

More and more parents, children and teens are having to learn to live and cope with food allergy. Can an awareness of the reciprocal effects of food allergy and the developmental process provide novel perspectives for prevention and intervention?



Growing up with allergy

Audrey DunnGalvin considers the impact of severe food allergy on the quality of life and development of children and adolescents.

Food allergy is a major public health concern, affecting an estimated 20 million Europeans, with high costs to public health services. The unintentional consumption of an allergen is common, causing frequent reactions. Admission rates for anaphylaxis have increased approximately three-fold between 2005 and 2017 in most western countries.

If you live with a life-threatening allergy, prevention is (in the words of Hugh Sampson) 'the cornerstone of therapy'. You're reliant on complete avoidance of the allergen, alongside emergency management in the form of 'the pen' of injectable epinephrine if you do accidentally ingest it. Because food is such an integral part of everyday life, the impact extends far beyond 'mealtimes'. Allergens such as peanuts, nuts, milk, eggs and soy, can be found in many foods, and in different forms.

Precautionary allergen labelling (PAL) is often inconsistent, false or misleading, and public awareness and understanding is generally low.

Now imagine you're a child. Your health is a product of complex, dynamic processes: family, social, and physical factors, alongside genes, biology, psychology and behaviours. Children are rapidly changing and developing in response to these interactions. So what does the research have to say about how certain biopsychosocial factors associated with food allergy can influence wellbeing and development, in both the short and long term? Could a developmental perspective be key to prevention and intervention?

The impact of food allergy on quality of life

Symptoms may develop within seconds after ingestion of a food allergen, with the vast majority of reactions occurring in the first hour. The most dangerous

include breathing difficulties and a drop in blood pressure, or shock, which are potentially fatal. Typical allergy medications such as antihistamines work too slowly and cannot reverse the effects of chemical mediators. The adrenaline auto-injector (AAI) is the treatment of choice and must be administered promptly. Those living with allergy must read food ingredient labels; pay attention to potential cross-contamination from other foods; be constantly vigilant in a variety of social situations and activities; explain safety needs to friends, acquaintances, teachers, staff at food venues; and carry or have immediate access to an AAI.

"Evidence shows that quality of life in food allergy is impacted by a range of psycho-social factors"

Inevitably, all this has an impact on quality of life for children, teens, adults and parents. Research in the last decade has placed the concerns and needs of patients and family at the centre of research and practice. The Food Allergy Quality of Life Questionnaires (FAQLQ) have been developed to assess the impact of food allergy on quality of life for all age groups (and for parents) and

are the most frequently used psychosocial measures. Evidence shows that quality of life in food allergy is impacted by a range of psycho-social factors including uncertainty and fear of reactions; food anxiety, and dietary and social restrictions. Quality of life may also be influenced by age and gender, country and culture, severity and type of allergy.

The most significant short term impairment seen in research on the psychosocial impact of food allergy for all age groups, is the persistent fear of an adverse reaction. Food allergic patients – and their families – can experience food allergy related fears 24 hours a day, 7 days a week, while on holidays, at parties, using public transportation, at school, and even at home. Thus, the risk of reaction is ever-present but the 'when', 'how', 'what' leads to uncertainty, fear, anxiety, embarrassment, and frustration. Many individuals and families avoid enjoyable activities like dining out, travelling, shopping and other everyday activities that

those of us without food allergy take for granted. Restrictions on diet also affect children's nutrition, school and extracurricular activities. In Italy, 20 per cent of young children living with allergy have never attended a birthday party, and 40 per cent report having a monotonous diet.

In school, reactions can be due in part to uncertainty around food safety from school authorities. Risk is sometimes managed by excluding or restricting the child from certain activities and setting them apart from others during lunch and treat times. This gives rise to a feeling of difference, stigma and certain peer behaviours, such as teasing and bullying.

Perceptions of risk around allergy do not develop or take place in a vacuum, but in the environmental context of everyday life. There are two main dimensions: cognitive (how much people know about and understand risks), and emotional (how they feel about them). The issues around Precautionary allergen labelling (PAL) illustrate how an environmental factor can influence perceptions of risk, along with health and wellbeing.

Such labelling is meant to inform consumers about a demonstrable and significant risk to an individual with food allergy. Yet current (mainly voluntary) practices have led to variations in the wording of these labels, and indeed whether or not they are used at all. A product with a PAL may be correctly labelled on the basis of an adequate risk assessment, or just be labelled to minimise a producer's liability. A product without a PAL may be completely safe or the unintended presence of an allergen may not have been considered. An incorrectly mislabelled product causing a reaction can result in a loss of credibility in PAL (and in the science underlying it) creating anxiety, uncertainty, mistrust, and dread. PAL therefore not only adversely impacts on quality of life, but also acts as a barrier to effective management.

Reciprocal effects of allergy and development

The impact of any chronic disease on everyday life (and on management) is mediated by our psychology – focusing just on 'medical issues' is not an option. Developmental theory provides an important insight into how certain biopsychosocial factors influence the way children respond to chronic disease on the pathway to adulthood. Theory and evidence from studies of children's cognitive, emotional, memory, and brain development have pointed to particular points during which structure, organisation, and flexibility in coping processes are likely to undergo significant qualitative and quantitative shifts. We now know that brain development (and hence adolescence) continues



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to 25 years and is vulnerable to experiences and environmental influences which affect not only the amount of brain cells – and number of connections among them – but also the way these connections are 'wired'.

We carried out two qualitative studies with the aim of creating a developmental model, called the Food Allergy Coping and Emotions (FACE) model. The first phase of development took place within Ireland and we then validated the model in a large data set from six countries (Ireland,

England, Scotland, US, Italy, Australia). The qualitative model illustrates on the experiences, emotions and management styles of children and teens growing up and living with food allergy. In our analysis, we paid particularly close attention to any external and internal mediators between emotions and coping.

Briefly, the FACE model describes how the emotions attached to living with food allergy (including embarrassment, fear, anger, frustration, worry, anxiety, and confusion) drive a search for 'normality'. This in turn gives rise to particular types of coping strategies, including anxiety/avoidance and frustration/risk. The link between emotions and coping is influenced by external and internal mediators (including context, developmental stage, type of allergen and experience of reactions, food allergy beliefs 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 broadly similar coping styles, although males felt less able to communicate their fears to friends and peers, particularly in adolescence and young adulthood.

The forgotten years

The 'First Five Years of Life' campaigns have made us all aware of the impact that early childhood has on a child's future. Between birth and six years, children feel a strong sense of protection from parents (primarily) and other adults (such as teachers). However, ages 6 to 12 – sometimes called the 'forgotten years' – are also a critical period that carries long-lasting influence.

In middle childhood, children's social networks start to change from networks in which children primarily interact with adults to networks in which children primarily interact with other children. That means exposure to social comparison and competition in school classrooms and peer groups. Children with food allergy need to cope with these normal developmental changes alongside their condition, placing increased stress on daily social interaction. Chronic diseases with dis-regulation of inflammation,

such as food allergy, are particularly susceptible to modulation by stress and emotion. Significant fear-eliciting experiences in middle childhood can disrupt the typical development of stress regulation as well as learning, memory, and social behaviour. The long term impact on the psychology of patients can be profound.

Adolescent challenges

Adolescence is characterised by significant biological, physical, and psychosocial changes marking the beginning of adulthood. For example, the ongoing maturation of neural connectivity leads to increased vulnerability for risk taking. Enhanced amygdala reactions to emotional stimuli means that the adolescent brain perceives emotions at two- to four-times greater intensity than adults, yet control systems are still developing as late as 21 years of age. There is also a 'heightened stress/threat response. Adolescents face a 'tension' as they attempt to balance a search for safety with integration and positive identity. The PAPRIQUA study (an online cross-sectional survey conducted among people with peanut allergy in the UK) found that adolescents had worse quality of life than both children and adults with peanut allergy (Gallop et al., 2018) and results from the PALISADE study (assessed using the FAQLQ) has similar findings.

Adolescents (12- to 25-year-olds) with food allergy are also at the highest risk of fatal food-induced anaphylaxis, with the majority triggered by food consumed outside the home. In France and Belgium, the MIRABEL study also found severe/potentially severe reactions more common in teenagers and adults than in younger children. Adolescent decision-making typically occurs within social environments that often involve complex motivations. These motivations can compete and conflict with one another and include maintaining status with peers, achieving goals in academic, athletic, or other arenas, finding independence, and maintaining harmony within the family. For example, sharing food has an important social value and uncertainty about PAL does not help in a teen's attempts to negotiate the tricky balance between keeping 'safe' and developing an individual sense of identity and a sense of autonomy that are important tasks of this period of development. Therefore, we see increased risk-taking behaviour (such as failure to carry an AAI), failure to avoid triggers, and use of alcohol), coupled with reduced ability of parents to manage exposure risk.

Working with development

A growing number of studies have shown the multi-dimensional adverse impact on the quality of life of children and teens living with severe food allergy –

physiologically, psychologically, socially and environmentally. Harmonised approaches should be developed based on a multilevel intervention perspective. In the past, research efforts in general (and in food allergy) concentrated on single-level analysis, yet these ignore the environment in which an individual operates or how changes at the organisation, institution and policy levels impact the individual and vice versa. There have also been debates in health contexts about the merits of 'upstream' versus 'downstream' approaches and whether funding and focus should be at individual or population-level approaches. These arguments ignore the importance of the interaction between the two.

Awareness of the reciprocal effects of food allergy and development can provide novel perspectives for prevention and intervention and can provide some answers to how we can help and support patients living with food allergy. For example, decision-making in adolescence is optimised for attaining specific developmental goals. However, the environment plays a strong role in whether adolescent vulnerability is translated into actual risk behaviours. Risk-taking is not a simple process, and is not only affected by attitudes toward known risks, but also

by attitudes toward situations, in which the likelihoods for positive and negative outcomes are not known. It is not that adolescents actually choose to engage in risks: rather, they are willing to gamble when they lack complete knowledge. When adolescents meaningfully understand a risky situation, they are even more risk averse than adults.

Adolescence also means a high receptivity to learning; idealism; a natural inclination to novel problem solving; and an eagerness to assume new challenges. Therefore, it presents an ideal opportunity for health care professionals to support healthy behaviours, encourage independence and active decision making, and successfully transition adolescents into the adult-centered healthcare system.

To conclude, food allergy experiences and management are psychologically mediated. Understanding the challenges and opportunities of the developmental process can help us to engage with children, teens and young people. We need to work with rather than against development.

Key sources

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