.

Developmental perspective- explains growth, change, and consistency through the lifespan.

Developmental trajectory/pathway- social, psychological, and environmental factors operating early in life can have major impacts on both short- and long-term health and well-being outcomes.

Developmental transitions- developmental pathways are marked by transitions that define the path direction over time.

Mediator variables- specify how or why a particular effect or relationship occurs and as such are always dynamic properties and can be internal (eg, emotions and beliefs) or external (eg, the environment or context).

Self-management in chronic disease- the tasks that individuals must undertake to live well with a chronic condition.

Food allergy (FA) is major public health concern affecting nearly 15 million Americans and 80 million Europeans, including approximately 8% of children, with high costs to public health services.¹⁻³

Studies have shown that adolescents and young people (between the ages of 13 and 25) with FA are at increased risk of developing problems such as anxiety, depression, relational difficulties, and psychological problems in general, when compared with their peers.⁴⁻⁸ This period is also associated with the highest death rate due to allergic reactions to foods.⁹⁻¹² Compliance with clinician advice on safety and management is often poor, leading to adverse outcomes.¹³⁻¹⁵

In 2002, the World Health Organization released *Innovative Care for Chronic Conditions: Building Blocks for Action*, drawing global attention to the rise of chronic conditions.¹⁶ The document emphasizes the importance of putting people at the

- Australia: 'School Nuts study' in Murdoch Children's Research Institute, Melbourne
- Scotland: 'Scottish Adolescents at Risk of Anaphylaxis (SARA)' study in Edinburgh.
- England: 'Coping in children and adolescents aged 8-16 years with food allergy' in Aston University, Birmingham, UK.
- Italy: 'Study on quality of life of food-allergic children and teenagers' in the Food Allergy Referral Centre, Padua.
- Ireland: 'Developmental Pathways in Food Allergy Study' in University College Cork.
- Ireland: 'The Experience of Living with, and Managing, Food Allergy for an Emerging Adult Population in Ireland' in University College Cork.
- U.S.A: 'Food Allergy Research and Resource Programme (FARRP) study' in Duke University Hospital and Boston Children's Hospital, Boston.

FIGURE 1. Participating centers. Participants consisted of 274 children and young people from 6 countries: Australia, England, Ireland, Italy, Scotland, and the USA. Each country had 1 participating study, except for Ireland, which had 2. Parent sample comprised 119 parents from 5 countries: Australia, Ireland, Italy, Scotland, and the USA.

forefront of their own care, that is, supporting, facilitating, and encouraging individuals to make informed decisions about management. Because the foundation for management begins at a young age, taking a developmental perspective in this area is also vital.^{15,17} Emotion can be defined as the body's adaptive response to a particular situation.¹⁸ Understanding the key emotional and coping factors that result from growing up with FA may guide individualized patient management strategies and ultimately improve patient outcomes in terms of safety and well-being.¹⁹⁻²¹

Qualitative studies can help to bridge the gap between scientific evidence and clinical practice,²²⁻²⁴ providing a nuanced picture of complex phenomena, while also allowing for cross case comparison. They are also an important step in the development of quantitative instruments.^{25,26} In FA, qualitative studies have typically been carried out with very small samples, making it difficult to discover the pathways between common factors.

We have previously described a developmental model on experiences, emotions, and management related to growing up and living with FA.²⁷ We analyzed data from 16 focus groups conducted in Ireland, with children aged 6 to 18 years, and found 3 main themes: experiences (living with uncertainty, living with difference, living with the rules); search for normality (integration, control, identity, health, well-being); and management and coping (maximization, balanced adaptation, minimization).

In the present study, we sought to investigate the applicability of this developmental model in a large data set from 6 countries, and to generate an item pool that will form the basis for 3 short user-friendly FA-specific questionnaires to measure coping and emotions in children, teens, and young people. In our analysis, we paid particularly close attention to any external and internal mediators between emotions and coping in FA.

METHODS

Participants

This study involved the analysis of secondary data. Recruitment and data collection were completed by each participating center. Age appropriate focus groups (ranging from 4 to 10 participants) used a semistructured interview schedule with questions on experiences and

1. The coders (ADG, GDG, LMcG, JW) familiarised themselves with the original model before coding commenced.
2. The coders individually grouped data under common codes using the constant comparison method.
3. The themes were assessed for any differences between centres, and clear definitions of each theme were developed.
4. The context and setting factors, including any patterns and change were evaluated in order to identify any mediators between emotions and coping.
5. The results of the analysis was compared to the previous model and to relevant literature.

FIGURE 2. The 5 steps used in thematic analysis of the data. Braun and Clarke's²⁸ steps for thematic analysis were used. Deductive thematic analysis builds on an existing model or framework, and is appropriate for case comparisons. An existing model²⁷ acted as the basis for synthesis, which could be built on, and/or modified by new data. Contradictions and nonconfirming reports from participants were sought.

coping. Parents were also invited to participate separately in focus groups, providing an added perspective on the data. The analysis of parent data will be described in detail elsewhere. Another perspective was also provided by children without FA, who were interviewed separately.

Data collection

All names used in this study are pseudonyms. Ethical approval was obtained from all centers who took part (Figure 1).

Inclusion criteria were children and/or young people aged 6 to 23 years at the date of interview, informed consent from all participants, IgE-mediated FA diagnosed by a medical professional by one of the accepted criteria,² and availability of transcript material on managing FA.

Rationale and procedure for analysis

We used deductive thematic analysis,^{28,29} which builds on an existing model or framework, and is appropriate for case comparisons. An existing model²⁷ acted as the basis for synthesis, which could be built on, and/or modified by new data. Contradictions and nonconfirming reports from participants were sought. Braun and Clarke's²⁸ steps for thematic analysis were used (Figure 2).

Throughout, inter-rater reliability was assessed. Each coder (ADG, GDG, LMcG, JW) submitted his or her coding to the group in a blinded fashion. In cases of disagreement, the investigators would stop and discuss the coding. If consensus was not reached, a fifth coder (AO'R) was used to arbitrate. A criterion of inter-rater reliability >0.8 was used and achieved. If this criterion had not been reached, the steps would have been repeated.

RESULTS

Participant profile

Participants consisted of 274 children and young people from 6 countries (Figure 3): Australia (N = 42), Ireland (N = 88), Italy (N = 37), the UK (England, N = 32; Scotland, N = 31), and the USA (N = 44). The participants were aged 6 to 23 years with 39.4% >13 years. The parent sample comprised 119 parents (80% mothers) from 5 countries: Australia (N = 2), Ireland (N = 55), Italy (N = 9), Scotland (N = 28), and the USA (N = 25). The mean age for participant group 6 to 12 years was 10.2 and 13 to 23 years was 17.5.

All participants were diagnosed with at least 1 allergy. The time passed since diagnosis ranged from 1 to 17 years. On average, the older the participant, the more time had elapsed since diagnosis.

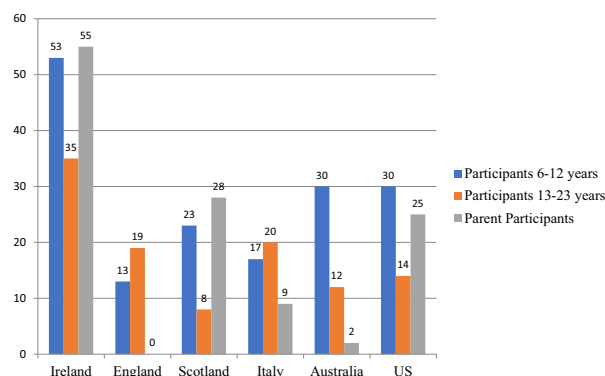


FIGURE 3. Participant number (N) per country for patients aged 6 to 12 years and 13 to 23 years and parents. Participants consisted of 274 children and young people from 6 countries: Australia (N = 42), Ireland (N = 88), Italy (N = 37), the UK (England, N = 32; Scotland, N = 31), and the USA (N = 44). The participants were aged 6-23 years with 39.4% >13 years. Parent sample comprised 119 parents (80% mothers) from 5 countries: Australia (N = 2), Ireland (N = 55), Italy (N = 9), Scotland (N = 28), and the USA (N = 25). The mean age for participant group 6 to 12 years was 10.2 and that of 13 to 23 years was 17.5.

All major allergens were reported (N = 30) with 72% to 89% reporting multiple allergies (>1) depending on center. Allergens included at least 1 of the following: milk/egg (43%), peanut/nut (35%), shellfish/fish (15%), or other allergens (7%). The majority (96%) of participants with milk and/or egg allergy were diagnosed before 1 year of age, and 90% were diagnosed with any allergy by 2 years old. A minority (21%) reported previous milk and/or egg allergy that had resolved, but these participants also had another current FA. Eighty-three percent of parents (mean age 38) had only 1 child (mean age 10) diagnosed with FA. Data were also available for children without FA (N = 12, aged 13-18 years) from the Australian School Nuts Study.

Major themes

The analysis resulted in 5 major themes in 2 clusters: cluster 1—"experiences/emotions," "search for normality," and "management/coping," and cluster 2—"external mediators" and "internal mediators" between emotions and coping. Mediator variables specify how or why a particular effect or relationship occurs and can be internal (eg, emotions and beliefs) or external (eg, environment).²³ The themes are illustrated in the form of a thematic map (Figure 4). Coded categories, their identifiable relationships, and the derived subthemes are provided in Tables E1 to E5 (available in this article's Online Repository at www.jaci-inpractice.org).

Emotions: internal and external mediators

Living with the rules. Within this sample, "Living with the rules" captures the boundaries within which children (and their parents) must live: checking foods, reading labels, recognizing and avoiding possible contamination of allergens, remembering to carry drugs, and dealing with possible reactions. Rules and restrictions ostensibly apply to food, but the impact extended far beyond "mealtimes." Restrictions in participants' lives as a whole were informed by restrictions in their diet, highlighting the integral role that food plays, particularly in socializing.

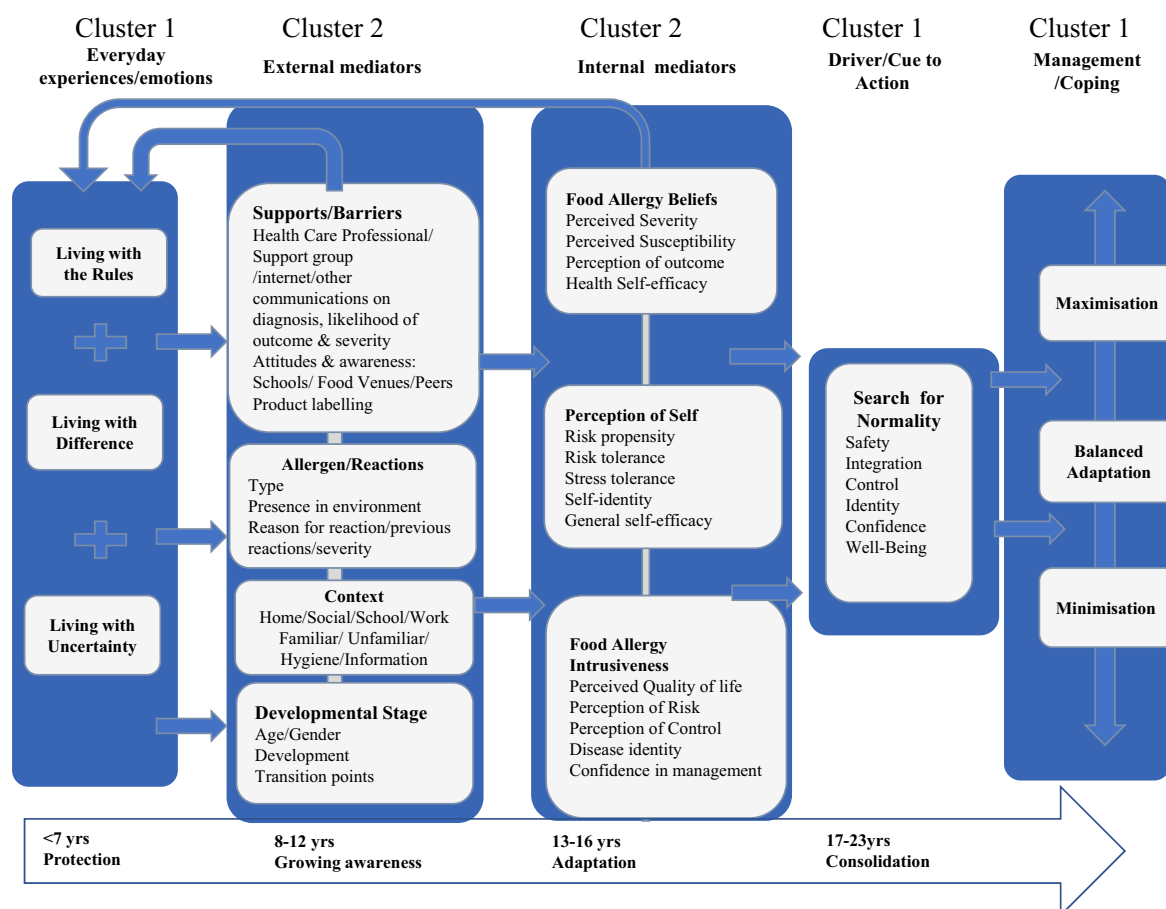


FIGURE 4. Thematic map illustrating the major themes and subthemes. Analysis resulted in 5 major themes in 2 clusters: cluster 1—“experiences/emotions,” “search for normality,” “management/coping”; and cluster 2—“external mediators” and “internal mediators” between emotions and coping. Mediator variables specify how or why a particular effect or relationship occurs and can be internal (eg, emotions and beliefs) or be external (eg, environment and context). The first developmental period occurs up until 7 years, when children feel a strong sense of protection. The period between 8 and 12 years is a time of “growing awareness.” Increasing autonomy between 13 and 16 years necessitates “adaptation” to new circumstances and unfamiliar contexts. In emerging adults (>17 years), we see a “consolidation” of coping style.

Developmental stage and context (external mediators) had a strong influence both on the type of event or food that is encountered and how that event is experienced and managed. When children are young, they relied on parents; home is a “safe base” and “Mum or Dad always checks” was a common response in children across countries. This includes speaking and negotiating with restaurant staff, teachers, and other parents, and ensuring an activity or food is safe.

Adolescents and young people experience increased freedom, but also increased fears, together with reduced perception of control (internal mediator), as the “safe base” of home was removed and had to be rebuilt. Rules also come to be seen as “restrictive” compared with making the younger child feel “special.”

You have to be more mature, because you grow up with this responsibility...since I was no longer a child, I had to understand what I could and couldn't do...your peers are allowed to be more thoughtless and free. (Maria, age 17, Italy)

Inconsistent information from health professionals and other sources (such as from the internet) on the likelihood of reactions

or level of avoidance needed, and poor quality labeling, lowers perception of control and confidence in management. This, together with low awareness, made diets more restrictive than participants believed they needed to be.

Everyone keeps telling me something different...It makes me unsure of myself, it all depends on you ask. (Lily, age 14, Ireland)

Perceived susceptibility, perception of risk, and self-efficacy (internal mediators) are also impacted and, although particularly noticeable in older age groups, the roots of related emotions such as frustration and anger were apparent in younger children.

... “may have traces of nuts” is on everything and it's like if I can't eat that and that and that, that then what can I eat? (Peter, age 8, USA)

Living with uncertainty. Because of parent protection, young children had a strong perception of control and safety (internal mediators); however, roots of uncertainty could be discerned. Even when carefully following “the rules,” children

could seldom pinpoint why a reaction occurred (external mediator) impacting confidence. In cases where a product or food did not cause a reaction, and was seen as “safe,” a subsequent reaction with the same or similar product/food created more worry and confusion.

I remember that Mum asked for no nuts, but the ice cream had one in, I could have died. (Kate, age 12, USA)

I need to kind of live my life on the risk that something is going to happen or something might never happen. (Jennie, age 16, UK)

Uncertainty did not appear to be linked to whether a participant had single or multiple allergies, but rather to the availability of the allergen in a particular environment (external mediator). For example, living in student accommodation or shared housing heightened feelings of uncertainty and participants described numerous reactions and fear of reactions, from poor kitchen hygiene and management. For participants who still lived at home, this source of uncertainty was less evident and experienced principally during social events. Uncertainty gave rise to perceived susceptibility and expectation of adverse outcome (internal mediators), because of the likely increased presence of a particular allergen, particularly in new or unfamiliar environments.

In China they cook everything in egg or peanut sauce. Thailand is the same. India is but... like there's so many things.....and then the planes themselves are a worry, it really stops me travelling anywhere. (Eileen, age 21, Ireland).

Flat mates.... I get so frustrated and angry. Clean your stuff, you know? (Ronan, age 19, Ireland)

Anxiety level did not vary between those who have experienced mild-to-moderate reactions and those who have experienced anaphylaxis. Young people who were no longer in constant contact with parents felt “unable to know” what symptoms required treatment with an adrenaline (epinephrine) auto-injector. Loss of control, trust, and self-efficacy (internal mediators) may induce “false” reactions.

I could smell popcorn and I was sure that I was going to die. (Anna, age 12, UK)

I am so paranoid, I gave myself a panic attack and I ended up having to go to the South Doc [out of hours General Practitioner service in Ireland]. (Rob, age 19, Ireland)

Gender appears to have an impact in terms of how “acceptable” it is to communicate feelings of worry, uncertainty, or anxiety about FA and potential reactions. Males feel less able to communicate their fears to friends and peers, particularly in adolescence and young adulthood.

Living with difference. As children grow up, they develop a gradual awareness of difference.

I hated sitting by myself at lunchtime, or having to get a ‘special’ treat...like there's something wrong with me. (Tim, age 12, USA)

You are anxious because you feel different from the others and the more you grow up, the more the differences increase. (Michela, age 16, Italy)

You were always like slightly separate. Cause it was like, building a huge glass wall. You don't get to hang out. (Barry, age 20, Ireland)

The inability to take part in social rituals, such as accepting food, and being subject to special considerations, gave rise to the feeling of “being apart” from others. Low general level of awareness (external mediator) compounds feelings of difference.

It's always the worse when they say ah go on, you'll be grand. And then you have to refuse a number of times and you get to the point where you're getting frustrated and embarrassed. (Barry, age 22, Ireland)

Some participants reported being teased or in a minority of cases bullied, because of their FA particularly at school, reinforcing the perception of FA as negative or embarrassing, and impacting both self- and disease identity (internal mediators). In Australia where peers themselves were interviewed, there was only a vague understanding of what FA means in terms of symptoms and lifestyle and how to help in an emergency.

Search for normality. Experiences and emotions in living with the rules, uncertainty, and difference operate as a trigger or “cue to action” named the “search for normality.”

He asked me when will I be normal and I did not know what to say to him. (Carrie, mother of Peter, age 9)

Being “normal,” however, is subjective and normality can have different meanings: “being safe,” “being in control,” “not causing a fuss,” or “being accepted.”

Coping and management: external and internal mediators. Experiences (and the emotions attached) appeared to heighten participants’ perception of threat without impacting constructively on their level of perceived control and confidence in management. During developmental transition points (external mediator), children are more vulnerable to environmental influence. A FA-specific transition point in middle childhood occurs when children learn or feel that parents (and therefore children themselves) cannot guarantee the prevention of an allergic reaction. This ultimately impacts on children’s self-efficacy, their perception that they are “in control,” and their confidence that they can effectively manage in different situations. Furthermore, overprotection by parents may inhibit normal development and delay the development of autonomy. Family conflict sometimes resulted from differences in attitude between parents, and between parents and children.

I was very, very protective of him and wouldn't let him have the freedom. (Mother of Peter, age 13, UK)

I always remind him to be careful...to check, to ask...but my husband says he has to learn to do it all by himself particularly now that he is in high school...we can end up arguing about it with Francesco in the middle. (Mother of Francesco, age 13, Italy)

Adolescence and emerging adulthood is a transition point when belonging to the group becomes a vital need, and peer relationships constitute the field where social identity and social self-esteem develop. The safe base of childhood must be rebuilt with regard to relationships and social occasions. Participants spoke about facing an uncomfortable cognitive dissonance (or

tension) as they attempted to negotiate the balance between the search for safety and the search for integration and positive identity (internal mediators of management style).

There is this awful moment when you know you need to say or do something to keep yourself safe and you are torn because you don't want to embarrass yourself or break up the party. (Declan, age 14, Ireland)

Before I leave [college dorm] to go out socializing it's like I hear my mother's voice in my head telling me what to do.... but then I think about the night ahead, and I'm sorta conflicted, you know. (Chrissie, age 18, USA)

The coping strategies that participants used to manage FA can be described on a continuum (indicated by the arrow in Figure 3).

"Maximization" includes extreme avoidance, constant and/or hypervigilance, constant "planning," and placing FA at the center of self. It is linked to emotions such as anxiety, fear of reaction, and negative expectations of outcome. Achieving "control" over safety is very important to this group.

Sometimes I am like should I get this or not? And then I have to just ring Mum. I also ring Mum if I think I am having a reaction and she tells me what to do and talks me through it. (Natalie, age 19, Ireland)

...so it's always a worry. I only try new stuff when I'm with my Mum because she will be better at checking than I am. (Kirsty, age 15, UK)

I had heart burn after a meal out and ended up, just like out of the stress of it, having to leave.... ended up just making myself sick.... (Tom, age 17, Ireland)

While socializing, particularly after alcohol, participants felt very vulnerable but many still consumed alcohol, which is seen as a necessary social ritual, but felt unable to relax. Some worried about kissing someone they had just met because of the risk of reaction. Social events are thus fraught with worry. For those at the more "extreme" end of the continuum, new friends are not actively sought, and new and unfamiliar experiences are avoided.

Coping becomes more rigid with age, even when the participant is aware that a particular strategy is not helpful for their well-being or may cause them distress. Participants often find it difficult to imagine managing FA in alternative ways. Alison (age 23, UK) has worked in the same place for many years, and cannot contemplate working anywhere else, even though she would like to do so. Vijay (age 15, UK) never goes out to eat because of his low level of trust in food venues.

"Minimization" includes deliberately not thinking about FA, "not caring" or denial about potential risk, not carrying the autoinjector, not planning, and "not telling others." This is more likely in those for whom FA is associated with emotions such as embarrassment, denial, and frustration, encountered through experiences when growing up with FA.

I don't like showing [the auto-injector]...so I try to hide it so I look just normal like. (Elliott, age 10, UK)

Well I do read the backs of [chocolate bars] ... but I take risks and just eat them anyway. (Jack, age 14, Australia)

Participants emphasize that planning reduces spontaneity with the result that feelings of difference can be heightened. Those who use minimization as a strategy are aware that they are taking risks, and would prefer not to do so, but feel that the benefits outweigh the costs in terms of their social lives and identities.

It's like reinforcing you're different...so if someone offers you something, you just take it even if it gives you a bit of worry. (Ronan, age 18, Ireland)

...sometimes he'll just chance it ... rather than be different from other folk. (Mother of David, age 15, UK)

"Balanced adaptation" described those who felt confident in explaining to others about their FA and yet felt that they are "mostly the same" as others, only being different with regard to a need for vigilance in certain situations, and a need to carry the autoinjector. Management style is flexible, and planning is viewed as an effective and useful strategy, which increases a sense of safety (internal mediator) if it is adapted to different contexts so that intrusiveness (internal mediator) is minimized.

Participants spoke about the need to inform others (external mediator) of issues surrounding FA and management, and felt confident in their ability to judge when situations needed a higher degree of vigilance and care. From this, they had a strong positive sense of self- and disease identity (internal mediators).

If I bring [the auto-injector] and nothing happens, then that's a result, isn't it? (Brendan, age 15, Ireland)

You feel vulnerable but on the other hand, you feel strong. (Luigi, age 17, Italy)

You learn to judge a situation and see if it's safe or risky and then you do what is needed. (Fred, age 16, UK)

Participants were encouraged as children to "speak up for themselves" in social contexts such as restaurants, to learn to read labels, to help in choosing when parents were food shopping, and to contribute to making decisions on risk and safety, supported by parents.

DISCUSSION

The Food Allergy Coping and Emotions (FACE) model has 5 major themes in 2 clusters. FACE describes how the emotions attached to living with FA (including embarrassment, fear, anger, frustration, worry, anxiety, and confusion) drive a search for "normality" that in turn gives rise to particular types of coping strategies. The link between emotions and coping is influenced by external and internal mediators (including context, developmental stage, type of allergen, and experience of reactions and perception of disease intrusiveness). The themes were present and consistent across countries, with remarkably similar wording and phrasing used by participants, although these differed according to age. Both genders had similar emotions and coping styles although males felt less able to communicate their fears to friends and peers, particularly in adolescence and young adulthood.

Early-life experiences provide the foundation for later behaviors. The first developmental period occurs up until 7 years, when children feel a strong sense of protection. The period between 8 and 12 years is a time of "growing awareness." As their social

worlds expand, feelings of “otherness” and difference develop, along with a perception of threat and uncertainty. Increasing autonomy, particularly between the years of 13 and 16, necessitates “adaptation” to new circumstances and unfamiliar contexts. Participants face a “tension” as they attempt to balance a search for safety with integration and positive identity. In emerging adults (>17 years), we see a “consolidation” of coping style.

Participants’ experiences and the emotions attached to these heighten their perception of threat without impacting constructively on their level of perceived control and confidence in management. Although some who use minimization or maximization are aware that this type of coping causes them distress or harm, they find it difficult to imagine alternative ways of coping. In contrast, participants who were adaptively balanced used “the rules” flexibly, minimizing risk while enjoying a high degree of social integration and positive self-identity.

Our findings confirm and extend previous qualitative and quantitative research on the experience of living with and managing FA.³⁰ The impact of FA is comparable cross-culturally.³¹ Adolescents and young people are at high risk of adverse outcomes relating to reactions,¹⁰⁻¹³ sense of self,^{9,27} management style,^{13,14} and mental health and well-being.^{5-8,15} Our findings have shown the possible precursors to these documented outcomes and why outcomes may differ in individual patients.

The FACE model has 2 main applications. First, taking into account the multifaceted factors involved in growing up with FA, this model will allow the clinician to be sensitive to any hidden messages. We are aware of the time constraints for physicians during consultation. With this in mind, the most important question to ask is how a patient feels about FA (with the use of prompt words if needed, eg, anxious, frustrated, and confident), which will then lead naturally to how he or she feels about coping. Negative emotions will alert the physician that additional help may be required. Secondly, the study findings will go to ensure that the most salient and age-appropriate items are selected for the 3 short, age-appropriate prototype FACE questionnaires in Phase 2 of this study. These measures will allow for quick and easy evaluation and tracking of patients for clinicians and researchers, and enable comparison with the results of other patient outcome measures such as health-related quality of life. Exemplar Case Studies are provided in Figures E1 to E3 (available in this article’s Online Repository at www.jaci-inpractice.org).

The strengths of this study include the use of a large data set gathered from multiple studies, which may provide a way forward for qualitative research in FA. Furthermore, the *a priori* identification of key constructs enabled the rapid coding of study data. Because the original source was a single published model,²⁶ the manner in which new themes were built is transparent. However, statistical design, control of variables, and analysis were not possible, limitations common to all qualitative analyses. We also acknowledge the need for further work in other regions and populations (with explicit analysis of culture, and socioeconomic status) to ensure representativeness and validity. This work is being undertaken at present.

In conclusion, we have shown that the FACE model is useful in explaining emotions and coping styles across a range of different age groups in Westernized countries. A thematic map highlights how FA impacts children and young people,

potential mediators of coping style, and demonstrates why effects and outcomes might vary from patient to patient. A paradigm shift toward a patient-centered self-management approach is required to support patients in building the skills and confidence they need to improve outcomes and this starts from the patients’ perspective. This extended insight into the experiences of people with FA may guide the development of individualized self-management strategies and interventions.

REFERENCES

- Prescott S, Allen KJ. Food allergy: riding the second wave of the allergy epidemic. *Pediatr Allergy Immunol* 2011;22:155-60.
- Burks AW, Tang M, Sicherer S, Muraro A, Eigenmann PA, Ebisawa M, et al. ICON: food allergy. *J Allergy Clin Immunol* 2012;129:906-20.
- Gupta RS, Springston EE, Warrier MR, Smith B, Kumar R, Pongracic J, et al. The prevalence, severity, and distribution of childhood food allergy in the United States. *Pediatrics* 2011;128:e9-17.
- Polloni L, Baldi I, Lazzarotto F, Bonaguro R, Toniolo A, Gregori D, et al. Multi-dimensional analysis of food-allergic children and adolescents’ self-concept: a comparison with a healthy matched sample. *J Health Psychol* 2015;20:850-7.
- Flokstra-de Blok BM, Dubois AE, Vlieg-Boerstra BJ, Oude Elberink JN, Raat H, DunnGalvin A, et al. Health-related quality of life of food allergic patients: comparison with the general population and other diseases. *Allergy* 2010;65:238-44.
- Polloni L, Ferruzza E, Ronconi L, Lazzarotto F, Bonaguro R, Toniolo A, et al. Mental health and behavior of food-allergic adolescents compared to a healthy matched sample. *Ann Allergy Asthma Immunol* 2015;115:158-60.
- Molzon ES, Hullmann SE, Eddington AR, Mullins LL. Depression, anxiety, and health-related quality of life in adolescents and young adults with allergies and asthma. *J Asthma Allergy Educ* 2011;2:288-94.
- MacKenzie H, Roberts G, Van Laar D, Dean T. Teenagers’ experiences of living with food hypersensitivity: a qualitative study. *Pediatr Allergy Immunol* 2010;21(Pt 1):595-602.
- Liew WK, Williamson E, Tang ML. Anaphylaxis fatalities and admissions in Australia. *J Allergy Clin Immunol* 2009;123:434-42.
- Mullins RJ, Dear KB, Tang ML. Time trends in Australian hospital anaphylaxis admissions in 1998-1999 to 2011-2012. *J Allergy Clin Immunol* 2015;136:367-75.
- Bock SA, Muñoz-Furlong A, Sampson HA. Further fatalities caused by anaphylactic reactions to food, 2001-2006. *J Allergy Clin Immunol* 2007;119:1016-8.
- Pumphrey RS, Gowland MH. Further fatal allergic reactions to food in the United Kingdom, 1999-2006. *J Allergy Clin Immunol* 2007;119:1018-9.
- Monks H, Gowland MH, MacKenzie H, Erlewyn-Lajeunesse M, King R, Lucas JS, et al. How do teenagers manage their food allergies? *ClinExp Allergy* 2010;40:1533-40.
- Kim JS, Sicherer SH. Living with food allergy: allergen avoidance. *Pediatr Clin North Am* 2011;58:459-70.
- DunnGalvin A, Hourihane JO. Health-related quality of life in food allergy: impact, correlates, and predictors. *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz* 2016;59:841-8.
- Tunstall-Pedoe H. Preventing Chronic Diseases. A Vital Investment: WHO Global Report. Geneva, Switzerland: World Health Organization; 2005:200.
- Damasio A. Fundamental feelings. *Nature* 2001;413:781.
- Halfon N, Hochstein M. Life course health development: an integrated framework for developing health, policy, and research. *Milbank Q* 2002;80:433-79.
- van Dijk-de Vries A, Moser A, Mertens VC, van der Linden J, van der Weijden T, van Eijk JT. The ideal of biopsychosocial chronic care: how to make it real? A qualitative study among Dutch stakeholders. *BMC Fam Pract* 2012;13:14.
- Harris JR, Wallace RB. The Institute of Medicine’s new report on living well with chronic illness. *Prev Chronic Dis* 2012;9:E148.
- Holman H, Lorig K. Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. *BMJ* 2000;320:526-7.
- Barbour RS. The role of qualitative research in broadening the ‘evidence base’ for clinical practice. *J Eval Clin Pract* 2000;6:155-63.
- Greenhalgh T. Integrating qualitative research into evidence based practice. *Endocrinol Metab Clin North Am* 2002;31:583-601.
- Reilly RE, Doyle J, Bretherton D, Rowley KG, Harvey JL, Briggs P, et al. Identifying psychosocial mediators of health amongst Indigenous Australians for the Heart Health Project. *Ethn Health* 2008;13:351-73.

25. Streiner DL, Norman GR, Cairney J. *Health Measurement Scales: A Practical Guide to Their Development and Use*. Oxford, UK: Oxford University Press; 2015.
26. Creswell JW, PlanoClark VL. *Designing and Conducting Mixed Methods Research*. Thousand Oaks, CA: Sage Publications; 2007.
27. DunnGalvin A, Gaffney A, Hourihane JB. Developmental pathways in food allergy: a new theoretical framework. *Allergy* 2009;64:560-8.
28. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101.
29. Strauss A, Corbin J. *Grounded Theory Procedures and Techniques, Basics of Qualitative Research*. Newbury Park, Calif: Sage Publications; 1990.
30. Longo G, Berti I, Burks AW, Krauss B, Barbi E. IgE-mediated food allergy in children. *The Lancet* 2013;382:1656-64.
31. DunnGalvin A, Koman E, Raver E, Frome H, Adams M, Keena A, et al. An examination of the food allergy quality of life questionnaire performance in a countrywide American sample of children: cross-cultural differences in age and impact in the United States and Europe. *J Allergy Clin Immunol Pract* 2017;5: 363-8.

ONLINE REPOSITORY:

Emma is a female child aged 6 years old. She has one older brother (15 years old) who does not have food allergy. She was formally diagnosed by a consultant allergist with Cow Milk Protein Allergy at 10 months and peanut allergy at 2 years. Emma has had several near misses in the past where the food product was mislabelled or misread, although her Mum had explained her allergies. She experienced mild to moderately severe reaction immediately on eating. She has recently started state primary school, having attending her local pre-school. She presented as an anxious child, very dependent on Mum. She thinks about food and reactions very frequently & believes that she will have a severe accidental reaction, and does not feel that she or her teachers, will be able to 'save her'. She interprets many social situations (having lunch at school or going to the cinema) as 'scary'. The last time she went to the cinema with her parents, she smelled popcorn and had a panic attack, which Emma interpreted as an anaphylactic reaction causing her great distress and embarrassment. 'I couldn't breathe, I couldn't talk, people were staring...' Emma's main goal is to 'feel safe'. The emotions and behaviours associated with being careful about food are beginning to generalise to all life situations, so that Emma is fearful of any 'new' people and places. She is suspicious of making new friends in case 'they would not get it' and limits her social life and her diet. Since she went to her new school, she has withdrawn socially. She is only feels comfortable if Mum has checked and re-checked a food product to ensure 'it is safe'.	<u>External mediators</u> <i>Developmental & Disease</i> <i>Support & Barriers</i> <u>Everyday Experiences</u> <i>Living with rules</i> <i>Living with uncertainty</i> <u>Internal Mediators</u> <i>Personality/self</i> <i>Intrusiveness & Health Beliefs</i> <u>External mediators</u> <i>Support & Barriers</i> <u>Everyday Experiences</u> <i>Living with differences</i> <u>Driver/Cue to Action</u> <i>Search for normality</i> <u>Management and Coping</u> <i>Maximisation</i> <u>Driver/Cue to Action</u> <i>Search for normality</i>
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FIGURE E1. The Food Allergy Coping and Emotions model has 5 major themes that can be applied within a clinical encounter. The emotions attached to living with food allergy drive a search for "normality" that in turn gives rise to particular types of coping strategies. In this example (female; 6 years old), Emma's high perception of threat drives her search safety and a sense of certainty.

Jack is a male child aged 12 years who has one younger sister who also has food allergy. He was formally diagnosed by a consultant allergist with allergies (peanut, hazelnut, fish) from 8 months to 3 years. He has experienced two moderate reactions at home in the relatively recent past from 'carelessness', and Mum is very worried about what may happen in 'out of home' contexts. Jack is resentful of his food allergy, describing his frustration on his parent's 'constant nagging' about his safety (carrying the auto-injector and being vigilant about food); and about his limited food choice 'everything says 'may contain' anyway so how do you know ? It's not real, they just put [may contain] on because it's easier for them'. He compares his life unfavourably with other children. He has been bullied in the past and has internalised the negative reactions of others to his food allergy impact his disease and self-identity. Bullying made Jack feel angry, isolated, confused and vulnerable. He moved school 12 months ago because of this. Jack's main goal is to 'fit in' and be 'normal'. He thinks wishfully of food he would like to eat and no longer having food allergy. In his new school, he is very reluctant to tell any of his classmates that he has food allergy, and will share and accept food from peers so that he is not seen as 'different'. He is angry at his Mum if she mentions his food allergy in out of home contexts or when his friends visit. He sometimes 'forgets' his pen. He does not 'bother with reading labels' because they are 'no help anyway'.	<u>External mediators</u> <i>Developmental & Disease</i> <i>Support & Barriers</i> <u>Everyday Experiences</u> <i>Living with rules</i> <i>Living with uncertainty</i> <u>Internal Mediators</u> <i>Personality/self</i> <i>Intrusiveness & Health Beliefs</i> <u>External mediators</u> <i>Support & Barriers</i> <u>Everyday Experiences</u> <i>Living with differences</i> <u>Driver/Cue to Action</u> <i>Search for normality</i> <u>Management and Coping</u> <i>Minimisation</i> <u>Driver/Cue to Action</u> <i>Search for normality</i>
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FIGURE E2. The Food Allergy Coping and Emotions model has 5 major themes that can be applied within a clinical encounter. The emotions attached to living with food allergy drive a search for "normality" that in turn gives rise to particular types of coping strategies. In this example (male; 12 years old), Jack's experience of bullying because of food allergy drives his search to "fit in" and be accepted by others.

Tom is 17 years, has a hazelnut allergy and is in his first year at university. He was diagnosed at 2 years. He plays football and has many friends. He has experienced 4 moderate to severe reactions during his childhood (in food venues where his needs had been stated to staff) and was hospitalised for anaphylaxis at age 14. During that incident, which took place in a coffee shop with friends, he did not use his auto-injector because <i>'[the reaction] did not feel real and I was not sure when to give it to myself...'; 'no, no, my friends wouldn't have a notion what to do'.</i> He failed a food challenge 9 months ago, and was very disappointed about this. He was <i>'fine'</i> about having food allergy when he was younger but now faces an uncomfortable cognitive dissonance (or tension) in certain social situations when there is an issue of safety :<i>'There is this awful moment when you know you need to say or do something and you are torn because you don't want to embarrass yourself or break up the party'.</i> Tom's main goal is <i>'not to make a fuss'</i>. His friends at university do not know that he has food allergy. He eats <i>'may contain stuff'</i> and <i>'doesn't usually have a reaction'</i> so he thinks he may be tolerant now, in spite of failing his last FC <i>'but I am getting older all the time so it's getting more likely'</i>. With regard to carrying the AAI; <i>'It's just the sheer hassle of having to take it, although I know I should, but...I have been fine so far....If I bring it along and I don't need it (again !), I feel it's been a complete waste of time and a bit stupid'</i>	<u>External mediators</u> <i>Developmental & Disease</i> <i>Support & Barriers</i> <u>Everyday Experiences</u> <i>Living with rules</i> <i>Living with uncertainty</i> <u>Internal Mediators</u> <i>Personality/self</i> <i>Intrusiveness & Health Beliefs</i> <u>External mediators</u> <i>Support & Barriers</i> <u>Everyday Experiences</u> <i>Living with differences</i> <u>Driver/Cue to Action</u> <i>Search for normality</i> <u>Management and Coping</u> <i>Minimisation</i> <u>Driver/Cue to Action</u> <i>Search for normality</i>
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FIGURE E3. The Food Allergy Coping and Emotions model has 5 major themes that can be applied within a clinical encounter. The emotions attached to living with food allergy drive a search for “normality” that in turn gives rise to particular types of coping strategies. In this example (Tom; 17 years old), a lack of general understanding of food allergy drives Tom to not “make a fuss” or be a burden in social contexts.

TABLE E1. Cluster 1: emotions

Open coded categories	Identifiable relationships	Axial coded category
Rules of food and eating Rules for living in a social world Role of parents Role of friends Role of self Rules are restrictive Meaning of food Meaning of social events Negotiating rules within family	Participants live everyday with rules and restrictions that apply to food and social events. Parents have an important role in putting rules and restrictions in place both implicitly through their actions and explicitly by reminding and teaching children of these rules. Close friends may also help in following the rules. Increasing responsibility in following the rules as independence increases. This responsibility is a heavy burden and participants worry that they might “get it wrong.” Social events and food have a particular meaning for children with food allergy because of rules and restrictions Living with the rules adds an extra layer to the “normal” challenges of development for participants and in their social lives. In family life, negotiation of rules can create conflict between parents and food allergic child, between siblings, and between mother and father.	Living with the rules
Feeling special Growing awareness of food as different Growing awareness of difference Resentment of parent protection Meaning of being different Low awareness Being excluded Special provision Those who do not understand (general awareness) Those who do not understand (peers) Feeling different because of low awareness An expanding social world Lack of spontaneity Low understanding affects how children see themselves Impact on sense of self- and disease identity Vigilance is an everyday burden that creates difference Those who do understand	Parents actively strive to make children feel special, but being food allergic means that children must live with a gradual awareness of difference. Living with rules often means feeling excluded and different, in many contexts. Frustration with food allergy encompasses resentment of what is seen as “nagging” by parents. Low awareness of food allergy means that participants feel excluded in activities where special provision, seen by others as different from usual treatment, is made for them. Participants feel different because of low general awareness that limits ability to enjoy and feel part of activities that those without food allergy take for granted. Sharing food has an important social value and food allergy was consequently felt as an obstacle in taking part in social gatherings that involve food. An expanding social world compounds this perception of difference Lack of spontaneity due to need for planning, caution, vigilance, “thoughtfulness” Among peers low awareness can be expressed through teasing and bullying and/or a perception that food allergy is not a “real” condition Children describe themselves as different to other children in terms of their ability to take full part in social events (food and nonfood), to enjoy events without planning, to enjoy food without worrying. Negative reactions from others reinforce the perception of food allergy as negative or embarrassing, and impacting both self- and disease identity. In contrast, those who do understand allow both parents and children to feel integrated, yet safe.	Living with difference
Experiencing allergic reactions Ingredients and labeling Food as a cause of reactions A growing awareness of uncertainty Feeling uncertain When accidents happen Not feeling in control of allergic reactions Feeling anxious about reactions Burden of others anxiety Not feeling in control (because of low awareness)	As children grow, they gradually become aware of uncertainty in their lives. Labeling of ingredients can change without warning so that food can be safe at one point and unsafe at another. Allergic reactions are uncertain; sometimes they are mild and sometimes they escalate. The cause may be difficult to determine. Even when carefully following the rules, children often cannot pinpoint why a reaction occurred. Even if food allergy was felt to be under control on a day-to-day basis, participants were still prone to feelings of uncertainty and anxiety in response to unexpected events such as accidents, change in labeling, or a “new” allergic food. When “accidents” happen, they can cause uncertainty, guilt, and anxiety and feelings of a lack of control. Children are also very aware of parent anxiety because of the uncertainty in living with food allergy. Low general awareness also contributes to uncertainty. High levels of anxiety felt to be justified because of the uncertainty. Such feelings were exacerbated if they felt they were perceived by others as “neurotic” or “paranoid.”	Living with uncertainty

(continued)

TABLE E1. (Continued)

Open coded categories	Identifiable relationships	Axial coded category
Parent anxiety	Living with uncertainty makes it difficult for children to feel in control of their safety and children often react with frustration, anger, denial, feelings of helplessness, overwhelm, fear, and anxiety.	
Feeling uncertain about safety because of low awareness (peer and general)	As children's social world expands, they are faced with the challenge of adapting the rules to different contexts, to feel both safe and included.	
Self-/disease identity		
Feeling not in control because of low general awareness	In contrast, home and the homes of friends are regarded as safe places.	
Low control/negative emotions		
A growing conflict in an expanding social world		
Safe places vs unsafe places		

Data were grouped under common codes, a process called "open coding," and then grouped according to shared meaning between codes to create major themes and subthemes, using the constant comparison method. This process aims to generate theories that explain how some aspect of the social world "works."

TABLE E2. Cluster 2: external mediators

Open coded categories	Identifiable relationships	Subthemes
Developmental pathway Age and developmental pathway Protection Rules work Growing awareness of difference Increased perception of threat and uncertainty Rules may not work/not socially acceptable Increasing independence (developmental transition point) New contexts/new friends/new situations New safe base needed Adaptation Cognitive dissonance Consolidation Inflexible Flexible Environment/context/vulnerability Transition point (food allergy specific) Transition point (food allergy specific) Gender Communication Permission Acceptable/Role	The developmental pathway evolves from infancy through to young adulthood. 0 and 7 y—a sense of protection, accompanied by feelings of being special. When away from the “safe base” of home, younger children accompanied by one or other of their parents or other trusted caregiver Sense of safety. 8 and 11 y—feelings of “otherness” and difference begin to develop, along with an increased perception of threat and uncertainty. Reaction of others, if negative, will impact disease and self-identity and confidence in control. 12-15 y—increasing autonomy necessitates a need to adapt “the rules” learned when younger, to new circumstances and unfamiliar contexts. “Rebuild” safe base of childhood with regard to relationships and alliances and social occasions. Cognitive dissonance (or tension) occurs in negotiating the balance between the search for safety and the search for integration and positive identity. 16 years + Habitual use of coping style. Inflexible—difficulty in managing food allergy in alternative ways. Flexible—ability to adapt a toolbox of coping strategies appropriately. Vulnerable to environmental influence. Disease-specific transition points interact with developmental transition points. Middle childhood—when children learn or feel that parents (and therefore children themselves) cannot guarantee the prevention of an allergic reaction. Adolescence and emerging adulthood—need to “rebuild” the safe base that they experienced as children with regard to relationships and alliances and social occasions. Gender appears to have an impact mainly in terms of how “acceptable” it is to communicate worry or anxiety about food allergy in general and possible reactions in particular. Females also express feelings of frustration and anger, and males experience much anxiety and fears (as would be expected in females) but do not feel able to communicate this to others, particularly peers in adolescence and beyond.	Developmental stage
Personalized/individual Inconsistent information HCP/internet/other communication on diagnosis Uncertainty Likelihood of outcome and severity Inconsistent information Poor quality labeling Inconsistent labelling Uncertainty Rules don't work Negative emotions Difference/restrictions Attitudes & awareness—Schools/food venues/peers Difference Negative emotions Confidence in management Impact on identity (disease/self)	Perception that information and support is personalized/individual to patient increases certainty and confidence in management. Inconsistent information from different health professionals and other sources (such as internet searches) on the likelihood of reactions or level of avoidance needed heightens uncertainty and lowers perception of control and confidence in management. Much uncertainty around quality of labeling. When a product did not cause a reaction, participants felt that the product was “safe” or they could tolerate traces of that allergen, and when a subsequent reaction did occur with the same food, it created worry and confusion. Among others, it creates a sense of frustration and then rejection of reading labeling as a helpful management strategy Poor quality labeling and low general and food venue awareness made diets linked and felt to be more restrictive than needed because of this. Low level of awareness among restaurants, coffee shops, schools, peers, and other social arenas, and among some health professionals impacts emotions, identity, and confidence in management.	supports/barriers

(continued)

TABLE E2. (Continued)

Open coded categories	Identifiable relationships	Subthemes
Type/presence/number of previous reactions/severity Past reactions reassure Past reactions—likelihood of future reactions Past reaction—condition to Others reactions—expectations and identity Individualized	Emotion type and coping style are not linked to the severity or number of past reactions. For example, high levels of anxiety are seen in those who have experienced only mild-to-moderate reactions as well as those who have experienced anaphylaxis. Past severe reactions can be seen as reassuring for some participants who perceived that they coped well and “survived.” Past reactions are seen as a confirming the likelihood of future reactions. Past reactions mean that they are something “not out of the ordinary” and can be ignored to a large extent. How a reaction is conceptualized by others impacts expectations, disease, and self-identity. Individual beliefs, emotional profile, and coping style are linked through past experiences.	Allergen/reactions
Home Social School/work New contexts Impacts on coping style Hygiene/information Communication Expectation of others reactions impact ability to communicate Familiar/unfamiliar Perceived likelihood of allergen presence Control when allergen present Unexpected/unfamiliar situations + perceived likelihood of presence = high anxiety Search for control	Home is a place of safety so that even if a reaction occurs only in the home, less worry. New contexts (eg, friends, social events, new school, work) create challenge/fear/need to fit in =Maximization/minimization/balanced adaptation Living in student accommodation or college housing heightened feelings of uncertainty. Reactions and fear of reactions from poor kitchen hygiene and management by housemates. But reluctance to communicate/“nag”/confront housemates or friends = anxiety — avoid as much as possible (eg, leave accommodation)/ignore anxiety — minimize possible outcomes. Good ability to communicate = balanced adaptation Visiting friends’ houses or social venues that were very familiar caused less anxiety for most. Higher levels of uncertainty and worry were created when the participants considered it more likely that the allergen would be present. Flexible coping needed. Difficult to avoid/control Unfamiliar environments, foods, and unexpected situations caused high levels of anxiety, thus search for normality. Maximization likely unless “integration” (self/social identity) more important to individual (minimization)	Context

Data were grouped under common codes, a process called “open coding,” and then grouped according to shared meaning between codes to create major themes and subthemes, using the constant comparison method. This process aims to generate theories that explain how some aspect of the social world “works.”

TABLE E3. Cluster 2: internal mediators

Open coded categories	Identifiable relationships	Subthemes
Perceived severity Perceived susceptibility Perception of outcome Impacted by disease/self-identity Health self-efficacy	If participants perceived themselves very susceptible to a reaction and if their expectation of the likelihood of an extreme reaction was high, this impacts on their emotions (more likely to be anxious) and coping style (maximization). Disease/self-identity has important role. If participants perceived themselves not very susceptible to a reaction and if their expectation of the likelihood of an extreme reaction was low, this impacts on their emotions (more likely to be frustrated) and coping style (minimization). Disease/self-identity has important role. If participants perceived themselves susceptible to a reaction in certain circumstances, but are confident that they can limit chance of occurrence and recognize and treat any reaction if it occurs, this impacts on their emotions (more likely to be confident and calm) and coping style (balanced adaptation). Disease/self-identity has an important role. Health self-efficacy is also impacted—confidence in self-ability to manage on a day-to-day basis and to manage a reaction should it occur.	Health beliefs
Risk propensity Risk tolerance Stress tolerance Approach/avoidance informed by experiences and modified by internal/external Self-esteem informed by self/disease identity Self-efficacy challenged during transition points	Some participants appear to have an innate higher tolerance to risk (although not measured) and risk approach, whereas others may have a risk avoidance approach and lower tolerance. In this sample, these innate tendencies (if present) appear to have been compounded by the emotions and experiences in growing up and living with food allergy. The normal developmental pathway (and challenges) is intertwined with the food allergy developmental pathway and vulnerability in relation to self-esteem and self-efficacy appears to be higher during transition points.	Personality/self-identity
Perceived quality of life Perception of risk Perception of control Disease identity Confidence in management Coping style	Food allergy intrusiveness represents the disease-induced disruptions to lifestyle, activities, and interests that can compromise psychosocial well-being and contribute to emotional distress. If perception of intrusiveness is low or high, this will impact perceived quality of life, risk, sense of day-to-day control, negative or positive disease identity and confidence in management in individual ways depending on child and subjective experiences. If perception of intrusiveness low, then likely to use minimization or balanced adaptation, depending on the other factors in model. If high, then likely to use maximization.	Food allergy intrusiveness

Data were grouped under common codes, a process called “open coding,” and then grouped according to shared meaning between codes to create major themes and subthemes, using the constant comparison method. This process aims to generate theories that explain how some aspect of the social world “works.”

TABLE E4. Cluster 1: search for normality

Open coded categories	Identifiable relationships	Axial coded category
Safety Integration Control Identity Confidence Well-being	Emotions from experiences (living with the rules, uncertainty and difference) operate as a trigger or “cue to action” named the “search for normality.” Being “normal,” however, is subjective in that can mean “being safe,” “being in control,” “being cool,” “being no trouble or not causing a fuss” or being “part of the group or accepted.”	Search for normality

Data were grouped under common codes, a process called “open coding,” and then grouped according to shared meaning between codes to create major themes and subthemes, using the constant comparison method. This process aims to generate theories that explain how some aspect of the social world “works.”

TABLE E5. Cluster 1: coping and management

Open coded categories	Identifiable relationships	Axial coded category
Thinking a lot about the possibility of reactions Distress Telling others Placing food allergy at center of self Disease/self-identity Control = safety Worrying or being anxious Perception of high risk/adverse outcome Being selective or avoiding new friends or places Being selective or avoiding food Being hypervigilant in social contexts High reliance on parents past expected time of independence High reliance on others for protection High reliance on friends Rigid problem solving Worries about the future	Although a certain amount of vigilance is important for all children with food allergy, some participants appear to be hypervigilant in many contexts. Participants think about food allergy and the possibility of reactions a great deal and this may cause distress. When speaking about the need for vigilance, they also report worrying about adverse events and often describe themselves as anxious or “paranoid.” Telling others is important, for safety reasons, but also because food allergy is an important part of their lives. They describe themselves primarily as “food allergic” when asked: “what are the best words to describe who you are?” They also describe themselves as “fussy” or “picky” about food or even try to avoid eating as much as possible. They do not feel in control of food allergy because of a perception of high risk in social contexts. Search for control is primarily about feeling “safe.” Home is a safe haven and preference for socializing at home. The likelihood of reactions and severe outcomes is thought to be high. New “close” friends are not actively sought, and new and unfamiliar experiences are avoided if possible. Food variety is small, and food is sometimes avoided if possible. Food sometimes seen as not enjoyable. Hypervigilance in social contexts may cause increased stress and feelings of overwhelm. The protective parental role is very important, even for teens and young adults. Parents are relied on for protection, even when not living at home through frequent phone calls and communication for both emotional and instrumental support. Best friends have clearly defined roles both in terms of emotional and instrumental support. Friends must also follow the rules with regard to avoiding unsafe places and introducing new people. Friends who do not follow the rules are sometimes rejected. Participants feel that, although coping strategies are not optimum, they are necessary and find it difficult to imagine alternate ways of coping. Worries about the future are expressed, particularly in relation to leaving the safety of home, and coping on their own.	Maximization
Denial Being angry Disease/self-identity Rules do not work Not thinking about/ignoring risk Not confronting Pointlessness Not bothering to read labels “Forgetting” the pen Not telling others Not thinking about risk Resenting parent protection Distraction Minimizing food allergy as part of identity Minimizing risk	Participants actively try not to think about risks and do not see food allergy as an important part of their lives. They are very frustrated by the rules and feel that they have a negative impact on their everyday lives. They feel that rules do not work because of the uncertainty of allergic reactions, differing and inconsistent advice and information, the labeling of ingredients, and lack of awareness. They are angry about low level of awareness in general about food allergy, but feel it is “pointless” to try to explain to others or ask for their needs to be catered for, because public or peers would not understand or would have a negative reaction. Although they may be privately worried about food allergy, publicly they minimize or deny or reject food allergy and its implications. This is often expressed in risky behavior (not bothering to read labels, taking chances with food, not telling others they are food allergic). They also do not tell others (particularly in the case of new friendships/alliances) to feel “normal,” are self-conscious about food allergy and value peer approval highly. They often resent parent protection which they regard as “nagging” and sometimes express this by deliberately “forgetting” the pen.	Minimization

(continued)

TABLE E5. (Continued)

Open coded categories	Identifiable relationships	Axial coded category
Hypothesis testing as way of coping with curiosity	If they find themselves thinking about food allergy, they will often use distraction techniques.	
Hypothesis testing as a way of determining risk thresholds	Although some have had “scary” experiences of reactions, the desire to “have a life” appears to take precedence over the fears of a food allergic reaction.	
Hypothesis testing as a way of coping in a social context	When younger, children will often use a “hypothesis” test of a “forbidden” food to try and determine how much they can eat without feeling unwell.	
Having a life: deliberately eating an allergic food on a regular basis	Hypothesis testing—deliberately eats an allergic food, often in the presence of peers or in a social context to fit in or to determine their “risk thresholds.”	
Being fatalistic about the future	Teens and young adults tend to do this as a habitual coping strategy.	
	They report not being worried about the future; “what will be, will be.”	
Confronting lack of awareness	Children who are adaptive appear to be able to balance living within the rules but also living within the social world.	Balanced adaptation
Balancing a food allergic identity	Food allergy forms a part of their identity but is balanced by valuing other aspects of the self.	
Balanced reliance on parents and friends	They use cognitive restructuring to cope with low awareness, rules, and restrictions. They feel confident enough to inform others and be vigilant in “risky” social situations when food is involved and may pose a threat to their safety.	
Seeking instrumental and emotional support	They are angry or upset at a lack of awareness but cope by confronting or informing others.	
Flexible problem solving	Friends are important for emotional and instrumental support, but this is a relatively small part of their role in participants’ lives.	
Cognitive restructuring	They report being encouraged by parents from a young age to order in restaurants and explain their needs to others. They worry sometimes about potential allergic reactions but are confident in their ability to cope.	
Telling others (when necessary)	Telling others of their food allergy happens once they feel it is appropriate (eg, in situations where food is served; once an acquaintance becomes a friend, etc.)	
Being vigilant (when necessary)	As they become older, they also report being able to increasingly recognize “risky” situations and choose an appropriate strategy.	
Positive disease and self-identity	They attribute positive aspects of the self to growing up with food allergy (eg, making them more empathetic to others, responsibility at a younger age contributing to good decision making in other areas of their lives).	

Data were grouped under common codes, a process called “open coding,” and then grouped according to shared meaning between codes to create major themes and subthemes, using the constant comparison method. This process aims to generate theories that explain how some aspect of the social world “works.”

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