



The psychosocial impact of food allergy and food hypersensitivity in children, adolescents and their families

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TITLE PAGE**Review Article**

Title: The psychosocial impact of food allergy and food hypersensitivity in children, adolescents and their families: a review.

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Abstract

Food allergy affects 6% of children but there is no cure and strict avoidance of index allergens along with immediate access to rescue medication is the current best management. With specialist care, morbidity from food allergy in children is generally low, and mortality is very rare. However, there is strong evidence that food allergy and food hypersensitivity has an impact on psychological distress and on the quality of life of children and adolescents, as well as their families. Until recently the measurement of quality of life in allergic children has proved difficult because of the lack of investigative tools available. New instruments for assessing quality of life in food allergic children have recently been developed and validated, which should provide further insights into the problems these children encounter, and will enable us to measure the effects of interventions in patients. This review examines the published impact of food allergy on affected children, adolescents and their families. It considers influences such as gender, age, disease severity, co-existing allergies and external influences, and examines how these may impact on allergy related quality of life and psychological distress including anxiety and depression. Implications of the impact are considered alongside avenues for future research.

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Introduction

Food allergy is an increasing problem in adults and children. The incidence has increased dramatically in recent years, with a possible doubling in the incidence of peanut allergy over 4 years (1). The severity of allergic disease also appears to be increasing as demonstrated by doubling of hospitalization for anaphylaxis over a 5 year period (2). A number of severe, life-threatening allergies that were once rare are now increasingly common, such as kiwifruit allergy in young children (3).

There is no cure or preventative treatment for food allergy at present. Therefore, management is restricted to avoidance of the implicated food via elimination diets, and emergency treatment of symptoms caused by accidental ingestion, with the aid of treatment plans, which aim to reduce morbidity, mortality and improve quality of life (QoL). Morbidity is low and mortality exceedingly rare in those suffering from food allergy(4). However, the impact of food allergy on aspects of daily living and quality of life, as well as emotional states such as anxiety and depression, has been shown to impact adversely on the child and family. These studies have varied in their sample characteristics, in the age of participants investigated, and in the instruments used, which have included a mixture of non-validated and validated generic health and food allergy-specific scales (Table 1). This review examines what is currently known about the psychosocial impact of food allergy and hypersensitivity on children and their families and explores the implications of this for health and management of food hypersensitivity, while highlighting further avenues of research.

The following databases were searched for studies published in English from 1990 to 2009: PubMed, Medline, PsycInfo, Cinahl, Web of Science. The following search terms were used: *food allergy, food hypersensitivity, food intolerance, adverse food reaction, exclusion diet, elimination diet, quality of life, well being, daily activities, psychological distress, anxiety, depression, allergic reactions, anaphylactic reactions, gender*. Papers were examined by all authors of this review for relevance. The term food hypersensitivity in this review is used to refer to allergic and nonallergic hypersensitivity and food intolerance. Food allergy is only used to refer to conditions where there is verified immunologic aetiology(5). When referring to specific studies, for clarity this review uses the terminology reported by the authors of those studies.

Impact of food hypersensitivity on quality of life of the patient

QoL studies have highlighted the subjective nature of living with an illness, where emotional, social and cognitive factors, in addition to expectations and coping style, influence personal perception (6;7). Health related QoL considers the effects of an illness and its treatment upon the patient, as perceived by the patient, looking at social, psychological and physical states. In a healthcare system where a patient centered approach is now favored, QoL research in patients with allergy can provide means for improving the management, care and experiences of patients and families.

Few studies have directly assessed the impact of food allergy on the quality of life of the patient using specific QoL scales rather than generic health scales. Those that have consistently report that food allergy has a detrimental impact on aspects of QoL. In the first study to directly ask children to report on their own QoL, Avery et al used a food-allergy specific (unvalidated) QoL scale and found that children with peanut allergy reported lower QoL scores than children with insulin dependent diabetes mellitus (IDDM) (8). Quality of life of management of the condition and eating were particularly important in children with peanut allergy, who were more afraid of accidentally eating peanuts than children with IDDM were of having a hypoglycemic event. In a study using validated generic QoL scales, children with peanut allergy reported significantly poorer QoL than their healthy siblings(9). This was particularly the case for physical QoL, QoL in school and overall QoL. They also reported poorer emotional QoL and psychosocial health than the norm means published for the scale(9). However, both studies used a small number of participants recruited from clinic, suffering from peanut allergy only and so may not be generalizable to a non-clinic based population suffering from a wider range of food allergies.

Clearly more work is needed in this area, using validated food allergy specific quality of life scales, which are now available, to more fully explore the impact of a range of food allergies in both clinic and non-clinic based populations. Generic QoL scales are also particularly useful when comparing patient populations with healthy controls and future studies should consider using both types of measures.

Affect of food hypersensitivity on general health and daily life

Many studies have not used QoL scales but have asked caregivers or patients about the impact of food hypersensitivity on their general health and on family and daily life. These studies, alongside those using more specific or validated scales, have found that food allergy can have a significant impact on a wide variety of daily activities.

Affect of food hypersensitivity on general health aspects of quality of life

The impact of food allergy on general health aspects of quality of life appears equivocal. Lyons et al described that a cohort of 24 food allergic or intolerant individuals aged 15-20 years, considered themselves as healthy as their peers (10). However it is worth noting that the study did not distinguish between allergy and intolerance and involved mainly females. Sicherer et al found that parental perception of general health were significantly decreased if their children had food allergy compared to healthy general population norms (11). Similarly Ostblom et al(12) found that parents of 9 year old children with food hypersensitivity reported that their child had significantly worse physical functioning, more social limitations and poorer general health than children with non-food related allergic diseases and children with no allergic diseases. Those with high levels of food-specific IgE-antibodies also had poorer mental health and general health.

When asking the children themselves King et al found that children with peanut allergy reported a greater impact on physical health aspects of quality of life than their siblings(9). However this was only in females with peanut allergy. Using a much larger study sample (n=1488) recruited through schools in Sweden, Marklund(13) asked adolescents aged 13 to 21 years to complete a generic health survey (the SF-36) and a study specific questionnaire. They reported that adolescents with allergy-like conditions scored lower on seven of the eight SF-36 scales than those with no allergy like conditions. In addition females with food hypersensitivity scored significantly lower on three of the health scales compared to females with no other allergy like conditions. There were no such differences in males however. There therefore appears to be gender effects in the perception of the impact on health. This is discussed more fully below and should be considered in the analysis of future studies of quality of life in food hypersensitivity.

Activities within the family

A number of studies have reported that activities undertaken as a family unit are limited by having a food allergic child (11). Primeau (14) compared adults and children with nut allergy to those with rheumatological disease using the Impact on Family Questionnaire and found that parents of children with nut allergy reported more disruption to daily activities and more family disruption as a direct consequence of the nut allergy (14). Bollinger et al investigated the caregiver's perspective of the impact of a child's food allergy on different aspects of daily life (15). Disrupted activities included family social events, field trips, parties, sleepovers and playing at friends' houses. Half of families reported significant disruption to these aspects of their lives. Many parents would rather minimize the risk and anxiety induced by such activities by avoiding them altogether (15), and parents report preventing their child from attending parties and school trips (14). Children also report anxiety in regards to going on holidays, attending parties and using public transport (8). Everyday activities such as shopping and eating out are frightening for children with food allergy and even perceived as life threatening. The restrictions that food hypersensitivity places upon an individuals' social activities is supported by the fact that following a negative food challenge, the social life of the child and family has been shown to significantly improve (16).

Many parents find it difficult separating from their child (15). As a result, parents with allergic children often accompany them in social situations beyond the age at which non-allergic children are accompanied. Although this hyper-vigilance is imposed by parents, they themselves express concern over the effect that such increased protectiveness will have on their child (17). This overprotection can extend beyond childhood. For example food allergic young adults (aged 18 to 22 years) who had experienced anaphylaxis rated their parents as more overprotective than food allergic young adults who had never experienced anaphylaxis(18).

Eating outside the home

Food allergy is the primary cause of anaphylaxis within the outpatient community setting, and its prevalence is increasing (2). A study of over 200 cases of anaphylactic reactions in the UK, showed that most cases of food induced anaphylaxis occur

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3 outside the home (19). 25% were reported to have occurred whilst dining at
4 restaurants and 15% occurred whilst at school or work. In another study of fatalities
5 due to food induced anaphylaxis, 20 out of 31 people experienced their reaction away
6 from the home environment (20). Locations included restaurants, schools, work and
7 friends' houses. Similarly a more recent study in the UK found that most fatalities
8 were outside of the home such as work, school or nursery, restaurants and at camp(4).
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16 Many food allergic children and their families will go to the same restaurants
17 repetitively as they cater for those with allergies (8). Reactions in restaurants are
18 usually a result of cross contamination or unexpected ingredients, particularly in
19 desserts or Asian foods (21). In most cases of allergic reactions at restaurants,
20 individuals believed the food they were eating to be safe (22). Peanuts and tree nuts
21 are common ingredients of Asian, Chinese and Mexican cookery (23) and families
22 need to be aware of the potential risks of eating takeaways as well as in restaurants.
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30 *School*

31 Concerns regarding disease management at school have been raised by allergic
32 individuals (8). Parents worry as they are not present whilst their child is at school, to
33 prevent allergen exposure and treat any potential reactions. These concerns may be
34 founded, as in a UK study of self-reported food induced anaphylactic reactions, nearly
35 20% of those affecting children reportedly occurred whilst at school (24). More than
36 30% of parents of children with food allergies make more than one visit per month to
37 their children's school to discuss issues surrounding their child's allergy (11).
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39 However, despite parent's concerns, proportionately fewer reactions occur in school
40 than other non-home situations, considering the amount of time spent there.
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49 Food hypersensitivity can affect the school attendance of the child. One third of
50 respondents to a USA study reported a significant impact on their child's school
51 attendance, and 10% of the study group home-schooled because of their food allergy
52 (15). Similarly, in two studies conducted in the Netherlands a higher absence from
53 school was reported for those with food allergy compared to healthy controls,
54 possibly due to the greater disease burden reported by those with food allergy(25;26).
55 This extended to early adulthood with a lower percentage of young adults with food
56 allergy in full-time work compared to health controls(27). Education, awareness and
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3 training of school personnel are necessary in order to reduce parental anxieties and to
4 prevent attendance being affected as a result and management plans should be
5 established at all schools.
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10 It is not just children who are affected whilst in educational establishments. Those
11 aged 18-21 years, still in education and living with food allergy, felt that wider
12 selections of safe meal options, allergen safe cafeteria areas, and selected members of
13 staff to discuss meals with, would improve their experience of living with food
14 allergy; 68% stated that education of other students would improve and ease their
15 ability to live with food allergy (28).
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23 **Effect of gender and age on quality of life**

24 In relation to general allergic conditions adolescent girls have been reported to have
25 significantly lower scores in the majority of health related QoL areas than boys (29).
26 Girls with food hypersensitivity also scored lower on general health, bodily pain and
27 social functioning compared to girls with non-food allergies (29). King et al also
28 found that girls with peanut allergy reported significantly greater impact on quality of
29 life compared to female siblings, particularly for QoL in school, physical health-
30 related QoL and overall QoL(9). Boys with peanut allergy only rated QoL in school
31 as significantly worse than male siblings. It may be that boys try to diminish the
32 importance of their condition in an attempt to reduce stigmatization, whereas girls
33 will integrate their condition into part of their social identity (30).
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44 When parents are asked, rather than the children themselves a slightly different
45 picture emerges. In a study which included children aged 8 to 19 years (29), parents
46 of food hypersensitive children reported boys with food allergy to have a poorer QoL
47 than girls in terms of physical functioning and general health, whilst girls were
48 reported to have poorer mental health scores than boys. A number of reasons for sex
49 and gender differences in people with food hypersensitivity have been suggested in
50 the literature(31) including biological vulnerability, perception of symptoms,
51 exposure to and evaluation of risk, information processing and role expectations. It is
52 clear that the mechanisms of sex and gender differences are an important area for
53 future study and that research assessing the impact of food hypersensitivity looks at
54 gender differences in outcome variables.
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5 Age is also associated with differences in the impact of food hypersensitivity.
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7 Marklund et al found that from a parent's perspective, the younger their food allergic
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9 child, the more negative an impact their food allergy has on everyday family activities
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11 (29). This may reflect children outgrowing some food allergies in early childhood or
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13 simply changes in coping over time. More research into the developmental aspect of
14
15 quality of life in those with food hypersensitivity is needed.
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17 **External influences on quality of life**

18 *Reactions of other people*

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20 Parent's major frustrations include a lack of public understanding, unwillingness of
21
22 others to accommodate, inconsistent medical information and mislabeling of products
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24 (17). The general public's perception of food allergy impacts on the life of
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26 adolescents (10). The knowledge and perceptions of others may influence how
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28 someone's food allergy is managed, for example, if a patient feels that their friends
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30 believe rituals such as asking about ingredients are not important, they may be less
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32 inclined to be as vigilant (10). In some cases children can experience teasing and
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34 harassment due to their food allergy, some reportedly being smeared with the allergic
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36 food (23). Adolescents have expressed feelings of being disregarded by others, and
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38 have faced unreliability and a lack of understanding from others (32). However,
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40 adolescents have also experienced and were appreciative of supportive environments
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42 (32).
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45 The allergy management plan recommended by health professionals may influence
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47 the quality of life and anxiety experienced by children and their parents. Prescribing
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49 auto-injectors is associated with reduced anxiety for nut allergic children and their
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51 mothers, but is not associated with whether the child carries the auto-injector(33).
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54 Parents have highlighted frustrations caused by hostility from others, particularly
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56 from school personnel and extended family (17). Some families have family
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58 members or friends who do not believe their child's food allergy diagnosis (23).
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60 Parents deem the cooperation of those who care for their allergic child and the
information that they provided to them key in maintaining safety (17). This allows
parents to exert some control when another person takes over the responsibility of

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3 their child.
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6 7 *Food Labeling*

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9 The vigilance required for allergen avoidance when shopping or eating out depends
10 on information which is often hidden or misleading (34). Clear food labelling
11 regarding allergens is essential to help allergic patients manage their allergy, although
12 precautionary labelling can lead to unnecessary restrictions. A study by Joshi et al
13 showed that in a group of parents avoiding peanuts, only 54% were able to correctly
14 identify their presence on a label (35). This was worse for those with a milk allergy,
15 where less than 10% correctly assessed the labels. Of those who scored perfectly,
16 90% were members of the Food Allergy and Anaphylaxis Network and it may be that
17 belonging to a support group enables parents to more easily access information
18 needed to successfully manage food allergy. Parents have described how they will
19 read labels up to three times before giving their child the food and this has been
20 justified by parents reporting to notice the allergen only on the third attempt (23). A
21 recent study of nut allergic children and their mothers by Cummings et al(33),
22 reported better allergy specific QoL in mothers and children who reported eating
23 products labeled 'may contain nuts' than those who strictly avoided all nuts.
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36 37 **Allergic features and their effect on quality of life**

38 39 *Previous allergic reactions to food*

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41 It has been reported that previous and concurrent allergic experiences impact on
42 present QoL. Bollinger et al reported that a history of an anaphylactic or severe
43 reaction to an allergen had no deteriorative impact on families' or individual's QoL
44 (15) and that the precautions taken and potential consequences of ingestion are more
45 influential on QoL than a serious past reaction. The authors discussed a phenomenon
46 observed in other conditions whereby one event (such as a past reaction) does not
47 have an overwhelming emotional impact, but the accumulation of daily frustrations
48 and strains, impact on QoL and enhance stress levels. Marklund et al also found the
49 risk of a potential reaction and the disruption caused by measures taken to avoid
50 allergen exposure were associated with a lower QoL, rather than the actual clinical
51 reactivity experienced on exposure to an allergen (29). It was also noted that the
52 larger the number of previous reactions to foods, the lower the parental reported
53 physical functioning of the child, and the higher the impact upon family social
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3 activities (29).
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7 In cases where children can not remember having a serious or anaphylactic reaction
8 teenagers with food allergy have reported that anaphylaxis has a low impact on their
9 day-to-day lives, in comparison to what their parents report(36). Conversely, it has
10 been suggested that post traumatic stress disorder may be triggered by experiencing or
11 observing an anaphylactic reaction (37). It has also been suggested that children who
12 have previously experienced a severe allergic reaction may become withdrawn and
13 fearful, or develop disordered eating (23). This suggests that some individuals may
14 be negatively emotionally affected by having a previous severe reaction to food.
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23 The fact that a child has not had a recent reaction is often viewed by parents with
24 mixed emotions. Some see it as reassuring sign that they are managing the allergy
25 effectively, whilst others worry that it will give them and their child a false sense of
26 security where a reaction is more likely to occur (38). This suggests that it may be
27 down to individual characteristics and personality traits as to whether the occurrence
28 of previous reactions will negatively or positively impact upon QoL, however
29 research is needed to assess this hypothesis.
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37 *Coexisting allergies*

38 Food allergy is frequently associated with other atopic conditions including asthma,
39 hay fever, and atopic eczema. In a questionnaire based study, Sicherer et al
40 questioned 253 parents of 5-18 year olds with food allergy, to ask about their child's
41 physical and psychosocial functioning (11). 33% had asthma and atopic dermatitis,
42 13% atopic dermatitis alone and 21% had neither. The study group as a whole had
43 poor scores for general health perception, emotional impact on the parents and
44 limitation of family activities. Those families whose child had associated asthma and
45 atopic dermatitis scored worse for general health perception, but these co-morbidities
46 had no effects on emotional, behavioural and family cohesion aspects of a child's
47 QoL. Similarly Ganemo et al asked 78 Swedish children with eczema to complete
48 validated dermatitis QoL scales and a Dermatitis Family Impact Questionnaire and
49 found higher scores on family impact for those with food allergy or intolerance in
50 addition to their eczema(39).
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3 Marklund et al investigated parental reported health-related QoL of school age food
4 hypersensitive children (29). They also found that co-existing atopic diseases were a
5 significant factor contributing towards lower levels of physical health QoL, and that
6 this correlated with the number of co-existing diseases. This is interesting, as
7 physical functioning dimensions were not reduced in those suffering from food
8 allergy alone (29). Marklund's study supported Sicherer's finding that co-existent
9 atopic eczema and asthma combined had the largest impact on general health related
10 QoL. They additionally found that areas of physical functioning, social timetables,
11 bodily pain and general health were all affected by coexisting atopic disease (29).
12 This is presumably because other allergic conditions such as asthma and hay fever are
13 largely physical diseases with somatic symptoms. The number of co-existent allergic
14 diseases also correlated with lower parental QoL in terms of time and emotional
15 impact, and increased disruption to family activities. However, parents considered
16 their child's psychosocial QoL, including emotional impact, general behaviour, self
17 esteem and mental health, to be affected by their food allergy, but not by the co-
18 existent allergic conditions. The reasons behind this were unclear. Coexisting
19 asthma, especially if poorly controlled, forms a risk factor for fatal allergic reactions
20 to food (22;40;41). Severe rhinitis is also associated with an increased risk of severe
21 pharyngeal oedema, severe asthma with an increased risk of bronchospasm, and
22 severe eczema with a risk of unconsciousness (42). However, as discussed by
23 Marklund et al, it is probably simply the physical impact of other atopic conditions
24 which are impeding QoL, rather than their potential risk of a more serious reaction.
25 Perhaps further qualitative work could investigate these issues in parents in more
26 detail.
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48 The higher the number of food allergies a child has, the higher the impact and the
49 lower their perceived overall health related QoL (11;15). There is also a greater
50 impact on family activities (29). The specific food to which a child is allergic has
51 been reported to have no relation to the impact of an allergy on QoL (15). This is
52 despite certain foods, for example peanuts, being particularly likely to cause severe
53 and even fatal reactions, whilst others such as milk are particularly difficult to avoid
54 for young children. However, much of the current research has focused on nut and
55 peanut allergy. The impact on QoL of a broader spectrum of allergenic food types is
56 needed.
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Effect of severity and symptoms on quality of life

Food induced allergic reactions can elicit a number of different symptoms. Marklund et al found that parents of children who experience gastrointestinal symptoms as a result of allergen exposure, report a higher emotional impact than for other reported symptoms (29). This is of importance as there are almost no medications available for gastrointestinal symptoms. Parents also perceived their food hypersensitive child to have lower physical functioning if they suffered from allergen induced breathing difficulties (29). Interestingly however, parents of children who reacted to food with severe symptoms including breathing difficulties and anaphylaxis reported better psychosocial wellbeing of their children. They also reported significantly higher family cohesion compared with those with other food induced symptoms. Perhaps the children and parents use greater cooperation and communication to develop strategies for coping with their food hypersensitivity, involving other family members in the process; or perhaps this group of patients receives better medical support. These findings are interesting as largely benign gastrointestinal symptoms have as much of a significant impact on QoL as breathing symptoms, which are potentially life threatening. Further research into this area is required to elucidate the reasons for these research findings.

Impact of food allergy on quality of life of caregivers

Caregivers for people with chronic conditions are known to suffer from greater psychological distress and poorer quality of life(43-46). This has also been reported in family members of children with food hypersensitivity. Mandell et al found that all members of an allergic child's family are significantly affected by restrictions put in place due to their child's allergy (17). In some cases it was observed that siblings avoided the allergenic food themselves (17). In some families, all members followed the allergy restricted diet, and therefore in terms of food limitations all family members are similarly affected when compared with the allergic patient (23). Marklund et al(29) reported on the parent's perception of the impact of food hypersensitivity in school children. Parents of more than one child with food allergy and those with children with a higher number of allergic diseases had lower parental health related QoL and more disruption to family activities.

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In the first study to directly assess QoL using validated measures in both parents of a peanut allergic child, King et al found mothers reported greater impact on psychological and physical QoL than fathers(9). However both mothers and fathers reported significantly better QoL than the UK norm means for almost all QoL subscales. It is possible that the generic nature of the QoL scale used meant that it was not sensitive enough to the specific aspects of QoL that are affected by having a child with food allergy. However the results are encouraging in that they support the idea that general QoL is not unduly affected by looking after a food allergic child. More interesting are the differences reported between mother and father, which may be due to mothers bearing more of the burden of responsibility than fathers in looking after the food allergic child.

Mothers often have the primary responsibility over their child's food allergy, whilst fathers help rather than share the responsibilities (17). Lack of support from spouses can increase the stress of living with a child's food allergy, and in many families it is largely due to a mother's efforts that the child can participate in normal activities (38). Mothers often feel alone and unsupported in the responsibility they undertake for their child's food allergy in terms of safety and trying to maintain an adequate QoL (17). Lack of cooperation among family members can create tension which may lead to breakdowns in support systems and has the potential to seriously damage relationships (17). Positively, food allergy in a child can promote greater family cohesion (11;15). Family support is obviously an important factor when looking after a child with a chronic condition. It may also help the parent to adjust and cope with the emotional and physical aspects of having a child with food allergy(47). Social support is extremely important in a number of health outcomes and has been shown to act as a buffer against stress, depression and anxiety(48;49). An important area of future study would be to assess the degree of social and familial support and its impact on the caregivers of children with food hypersensitivity.

A small number of studies have looked at the siblings of food allergic children. Marklund et al reported that food allergic children with a food allergic sibling are more likely to have a lower psychosocial QoL than those without food allergic siblings (29). This is significant because it is common for food allergies to co-exist in siblings. However research looking at the impact on a healthy sibling found that they

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3 reported better physical health-related QoL, QoL within school and overall QoL than
4 the norm means(9). There were no ratings of QoL that were significantly worse than
5 their peanut allergic sibling. More research on siblings of food hypersensitive
6 children is clearly needed. At present there are no validated scales to measure the
7 impact of having a food allergic sibling on QoL and generic health related QoL scales
8 may not be sensitive enough to measure the important factors. More qualitative work
9 using interviews or focus groups with siblings may reveal richer data with which to
10 explore these issues.
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19 **Burden of responsibility**

20 The burden of responsibility that food allergy exerts upon individuals and their
21 families can have a significant influence on QoL. Primeau et al found that peanut
22 allergy is a condition which forces parents to exert extreme dietary vigilance and face
23 continuous uncertainty over the possibility of accidental exposures (14). Avoidance
24 of food allergens requires constant alertness, and is complicated as the presence of
25 allergens is not always obvious. 60% of participants in a study of community allergic
26 reactions to foods, were aware that they had a food allergy, yet over 50% were
27 unaware that the food they were consuming contained the allergen (24). This reflects
28 the difficulties associated with total allergen avoidance, and the burden taken on by
29 those who see themselves as responsible for that avoidance.
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40 Marklund et al found that in terms of adolescent food allergy it is the measures to
41 avoid allergens, as well as the actual allergic reactions, which negatively impacts on
42 QoL (32). This suggests that adolescents experience a burden of responsibility which
43 negatively impacts upon their lives. Others have highlighted the fact that constant
44 vigilance can be a source of stress (23). Children with peanut allergy perceive a
45 higher risk than children with diabetes, with 85% of peanut allergic children
46 compared with 50% of diabetic children reporting the need for constant care regarding
47 the food they ate (8). This shows that it is not only parents and adults who bear the
48 burden of responsibility but children also. Interestingly a literature review by
49 Feuillet-Dassonval et al concluded that the benefits of strict avoidance-diets are
50 limited, as reactions to low doses of allergen are rare and often minimal (50). They
51 suggested that avoidance should be limited to the non-hidden allergen or adapted to
52 the dose which is known to elicit a reaction.
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5 As well as avoiding exposure to allergens, individuals also need to be prepared to
6 respond to unexpected reactions. Burden seems to be related to this element of living
7 with risk that is associated with food allergy. Gillespie et al interviewed mothers
8 caring for food allergic children aged 6-12 years (38). The feeling of 'living with
9 risk' was predominant. Risks were said to evolve from different people and
10 environments as well as foods and experiences. Once mothers understood the risks,
11 they described an emerging feeling of 'living with fear'. This was described as
12 including fear for risk to life, fear following diagnosis, fear for the present and future,
13 and fear as their child's world develops. The element of living with risk differs in its
14 severity between families. Some mothers reported adapting to the risks of food
15 allergy, and incorporating it into their daily lives. However, others expressed massive
16 implications for their lifestyle (38).
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28 **Effect of food hypersensitivity on psychological distress**

29 Food hypersensitivity has been reported to be associated with psychological distress,
30 including anxiety, depression and stress in both the sufferer and the parents.
31 Sicherer et al found that parents of food allergic children reported stress, worry
32 distress and anxiety (11). King et al(9) also found that mothers of peanut allergic
33 children had higher levels of state and trait anxiety and stress than fathers, with the
34 trait anxiety and stress also being higher than norm means. Parents can be highly
35 anxious prior to diagnosis in their child. Knibb and Semper(51) reported that a third
36 of 124 parents of children attending allergy clinic to have their child tested for food
37 allergy had mild to severe levels of anxiety and almost a fifth had mild to moderate
38 levels of depression, with levels not reducing after the clinic visit.
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49 Food hypersensitivity can also have an effect on anxiety in the sufferer. Lyons et al
50 found that food allergy in adolescents was associated with increased anxiety levels
51 (10) and Avery et al reported that peanut allergic children expressed more anxieties
52 about eating and had higher levels of anxiety and fear associated with managing their
53 allergy than children with IDDM (8). Perhaps food allergic children are aware of the
54 immediate risk associated with accidental ingestion of allergen, whereas diabetic
55 children are less aware of long-term implications of their condition. In contrast, King
56 et al(9) asked children with peanut allergy and their siblings to complete a validated
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3 child anxiety scale and found that all anxiety scores were significantly lower than
4 published healthy age-related norms. This was possibly due to the norms coming
5 from a sample of children in a different country. The scale was also developed to
6 assess clinical levels of anxiety and so may not have been sensitive enough for food
7 allergy related anxiety. King et al however did find that children with peanut allergy
8 rated separation anxiety as significantly higher than their siblings and girls with
9 peanut allergy had greater anxiety over physical injury than boys with peanut allergy.
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17 Patten and Williams(52) investigated the association between food allergy and anxiety
18 and depression in a large cohort of people aged 15 years and over using diagnostic
19 interviews. Those with self-reported professionally diagnosed food allergy reported
20 significantly higher rates of major depression, bipolar disorder, panic disorder and
21 social phobia than those with no food allergy. Although this is the first paper to
22 report elevated levels of mental disorder using diagnostic interviews, it is cross-
23 sectional in nature and relies on self-report of food allergy and so results should be
24 treated with caution and causality can not be inferred. In a study of 18 to 22 year olds
25 Herbert and Dahlquist(18) found that only those who reported a history of
26 anaphylaxis reported more worry about their food allergy. There were no significant
27 differences in anxiety or depression in those with food allergy and those without.
28 However, online self-report measures were used in this study rather than clinical
29 interviews and the majority of participants were college students, which may have
30 resulted in a bias in the levels of distress reported.
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44 *Changes in distress over time*

45 A great deal of anxiety is experienced by patients and families around the time of
46 diagnosis of food allergy(14;51). Following diagnosis, parents and children will often
47 follow a period of psychosocial adjustment (17). Once parents understand the risks
48 associated with their child's food allergy, fear begins to emerge as a predominant
49 emotion (38). It is likely to be this fear which promotes patients and parents to
50 develop coping strategies to manage allergy and minimize risk. The majority of
51 mothers with food allergic children state that in time, they learn to adjust to living
52 with food allergy, gaining confidence and control and losing some elements of fear.
53 Mothers often stated that they work hard to achieve a normal life for their food
54 allergic child, and that once management is established, they no longer found it hard
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3 on a daily basis (38). This suggests that the longer the duration since food allergy
4 diagnosis, the lower the impact upon QoL and psychological distress. It has also been
5 shown that anaphylactic reaction free periods also result in a decrease in anxiety
6 levels (17). However new situations, including parties or school trips, can cause fear
7 and anxiety in relation to food allergy, to resurface at higher levels (38). In some
8 cases overprotective parenting has been reported by young adults with food allergy
9 who have a history of anaphylaxis(18).
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17 Mandell et al has described how normal development throughout childhood itself
18 poses a cause for variation in anxiety levels of both allergic children and their parents
19 (17). Most anxiety is observed between the ages of 6-11 years when children are able
20 to begin comprehending their allergy, but their level of ability to self-protect against
21 exposure remains inadequate. This age range in children also involves a development
22 of independence and poses circumstances of less supervision, which also act to
23 promote higher anxiety levels. The period of starting school is also a concern for
24 parents. Mothers often find it difficult to completely relax when their children are
25 attending school, away from their supervision (38). As children grow into teenagers,
26 parents have reported anxiety in handing over the responsibility to their child for their
27 risk assessment, avoidance strategies and management of their food allergy and it is
28 suggested there is a risk that they may transfer their anxieties to their children (36).
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41 *Mechanisms for the link between psychological distress and food allergy*

42 In a review of the literature on allergies and anxiety in children and adolescents
43 Friedman and Morris(53) put forward cognitive behavioural and biological
44 explanations for the link between anxiety and food allergy. The role of learning and
45 parental modeling of anxious behaviour to activities such as administering emergency
46 treatment can lead to increased anxiety in the child. Alternatively greater sympathetic
47 or autonomic nervous system activity, or a genetic link between anxiety and allergic
48 disorders could be responsible. However the authors point out that at present the
49 theories have little empirical support and do not offer a causal explanation, instead
50 suggesting there may be a bidirectional effect and biological and environmental
51 factors may influence each other.
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There is also debate as to whether or not anxiety could be perceived as beneficial.

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4 Avery et al suggested that the high levels of anxiety experienced by food allergic
5 children, although impacting adversely upon QoL, could be interpreted as protective
6 if it encourages them to comply with adequate avoidance measures and management
7 plans (8). Mandell et al supported this theory, stating that appropriate levels of
8 anxiety can be constructive in enabling families to manage the allergy (17). They
9 found that anxiety motivated parents to gain information and support regarding
10 allergy management. Lower levels of anxiety were accompanied by decreased
11 vigilance and preparedness for potential reactions, suggesting that a certain level of
12 anxiety is mandatory for adequate management (17). However, high levels of anxiety
13 may be maladaptive, for example, if it places unrealistic restrictions on an individual's
14 life (8).
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25 It is clear that the mechanisms involved need further investigation, utilizing
26 longitudinal methodology in order to explore how food hypersensitivity impacts on
27 psychological distress and in turn how such distress affects management of food
28 hypersensitivity and future health, not just in the patient but also in the carer.
29 Prolonged stress and anxiety and depression have been shown to impact on other
30 areas of health(54;55). Strategies to reduce psychological distress in those suffering
31 from or caring for those with food hypersensitivity also need to be put into place and
32 properly evaluated.
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41 **Summary and conclusions**

42 It is evident that food allergy has a profound psychosocial impact on children,
43 adolescents, and their families. **In particular the constant vigilance needed to avoid
44 allergens and the daily management of food allergy impacts on daily family activities
45 and social events. Food allergy also appears to have a considerable detrimental affect
46 on certain aspects of quality of life such as emotional quality of life, physical
47 functioning and quality of school life. Certain subgroups of patients and care-givers
48 seem to be most affected. Females with food allergy, those with a larger number of
49 food allergies or a larger number of previous reactions and those with coexisting
50 atopic diseases report poorer quality of life. Parents of younger children report a
51 more negative impact on family activities, whilst adolescents are clearly at greater
52 risk of adverse reactions as their autonomy develops. The psychosocial well being of
53 mothers of children with food allergy also seems to be particularly affected.**
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5 There have been no intervention programmes to indicate how we can alleviate the
6 burdens for food allergic children or their families, however the studies discussed in
7 this review enable us to speculate strategies that may be beneficial. Extreme dietary
8 vigilance is often necessary for children with food allergies, and this itself imparts a
9 burden on the food allergic family. Patients can be reassured that by adhering to
10 management plans accidental reactions are uncommon and are usually mild(56).
11 Educating children and families to understand the relative risks of their allergy and
12 providing them with communication skills through role play (e.g., being offered
13 sweets, ordering in restaurants) should relieve the burden by empowering the children
14 and their parents. Food allergy is unusual in that the child has a chronic condition but
15 remains well with the potential to become acutely very sick. There is a need to
16 educate the wider community including educators, the wider family and friends to
17 understand the constant need for vigilance, with potential need for emergency
18 treatment, whilst striving to maintain a normal home, school and social life. Training
19 of school personnel and management plans for use in school may help to reduce
20 parental anxieties. Labelling of allergens continues to cause frustration and confusion
21 to food allergic consumers. The food industry and its regulators need to continue
22 seeking a solution which provides safe information whilst avoiding unnecessary
23 precautionary labels.
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40 To date, interpretation of, and comparisons between studies investigating
41 psychological outcomes in children with food allergies has been limited by lack of
42 appropriate study tools, questioning of parents rather than children, and of poor
43 phenotyping of the allergic disorder. Current literature has shown that assessing the
44 psychosocial impact of food allergy can be difficult. In order to rectify this food
45 allergy-specific QoL instruments for children, adolescents and adults have recently
46 been developed and validated(57), and it is anticipated that this will facilitate an
47 expansion of research in the field. The Food Allergy QoL Parental Burden
48 questionnaire (FAQL-PB) measures the parental burden associated with having a food
49 allergic child (58). More recently instruments have been developed and validated to
50 allow parents to report on QoL in the child from the child's perspective (59), and for
51 children and teenagers to report on their own QoL(60;61).
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3 The number of studies looking at the impact of food allergy has increased within the
4 last few years and this recent development of validated, food allergy-specific tools for
5 studying QoL in children and adolescents should facilitate further research. Studies
6 will need to distinguish between IgE mediated food allergy and other types of adverse
7 food reactions and future studies need to question the child in addition to obtaining
8 parental perceptions. The effective management of food allergy in terms of
9 optimizing a patient's and family's QoL, is currently restricted by the availability of
10 good quality information. Therefore, further data is required in order to achieve an
11 optimum standard of management, which itself can influence and improve QoL and
12 reduce the psychological distress felt by all.
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Table 1. Summary of studies investigating quality of life in food allergic children and adolescents (QoL= quality of life; y= years; IDDM= insulin dependent diabetes; IBD=Inflammatory Bowel Disease)

Author	Country	Study population	Study methods	Study aim	Result
Akeson et al., 2007	Scotland	7 adolescences 13-16y, and their parents. Self-report of physician diagnosed anaphylaxis.	In depth interview.	Explore the psychosocial impact of living with anaphylaxis on adolescents and their parents; their management of the condition; and perceptions of health care provision.	Most adolescents could not remember a severe reaction (parents had vivid recall), and reported less impact on life than parents reported. Parental anxieties included handing responsibility to child.
Avery et al., 2003	England	Children (7-12y), 20 peanut allergic and 20 IDDM children. Diagnosed in specialist clinics.	Researcher designed questionnaires; cameras to record impact of allergy/ IDDM on QoL over 24hours.	Compare QoL between patients with peanut allergy and IDDM.	Allergic children had more fear of adverse events, more anxiety about eating than diabetic children.
Bollinger et al., 2006	USA	Caregivers of food allergic children from 87 families. Food allergy diagnosed in specialist allergy clinic.	Questionnaire to evaluated effect of food allergy on family activities.	Impact of food allergy on the daily activities of food allergic children and their families.	Significant effect on daily family life e.g. meal preparation and family social activities.
Calsbeek et al., 2002	The Netherlands	758 adolescents and young adults (12-25y) with chronic digestive disorders including IBD and coeliac disease, chronic liver disease. 98 had food allergy. Population based control group (n=306).	Postal self-report questionnaire to measure friendships, partners, leisure activities, education, financial situation.	Investigate consequences of having a chronic digestive disorder (including food allergy) on the social position of adolescents.	Food allergic group had higher rate of absence from school compared to controls but social position was less affected than those with IBD or liver disease.
Calsbeek et al., 2006	The Netherlands	758 adolescents and young adults (12-25y) with chronic digestive disorders including IBD and coeliac disease, chronic liver disease. 98 had food allergy. Population based control group (n=306).	Postal self-report questionnaire to measure burden of disease such as physical complaints, hospitalisation, use of medication and school and leisure activities, going out and friendships. Hospital Anxiety and Depression Scale (HADS).	Describe the nature of the burden of disease in those with chronic digestive disorders (including food allergy). Determine whether burden of disease is associated with difficulties in school and leisure activities.	Food allergy group experienced a greater burden of disease compared to the control group, particularly for physical complaints.
Calsbeek et al., 2006	The Netherlands	622 young adults (15-24y) with chronic digestive disorders including IBD, coeliac disease, chronic liver disease. 77 had food allergy. Population based control group and national statistics.	Postal self-report questionnaire to measure burden of disease such as physical complaints, hospitalisation, use of medication. Labour participation was measured by number of hours employed per week. Hospital Anxiety and Depression Scale (HADS).	To compare disease burden and employment status in young adults with chronic digestive disorders (including food allergy) with healthy controls.	Food allergy group experienced a greater disease burden compared to control group and a higher percentage of those with food allergy, IBD and chronic liver disease did not participate in the labour market.
Cummings et al. 2009	England	41 peanut and nut allergic children, and their mothers. Diagnosed in specialist clinic.	Postal questionnaire to assess maternal and children's QoL (PedsQLTM, WHOQOL-BREF, FAQL-PB), anxiety (SCAS, STAI) and perceived stress scale (PSS). Children also completed a nut allergy specific QoL questionnaire.	To investigate the impact of nut allergy on QoL and anxiety in mothers and children with nut allergy in order to identify management strategies that may influence these factors.	Mother and child reported lower anxiety when the child was prescribed an epinephrine auto-injector. Anxiety was not associated with whether the child carried the auto-injector or whether they strictly avoided traces of nuts in foods.
Gillespie et al., 2007	Canada	6 mothers of 6-12 year olds considered at risk of anaphylaxis and carrying adrenaline. Risk diagnosed by private clinic allergist or parent was member of support group.	Semi structured interviews.	Understand the mother's experience of parenting a child at risk of anaphylaxis.	The feeling of 'living with risk' was predominant. Risks were said to evolve from different people and environments as well as foods and experiences. Once mothers understood the risks, they described an emerging feeling of 'living with fear' including fear for risk to life, fear following diagnosis, fear for the present and future, and fear as their child's world develops.
King et al., 2009	England	46 families with a child with peanut allergy, which included mother, father and an older sibling all with no history of food allergy.	Self-report validated scales to measure quality of life, (Peds-QL; WHOQOL-BREF), anxiety (SCAS, STAI), stress (PSS) and study specific questionnaire.	Establish impact of peanut allergy on quality of life, anxiety and stress in children with peanut allergy, their parents and siblings.	Mothers had worse psychological and physical QoL and higher anxiety and stress than fathers. Children with peanut allergy had poorer QoL than siblings. Mothers rated greater impact on QoL for their allergic child than the child rated themselves.
Lyons &	England	162 adolescences (15-20y) attending	Study specific questionnaires, State Trait	To measure differences in	Those with allergy reported their allergy has less

1	Forde, 2004		a university psychology open day. 24 (15%) had self reported food allergy.	Anxiety Inventory (STA) and Perceived Health Competence Scale (Smith 1995).	awareness and perceptions of food allergy and anxiety between young people with and without food allergy.	impact on their lives than others believed it would. Those with perceived allergy and high health competence reported greatest anxiety levels.
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3	Mandell et al., 2005	Canada	Parents of 17 children with peanut allergy and anaphylaxis.	Qualitative semi-structured interviews to investigate experiences adjusting to diagnosis of anaphylaxis and life thereafter, and sources of information and support.	Investigate the experience and needs of families coping with life-threatening allergies in a child	Lack of information at diagnosis increases anxiety and uncertainty in how to manage risk and safety for their child. Mothers felt inadequately supported in bearing the responsibility for their child. Potential interventions recommended.
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7	Marklund et al., 2004	Sweden	1488 adolescents (13-21y), 271 (19%) with self reported food hypersensitivity.	Study specific questionnaire and generic health related QoL questionnaire (SF-36).	Investigate effect of allergies, particularly food, on QoL in adolescents.	Perceived food hypersensitivity was associated with poor health related QOL, whether or not the diagnosis was made by a physician. Females reported more food hypersensitivity and lower QoL than males.
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10	Marklund et al., 2006	Sweden	134 parents of 8-19 year olds with parent-reported food hypersensitivity.	Generic health related QoL (child and family) questionnaire (CHQ-PF28) and study specific questionnaire relating to food hypersensitivity .	Investigate parent-reported health related QoL in families of children considered to be food hypersensitive	Worse physical health related QoL was associated with coexisting atopic diseases. Boys were perceived to have lower physical QoL than girls.
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13	Marklund et al., 2007	Sweden	17 adolescents (14-18y) with exclusion diets at school for food hypersensitivity (not necessarily under medical supervision).	Focus groups.	Investigate the experiences of being a food-hypersensitive adolescent.	Adolescents strive to normalise their experiences and tone down negative experiences. Some expressed insecurity and frustration.
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16	Ostblom et al., 2008	Sweden	Parents of 1378 children aged 9y from a population based birth cohort; 212 children had food hypersensitivity.	Generic health questionnaire (CHQ-PF28) and disease specific questions	Investigate impact of food hypersensitivity on health-related QoL in children.	Children with food hypersensitivity had lower scores for physical functioning and role/social limitations than those without. Children with food-related lower airways symptoms had lower scores for self-esteem, family cohesion and parental impact of time.
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20	Primeau et al., 2000	Canada	153 peanut allergic children (<18y), 37 peanut allergic adults (18-45y). 76% diagnosed by specialist allergy clinics. Remainder recruited from support organisation and media. Compared to group with rheumatological disease.	Visual analogue scale adapted from European QoL questionnaire (EuroQoL-5D); Impact on Family questionnaire (IFQ); Child Health Questionnaire (CHQ) or generic health questionnaire (SF-36); asthma severity questionnaire; study questionnaire for food allergy details.	Compare QoL and family relations of adults and children with food allergy and people with rheumatological disease.	For children with food allergy there was more disruption of daily activities and impairment in the familial-social dimension of IFQ compared to children with rheumatological disease. Adults with rheumatological disease reported more family disruption than adults with peanut allergy.
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26	Sicherer et al., 2001	USA	253 parents of food hypersensitive children (5-18y) belonging to Food Allergy and Anaphylaxis Network with self reported allergy (96% under specialist allergy care) compared to population norms.	Children's Generic Health Questionnaire (CHQ-PF50) and study specific allergy related questionnaire.	Investigate parental perception of health related QOL in food hypersensitive children.	Scores were worse in study cohort than norms for general health perception, parental distress and worry, and interruptions and limitations in usual family activities.
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