

Living with Food Allergy: Cause for Concern

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INTRODUCTION

Since, at present, there is no ‘cure’ for food allergy, avoidance of the responsible allergenic food and emergency management in the form of injectable epinephrine (EpiPen or Anapen), in case a food allergen is accidentally ingested, is the only reliable therapy offered to those living with such conditions. However, ‘avoidance’ is not as straightforward as it might first appear. Firstly, it is complicated by the fact that foods like peanuts, nuts, or soy can be found in many foods (e.g., breads, muffins, pastries, biscuits, cereals,

soups, ice creams, seasoning, sauces) and in different forms. Living with a food allergy also means constantly reading food ingredient labels, concern for cross-contamination, vigilance in a variety of social activities, and immediate access to an auto-injector [1]. Secondly, symptoms may occur within minutes of ingesting a food allergen, include itching and swelling of the lips, tongue, and soft palate as well as nausea, abdominal pain, vomiting, and diarrhea. Anaphylaxis refers to a sudden, severe, potentially fatal, systemic allergic reaction that can involve the skin, respiratory tract, gastrointestinal tract, and cardiovascular system. The most dangerous symptoms include breathing difficulties and a drop in blood pressure, or shock, which are potentially fatal. Therefore, although the life-threatening nature of anaphylaxis makes prevention the cornerstone of therapy, it also has implications for the health-related quality of life of the children, teens, and adults living with the allergy.

In the past, the medical community defined health as an absence of disease. It is now recognized that health consists of physical, psychological, and social aspects. Because the concept of health has changed, the way we measure health or the impact of any disease has also changed. Health professionals now know that it is essential to use outcome measures that reflect the patient's perspective in order to gain a truly meaningful picture of the impact of a disease on a patient's everyday life [2]. We call this health-related quality of life (HRQL). The perception of HRQL is influenced by the individuality and subjectivity of experience and response, and may depend on many factors, such as age, gender, context, and culture [3–7]. Therefore, physiological measures often relate poorly with *perceived* physical well-being [8], and patients with the same clinical criteria often have dramatically different responses. To give an example, two patients with the same prognosis following an operation for a heart bypass can have two very different perspectives on how their lives have changed. For one it may be an opportunity, for others it may be perceived as a catastrophic event that changes how they see themselves, how they interact with others, and how they perceive the overall quality of their everyday lives. In turn, this can impact on how well they follow medical advice for their future health. It has become increasingly important, therefore, for researchers and healthcare professionals to understand how the perceptions, experience, and impact of a chronic disease might influence a patient's interpretation and response to it, so that we in turn can respond more appropriately. Furthermore, involving children as well as adults and parents in research is important, because children are now acknowledged to have rights in the determination of medical decisions that affect them [9]. This has encouraged research to be undertaken with children themselves to understand their views on the impact of a disease on their experiences and relationships.

Although a growing number of families must live and cope with food allergy on a day-to-day basis, it is only in recent years that the socio-emotional impact of food allergies on children, teens, adults, and parents has been researched in depth. The EuroPrevall project (europrevall@bbsrc.ac.uk) gave great impetus to research in the area of HRQL. In addition to clinical

research on the prevalence, mechanisms, and causes of food allergy, research output in the area of psychosocial impact included HRQL measures for all age groups, and an examination of its socio-economic impact.

HRQL is measured by two major types of instruments; generic and disease-specific. Generic HRQL instruments are not specific to any particular disease and are therefore useful for comparing HRQL across different conditions, whereas disease-specific questionnaires focus on issues pertinent to one disease. However, generic instruments are necessarily more 'general' and therefore less sensitive to the particular problems associated with a particular condition [9]. For example, asking parents of children with food allergy if their disease impacts on their children's ability to run up and down stairs will provide meaningless results. In contrast, asking the same parents if children feel left out at birthday parties because of their food allergy provides a picture of its impact on the children's ability to take part fully in everyday social events – activities that children without food allergy enjoy without much thought or restriction. Disease-specific HRQL questionnaires provide an in-depth picture of the day-to-day concerns of patients and are also able to capture small changes in HRQL that may occur as a result of clinical or therapeutic treatment.

Several disease-specific measures have been developed under the aegis of EuroPrevall to assess quality of life in children and teens. These include the Food Allergy Quality of Life Questionnaire – Parent Form (parent-administered for children aged 0–12 years); the Food Allergy Quality of Life Questionnaire – Child/Teen Form (self-administered for children and teens aged 8–17 years) and the Adult Form (for those aged 18+). These questionnaires were developed according to gold standard methodologies [10–15].

Health-related quality of life instruments capture the impact of food allergy; however, the manner in which it is experienced and managed every day (coping) must also be evaluated [1,3,7]. Coping has not only been shown to be related to patient HRQL, but is also strongly linked to health behavior [16], having both the short- and long-term impacts. To illustrate this, we return to our earlier example of the two patients with the same prognosis following heart bypass surgery. They may, for example, be unable to return to their previous employment because of their changed health circumstances. Whereas one may cope with this experience by viewing the surgery as an opportunity to change their lives, to become healthier, to experience new challenges, others could 'give up,' become depressed, reject the company of friends, and feel that they no longer have a meaningful contribution to make to society. Here we have the same prognosis, but very different coping strategies. Research tells us that children with any chronic condition have twice the risk of developing mental health disorders as do healthy children, even without an accompanying physical disability [17]. Therefore, efforts have increasingly been made to assess how well children and adolescents cope with chronic conditions. In the context of research in children, qualitative research also provides an opportunity to tap into the richness of children's thoughts and feelings about themselves, their environments, and the world in which they live.

In this chapter, we will look at the impact of food allergy on HRQL and subsequent risk management. Firstly, we will let the children, teens, and families describe, in their own words, what it is like to live and cope with a food allergy every day. Qualitative studies were also carried out under EuroPrevall, both in the initial focus groups put in place to generate items for the questionnaires, and independently thereafter. The findings will be presented in the context of a developmental model that captures the pathway from childhood to adolescence and explains why some children are ‘anxious’ while others are ‘risky.’

We will then discuss some scientific research on HRQL, the majority generated over the life of the EuroPrevall project. Research on factors (such as risk perception) that are related to, and impact on, HRQL are also examined. There is a strong emphasis throughout on developmental considerations in food allergies, from infants to adults. We conclude by offering some recommendations for future research and practice in food allergy risk management, based on the findings in this review.

QUALITATIVE STUDIES ON THE IMPACT OF FOOD ALLERGY ON HRQL

Experience and coping in any chronic disease is an intricate pattern of ‘facts’ and ‘feelings’ interwoven into a child’s developmental pathway from birth to adulthood. Lay perceptions of risk may seem irrational to some clinicians, but have their own logic and validity from the perspective of those living and coping with food allergy. Here we use the patients’ and parents’ own voices to explore what it is like to live with food allergy, in order to better understand the decisions they make about managing their condition.

The findings will be framed within an integrated developmental framework [3] to explain the onset, development, and maintenance of food allergy—related cognitions, emotions, and behavior. In order to develop this framework we interviewed 120 children/teenagers aged 6–18 years in 15 age-appropriate focus groups. Fifty-two percent of the children were female. Parents were also interviewed. All children were physician diagnosed with IgE-mediated food allergy and had been issued an Anapen/EpiPen. Developmentally appropriate techniques such as vignettes or stories (where children could comment on characters in the third person) and activity books were designed to stimulate discussion, maintain interest, and minimize threats to the child’s self-esteem.

Analyses of the data encompassed precipitating events (stressful events in the children’s lives caused by food allergy—related factors); psychological impact (cognitive appraisal and emotional effects); and behavioral consequences or coping strategies. Our findings indicated that experience and coping in food allergy situations is complex and dynamic, comprising a series of interactive processes (both age-, gender-, and disease-specific) that are embedded in a child’s developmental path.

Subsequently, we also analyzed data from focus groups and interviews held in Australia (N=60), the UK (N=72), Italy (N=45), Singapore (N=20), and the US (N=45). The themes that emerged from other countries were strikingly similar to our previous research, including the impact of *living with uncertainty*, with *difference*, with *rules* and the coping strategies used (Figure 1.1). The findings [3–4,18–21] are discussed below using direct quotes from parents, children, teens, and young adults.

CHILDREN AND TEENS: THE EVOLUTION OF UNCERTAINTY

Because children are rapidly changing in response to physiological, social, and psychological influences, the developmental process plays an important role in shaping and determining their health and HQRL. Children’s social and emotional experiences are essential in shaping how the child will manage and live with their illness, both in the short and long term. Sensitive transition points occur along the developmental pathway when physiological

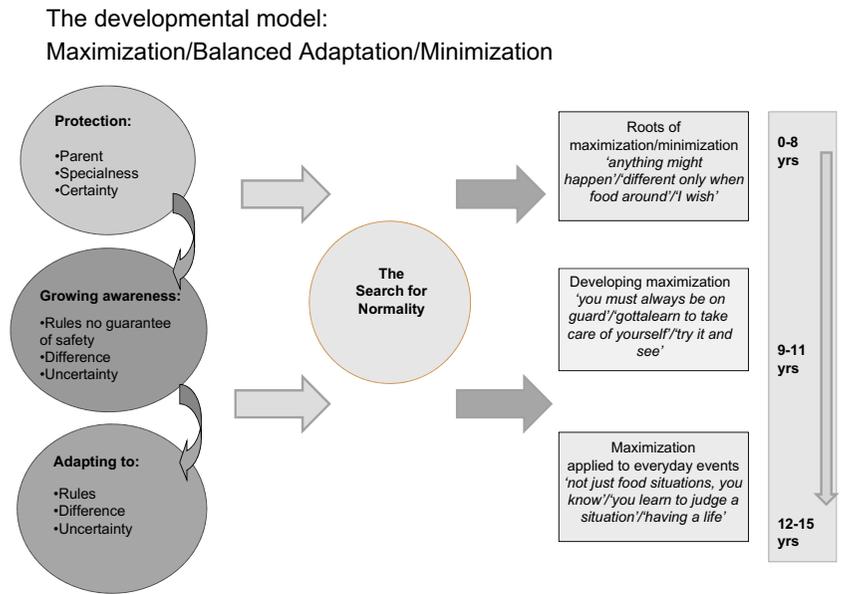


FIGURE 1.1 An illustration of the developmental model. Because they were diagnosed when infants, young children feel that they are ‘the same’ as other children and parents help them to feel normal and protected in their everyday lives. They therefore have an illusory perception of control and certainty. As children become more aware of the rules as restrictive, together with a growing awareness of difference and uncertainty, the search for normality becomes stronger and children evolve strategies in order to cope. Although their roots may be discerned in children in the youngest age group, by adolescence, children’s coping strategies become more defined, and in some cases more rigid, and an expanding social world gives further impetus to the search for normality. Dunn-Galvin and Hourihane JACI, 2009.