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Authors	Stensgaard, A.;Bindslev-Jensen, Carsten;Nielsen, D.;Munch, M.;Dunn Galvin, Audrey
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Quality of life in childhood, adolescence and adult food allergy

- Patient and parent perspectives

A. Stensgaard[1], C. Bindslev-Jensen[1], D. Nielsen[2], M. Munch[3], A. DunnGalvin[4]

[1]Odense Research Center for Anaphylaxis (ORCA), Department of Dermatology and Allergy Center, Odense University Hospital, Odense C, Denmark

[2]Migrant Health Clinic, Odense University Hospital, Odense C, Denmark

[3]Research Unit of General practice, Department of Public Health, University of Southern Denmark

[4]School of Applied Psychology, University College Cork, Ireland

Correspondence:

Anette Stensgaard, Odense Research Center for Anaphylaxis (ORCA), Department of Dermatology and Allergy Center, Odense University Hospital, Odense C, Denmark

Anette.stensgaard@rsyd.dk

Abstract

Background: Studies of children with food allergy typically only include the mother, and have not investigated the relationship between the amount of allergen needed to elicit a clinical reaction (threshold) and health-related quality of life (HRQL). Our aims were 1) to compare self-reported and parent-reported HRQL in different age groups, 2) to evaluate the impact of severity of allergic reaction and threshold on HRQL, and 3) to investigate factors associated with patient-reported and parent-reported HRQL.

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Methods: Age-appropriate Food Allergy Quality of Life Questionnaires (FAQLQ) were completed by 73 children, 49 adolescents, and 29 adults with peanut, hazelnut or egg allergy. Parents (197 mothers, 120 fathers) assessed their child's HRQL using the FAQLQ-Parent form. Clinical data and threshold values were obtained from a hospital database. Significant factors for HRQL were investigated using univariate and multivariate regression.

Results: Female patients reported greater impact of food allergy on HRQL than males did. Egg and hazelnut thresholds did not affect HRQL, but lower peanut threshold was associated with worse HRQL. Both parents scored their child's HRQL better than the child's own assessment, but whereas mother-reported HRQL was significantly affected by limitations in the child's social life, father-reported HRQL was affected by limitations in the family's social life. Severity of allergic reaction did not contribute significantly to HRQL.

Conclusion: The risk of accidental allergen ingestion and limitations in social life are associated with worse HRQL. Fathers provide a unique perspective and should have a greater opportunity to contribute to food allergy research.

Keywords: Adolescent, Adult, Child, Food allergy, Quality of life

Introduction

Food allergy affects the health-related quality of life (HRQL) of both the allergic person and their family, and stress and anxiety have been reported in families living with the risk of anaphylaxis (1, 2). Several instruments have been developed and validated for measuring HRQL in all ages, and show that food allergy has a high psychosocial impact on children, adolescents, adults and their families (3-10). In most studies where parents have reported HRQL on their child's behalf, typically only the mother has participated in the research. The father's perspective has not usually been taken into account, and this may be a limitation in the comprehensiveness of the findings. Only two studies were found involving fathers (11, 12) and in these studies fathers reported lesser impact on their quality of life than the mothers.

The success of allergen avoidance when eating outside the home or shopping for food depends on the individual's way of managing the allergy. The availability and quality of information as well as the clarity of food allergen labeling are key factors in the management of food allergy. Food labeling is often misleading (13), however, and other major obstacles to successful coping are a lack of public understanding, unwillingness to accommodate the needs of those with food allergy, and even hostility. This lack of understanding extends to restaurant staff, school personnel, family, friends, and other social groups (1, 14).

As there is no cure for food allergy, the condition must be managed on a daily basis and the family has a central role in ensuring safety and minimizing risk. For example, carrying the Epinephrine auto-injector is a vital tool in keeping the child safe and it is the parent who takes this responsibility for younger children. Later on, it is the responsibility of the teenager and the young adult to ensure that the auto-injector is always available (15-18).

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Two separate, but connected, parameters determine an individual's level of overall risk if an allergen is ingested, accidentally or otherwise. These are the severity of the allergic reaction elicited by ingestion of the offending food, and the amount of food necessary to elicit a reaction (the threshold). Several algorithms for assessment of severity have been developed (19), the most widely used being the 5-point scale by Sampson (20). Patient cohorts demonstrate a large variability in threshold, which may vary from milligram to gram of the offending food (21).

A direct correlation between the severity of the allergic reaction experienced by a patient and the impact on HRQL seems logical. Patients with a low threshold and thereby a higher risk from accidental intake could also be expected to have worse HRQL. It is possible, however, that the avoidance necessary to ensure safety may have a stronger impact on HRQL than the severity of the allergic reaction itself. To date, the relationship between the amount of allergen needed to elicit a clinical reaction (the threshold) and its influence on HRQL has not been reported.

The aims of this study were 1) to compare self-reported and parent-reported (mother and father separately) HRQL in different patient age groups, 2) to evaluate the impact of the severity of the allergic reaction and threshold on patient HRQL, and 3) to investigate factors associated with patient HRQL, taking gender, age and parent perspective (mother/father) into account.

Methods

Participants

From the database of the Allergy Center at Odense University Hospital, we identified 386 Danish children, adolescents and adults with ongoing food allergy to peanut, egg or hazelnut diagnosed in accordance with the European Academy of Allergy and Clinical Immunology (EAACI) guidelines (21-24).

Data extracted from the hospital database included case history, skin test results, specific IgE, threshold and severity of reaction to food challenge. All patient participants had undergone previous challenge to confirm allergy, and had previous serum IgE and skin tests.

In May to December 2013, patients and their parents were invited by letter to participate in the study. The patients completed either the FAQLQ CF/TF/AF, except for children aged 0-7 years. The parents completed the FAQLQ-PF, regardless of patient age.

For the purpose of this paper we refer to children, adolescents, adults as "patients" to distinguish them from their mothers and fathers.

The study was evaluated by the regional ethics committee, and was accepted without formal review.

Measures

We used age-appropriate forms of the Food Allergy Quality of Life Questionnaires (FAQLQ) to measure health-related quality of life of people with food allergy, and the Food Allergy Independent Measure (FAIM) to evaluate the participants' perceived chance of accidental exposure to allergens and perception of disease severity. The FAQLQs have been widely validated and are recommended by the European Academy of Allergy and Clinical Immunology (25).

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For HRQL, children aged 8-12 years completed the 24-item Child Form (FAQLQ-CF) (26), adolescents aged 13-17 years completed the 23-item Teenage Form (FAQLQ-TF) (27), and adult patients aged 18 years and above completed the 29-item Adult Form (FAQLQ-AF) (28). Parents completed the FAQLQ-PF (29) on their child's behalf; this contains 14 items (0-3yrs), 25 items (4-6yrs) or 30 items (7-12yrs). The mother and father were asked to complete the questionnaire independently. If the child was aged 13 years or over, 'high school' or 'university' replaced 'school', and 'my daughter' or 'my son' replaced 'my child'. FAQLQ items were scored on a 7-point scale with 1 as the best possible score.

We chose to use the FAQLQ-PF for parents of children older than 12 years even though it has not yet been validated in that age group, as we wanted to compare parental responses for children of all ages. We adjusted the FAQLQ-PF version for use by parents of children over 12 years or young adults by replacing the term 'school' by 'high school/university' and replacing 'my child' by 'my daughter/ son'. The revised version was pilot-tested with five mothers and five fathers to ensure that it was appropriate for use for older patients.

The FAIM consists of six questions in total (30). Four questions deal with the perceived chance of accidental exposure to allergens and the likelihood of severe reaction, i.e. How great do you think the chance is that you: 1) Will accidentally eat something to which you are allergic? 2) Will have a severe reaction if you accidentally eat something to which you are allergic? 3) Will die if you accidentally eat something to which you are allergic? 4) Cannot effectively deal with an allergic reaction should you accidentally eat something to which you are allergic? Each of these exposure questions was scored on a scale from 1 (0% chance) to 7 (100% chance)

Two questions reflect disease severity and ask 5) 'How many foods must you avoid because of your food allergy? (7 options from None to Almost all) and 6) 'How great is the impact of your food allergy on your social life? (7 options from Negligently small to Extremely great).

We considered these two question types to provide different information and thus analyzed them separately. Patients aged 8-12 years completed the FAIM-CF (slightly easier wording), those aged 13-17 years completed the FAIM-TF, and those aged 18+ completed the FAIM-AF. Parents completed the FAIM-PF and answered slightly altered questions but using the same response options: 'What chance do you think your child has of….?' and 'What chance does your child think he/she has of…?' (30). Regarding the two severity questions, parents reported on the number of foods avoided by the child (4 categories of 0-2, 3-6, 7-10 and 10+) and their opinion of how much food allergy limited the types of activities that the family could do and that the child could take part in (5 options from None at all to A lot).

After completing the FAQLQ and FAIM, parents were asked about the impact of their child's food allergy on i) the parents' own general health (7 options from Excellent to Very poor) and emotional wellbeing (5 options from None at all to A lot), and ii) on their child's general health and emotional wellbeing. Then they rated their level of stress due to their child's food allergy - for themselves, for their partner (if relevant) and for their family (5 options from None at all to A lot).

Regarding knowledge and use of the auto-injector, adolescent and adult patients were asked i) whether they had been issued with an auto-injector, and if that gave reassurance or caused anxiety, and ii) if they had ever experienced an anaphylactic reaction. Parents were also asked i) whether

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their child had been issued with an auto-injector and if that had given the child reassurance or caused them anxiety, and ii) if their child had ever experienced an anaphylactic reaction.

Two criteria were used to determine severity of symptoms:

1) The self-report FAQLQ question 10, in which the respondent (patient aged 13+ or parent) indicated which of 30 possible symptoms listed they (or their child) had experienced as part of a food allergy reaction (outside of hospital). Parents' reports were used for children under 13 years old. A clinician graded these responses using Sampson's severity score from 1 (mild) to 5 (severe) (20). If there was a disparity between the mother's and father's answers, the higher symptom severity score was used.

2) The results of the food challenge at the Allergy Center, where symptoms were graded by a clinician, also according to Sampson's severity score from 1 (mild) to 5 (severe)(20).

Threshold values for peanut, hazelnut and egg were extracted from the Allergy Center database and plotted against self-reported HRQL.

The FAQLQ and FAIM questionnaires were translated from English into Danish and validated using established guidelines (31). They were then pilot-tested by parents and patients in each age group. The web-based Danish versions of FAQLQ and the FAIM were created using the web-based tool SurveyXact. Patients and their parents were invited to participate by a letter containing a code to access their specific questionnaires and a link to the homepage www.datafabrikken.dk.

Statistical analysis

Statistical analysis was performed using STATA version 14.0. Total scores and domain scores were calculated for all versions of FAQLQ.

To investigate the construct validity of the FAQLQ, we used the Pearso**n** product-moment correlation coefficient to compare the FAQLQ and FAIM answers. We expected low to moderate relationships between the questionnaires for each age group, as the FAQLQ and FAIM measure different (though related) constructs, as the FAIM is not a quality of life measure but examines perception of outcome after accidental ingestion of an allergen.

Univariate linear regression was used to identify variables that had a significant impact on HRQL, as a basis for developing multivariate models.

Three multivariate models were developed:

i) With patient HRQL as independent variable, we investigated the effect of gender, self-reported risk of accidental ingestion (i.e. FAIM question 1), number of products avoided (i.e. FAIM question 5) and limitation to social life (i.e. FAIM question 6), while controlling for age group and FAIM questions 2-4. Data on Sampson severity were not available for patients under 13 years old.

ii) With mother-reported patient HRQL as independent variable, we investigated the effect of child gender, self-reported risk of accidental ingestion (i.e. FAIM question 1), number of products avoided

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(i.e. FAIM question 5), limitation to social life for child and family (i.e. FAIM question 6), family stress and Sampson score, while controlling for child age, FAIM questions 2-4 and parent ethnicity.

iii) With father-reported patient HRQL as independent variable, we investigated the effect of the same factors as for mother-reported HRQL.

Effect size was assessed using the approach of Cohen, where 0.8 or above was considered a large effect size (32).

Results

Participant characteristics at baseline

In total, 67% of the 386 patients were represented either by their own self-completed HRQL measure (Table 1) and/or by parental-report HRQL on the child's behalf (Table 2). The response rate for self-reported HRQL was 55% of the 132 children aged 8-12, 60% of the 82 adolescents, and 54% of the 55 adults. Out of 744 parents to patients, 43% rated their child's HRQL: 120 fathers and 197 mothers, representing 123 male and 95 female patients (including the responses in the 0-7 year group). We excluded eight patients and 19 parents who had either out-grown their allergy or had incomplete responses.

Most patients (76%) had allergy to peanut, followed by nuts (55%) and egg (22%), Table 1. There was high agreement between patients and parents on self-reported allergy to peanut, egg and hazelnut and a positive food challenge for the allergen.

The majority (78%) of patients over 13 years of age reported their most severe reaction to be a grade 4 reaction (e.g. difficulty swallowing or breathing) and 15% reported grade 3 (e.g. throat tightness), while 40% reported never having had an anaphylactic reaction (Table 1). In comparison, 72% of parents reported their child's worst symptoms as a grade 4, and 21% as grade 3. In total, 36% parents reported time elapsed since anaphylaxis as more than 2 years, and 33% reported that their child had never had an anaphylactic reaction (Table 2).

74% of adolescents (n=36) and adults (n=22) reported that they had been issued with an auto-injector, and 5% (n=3) considered this to have caused them anxiety.

Parents of all age groups reported that 83% of their children (n=181) were issued with an auto-injector. While 6% (n=14) of children had at least one parent who considered that the auto-injector caused anxiety to themselves, 8% (n=18) thought the auto-injector caused their child anxiety. Anxiety related to the auto-injector was mainly reported by mothers (6% for mothers and 2% for fathers). Experience of an anaphylactic reaction in their child was reported by 64% of fathers and 61% of mothers.

Construct validity of the FAQLQ in Danish

Pearson's correlation coefficient showed positive correlations between FAQLQ and FAIM of 0.69 for CF, 0.59 for TF and 0.52 for AF. Correlations between FAQLQ-PF and FAIM were 0.37 for 0-12 years, 0.21 for 13-17 years and 0.57 for 18+years.

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Univariate linear regression: HRQL and age/gender/symptom severity

Average HRQL scores were similar in the three patient age groups (Table 3), but females reported significantly higher impact of food allergy on HRQL than males (p=0.02). Parent-reported HRQL (Table 4) showed significant differences according to the age of the child (p<0.001), where the older the child, the greater the estimated impact on HRQL. There was no significant difference in the mean child HRQL assessed by the mothers and fathers (p=0.42), and the gender of the child had no significant impact (p=0.07 mother; 0.5 father).

Previous experience of an anaphylactic reaction did not significantly influence patient HRQL as reported by the patients themselves (p=0.70) or their fathers (p=0.20), but was associated with a worse HRQL score from mothers (p=0.04).

Severity according to Sampson's rating scale was not a significant predictor of self-reported patient HRQL (>13 years). However, in mother reported HRQL, where a Sampson grade 4 or 5 (severe reaction) was experienced by the child, we found a significant adverse effect on HRQL compared to grade 2 (both p<0.001). When fathers reported HRQL for their child, we found a significant impact on HRQL for Sampson grade 4 compared to grade 2 (p=0.019). When comparing the mother's and father's responses for the same child, we found many cases where the Sampson severity score differed (Table 2). This was primarily for the middle severity levels. Self-reported symptom severity experienced at home was the same grade or worse than symptoms and signs elicited during a food challenge in the clinic.

For all respondent groups, there was significant correlation between the number of foods avoided and HRQL (p=0.01 for mothers, p<0.001 for fathers and p<0.001 for children). Parents reported significantly better HRQL for their food-allergic children than the children themselves reported (<0.001), while the mean HRQL scores from mothers (2.89) and fathers (2.87) were similar (p=0.42). Within the same family, it was equally likely to be the father or the mother who scored highest in relation to the impact of food allergy on HRQL.

Univariate linear regression: HRQL and social life/allergy threshold

Children, adolescents and adults who reported that food allergy had a 'high impact on their social life in general' also had worse HRQL (p=<0.001) (Table 5). Similarly, worse parental HRQL scores were related to greater restriction of family activities and child activities due to food allergy (p<0.001 and p<0.001, respectively). Worse parental HRQL scores were also associated with poorer parental health (p=0.05 mother/0.01 father) and poorer child health (p<0.001).

Higher levels of parent-reported worry about their child's physical and emotional well-being and higher patient- and parent-reported stress levels predicted worse HRQL (both p<0.001).

Mean FAQLQ scores plotted against the thresholds for each allergy (Figure 1) showed that the lower the threshold for peanut, the greater the negative impact on patient-reported HRQL (p=0.03), mother-reported HRQL (p<0.001) and father-reported HRQL (p=0.05). There were no significant correlations between HRQL score and thresholds for egg and hazelnut.

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Multivariate linear regression: **patient and parental HRQL**

All three models (Table 5) had large effect sizes. The included variables explained 67.5% of the total variance in self-reported patient HRQL, $F(8,142)=36.89, p<0.001$, $r=0.8$, with the strongest predictors being limitation in social life ($\beta=0.35$, $p<0.001$), FAIM question 1 (the chance of accidentally ingesting an allergen) ($\beta=0.33$, $p<0.001$) and the number of products avoided ($\beta=0.16$, $p=0.006$). Gender was not significant for patient HRQL.

The included variables explained 63% of the total variance in mother-reported HRQL, $F(14,182)=22.09$, $p<0.001$, $r=0.8$, with the strongest predictors being limitation in the child's social life ($\beta=0.45$, $p<0.001$), child gender ($\beta=0.31$, $p=0.008$), family stress ($\beta=0.28$, $p<0.001$) and FAIM question 1 ($\beta=0.12$, $p=0.04$). Number of products avoided, mother-reported severity and limitation in family social life had no significant impact on mother-reported HRQL.

The included variables explained 66% of the total variance in father-reported HRQL, $F(15,102)=13.47$, $p<0.001$, $r=0.8$, with the strongest predictors being family stress ($\beta=0.33$, $p<0.001$), FAIM question 1 ($\beta=0.28$, $p<0.001$) and limitation in family social life ($\beta=0.21$, $p=0.03$). Gender and limitation in the child's social life had no significant impact on father-reported HRQL.

Regarding effects on social life, we found a tendency for both parents to report food allergy to have an impact on both the family's and the child's social life (Table 5). Mother reported HRQL was significantly affected by limitations in child's social life ($p<0.001$), and this tendency was also seen in father reported HRQL ($p=0.095$). Father reported HRQL was significantly affected by limitations in family's social life ($p=0.037$), and this tendency was also seen in mother reported HRQL ($p=0.062$). Only mother reported HRQL was significantly affected by gender ($p=0.008$).

Discussion

While we know that food allergy negatively affects the HRQL of patients and their family, this is the first study to investigate patients of all ages within one study using questionnaires specifically developed for food allergies. We also asked both parents to assess their child's HRQL. In most previous studies on HRQL in food allergy, only one parent has been included, usually the mother. The parents in our study gave similar HRQL assessments to those given by their sons and daughters but mothers report greater impact on child's HRQL and have more anxiety and stress than fathers (11, 12, 33-35).

The multivariate models showed no significant differences in patient-reported HRQL by age, but female patients with food allergy had significantly lower HRQL than male patients, as seen in previous studies (33, 36, 37). Worse patient reported HRQL was also associated with a greater chance of accidental ingestion of an allergen, a higher number of food products avoided, and a more limited social life. Food is important for social interaction, and the need to be continuously alert when eating, especially outside the home, influences HRQL (13, 14).

While thresholds from food challenges to hazelnut and egg showed no association with HRQL, we found that the lower the threshold for peanut, the more adverse effect on HRQL. This is presumably related to the greater risks from accidental ingestion and the resulting higher stress levels. Another

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explanation could be that peanut allergy was more common than egg allergy, or that peanut allergy elicited more severe reactions than hazelnut or egg.

Our HRQL scores were mostly similar to those previously reported. Thus mean self-reported HRQL for our children aged 8-12 years was 3.9 compared to 4.0 in the Netherlands (38) and 3.7 in Switzerland (36). Mean HRQL for our adults was 3.6 compared to 3.2-5.0 in other European countries (39). However, mean HRQL for our adolescents of 3.4 was lower that than the 4.2 reported in the Netherlands (38).

The parents in our study scored their own children aged 0-12 years as having mean HRQL of 2.6, compared to scores of 2.7 in the Netherlands (35), 2.8 in Switzerland (36), and 3.6 in Ireland (40), suggesting that parents across Europe have similar perceptions of their children's HRQL. The child's gender did not influence the parent's assessment of reported HRQL, in line with previous reports (36).

We could thus see some interesting differences between parent and patient perceptions of the impact of food allergy. While female patients had worse self-reported HRQL than males, the parents gave similar HRQL assessments to their sons and daughters, although mothers reported that limitations in social life had a greater effect on daughters' HRQL than sons' HRQL. This finding may reflect greater impact on female than male children, previously reported (33, 36, 37). We also found no differences between the mothers' and fathers' assessments of the child, but that both parents scored the child's HRQL better than the child's own assessment, a finding also reported by Van der Velde (35, 41). Similar to our study, Wassenberg et al. found that parents scored the child's HRQL worse as the allergic child grew older (36).

Individuals with food allergy have been found to have poorer HRQL than the general population and individuals with diabetes, but better HRQL than patients with rheumatic arthritis, asthma, or irritable bowel syndrome (10). Although validated instruments were not used, it was shown that children with peanut allergy reported more impact on HRQL and more fear than children with insulin-dependent diabetes (9). Parents to children with peanut allergy reported significantly more disruption in daily activities and social problems compared to parents to children with rheumatologic disease (6), while another study reported that parents to children with food allergy had poorer health and more distress and worry than the general population (42).

We found good construct validity for the Danish version of the FAQLQ, demonstrating that it is suitable for use in a Danish population. The lower correlation for the FAQLQ-PF version with FAIM could reflect lower validity of this version, but may also reflect greater differences between parents' and children's responses, especially for younger children. Excellent internal consistency has previously been shown by a Cronbach's alpha of 0.96-0.97 for CF, TF, AF and PF (32).

The strengths of this study are the homogeneity of the study population, with recruitment based on confirmed IgE-mediated systemic food allergy, and the inclusion of patients of all age groups. We also investigated both mothers' and fathers' perspectives, and had an exceptionally high number of fathers participating compared to previous studies.

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A limitation of our study is possible information bias, where parents may have prompted their children to answer in particular ways, or that the parents' own fears and insecurities have affected their assessment of their child's HRQL. Furthermore, the FAQLQ-PF has not yet been validated for use by parents of children aged 13+, but these results are expected to be published in the near future. The FAQLQ was well accepted as a measure of HRQL in food allergy, and it would be useful to understand the relationship between severity and HRQL. Although the self-report information on symptoms experienced was subjective, a clinician used a validated reporting system to grade the severity of these symptoms in a clinical setting with informed participants. We found that many parents gave differing answers to presence of symptoms in the child, which resulted in a different Sampson severity grading. By taking the higher reported severity score, we may have overestimated symptom severity, and we are also relying on the ability of the Sampson grading system to discriminate between different levels of severity. Finally, we have pooled the patient HRQL scores from different questionnaires into one multivariate model. However, although these questionnaires were designed and validated for different age groups, they are closely related, and we have controlled for age group (and thus for the use of different questionnaires) in the model.

Our findings that the risk of accidental allergen ingestion and limitations in the child's or the family's social life are associated with worse HRQL have implications for clinical practice and research. These are daily challenges in the lives of families with food allergy, and appear to be a source of considerable concern and stress. Besides the patient's own assessment of HRQL, we need to take into account the perspective of each member of the family to obtain a more complete picture of living with food allergy. It is especially recommended that fathers be given the opportunity to contribute to studies involving their children.

In clinical practice, is it important to recognize that management of food allergy is a family project and that it will affect all family members. We have seen that parents can differ in their perceptions of their child's allergy and its impact on everyday life. And that the child's responses can be different to those of the parents. Therefore, both the mother and father should be routinely invited to accompany the patient to the clinic and be able to ask questions (with the patient's acceptance). Health professionals should acknowledge the expertise of patients and their families in managing health problems, by asking about routines at home and enquiring into experiences about disease and illness.

A more inclusive research design, perhaps also involving siblings and close friends of the child with food allergy, could be useful in providing a better understanding of food allergy along the developmental pathway and a more valid communication tool for use in clinical practice. A greater focus on the safe and risky situations in everyday life could help to improve management of food allergy, and thus also the health and well-being of the patient and family.

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Conflicts of interest
The authors declare no conflict of interests in relation to this study.

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Table 1. Descriptive characteristics of children, adolescents and adults with food allergy (the data for children were provided by parents)

	Reported by patients			
	8-12yrs	**13-17yrs**	**18+yrs**	**All**
Participants, n	73	49	29	151
Participants sex (male/female)	42/31	25/24	9/20	76/75
Participants age: mean (SD)	10.33(1.44)	14.94(1.42)	26.89(11.67)	15.01(8.07)
Type of food allergy, n (%)				
Peanut		41(84)	18(62)	59(76)
Nut		25(51)	18(62)	43(55)
Milk		4(8)	4(14)	8(10)
Egg		8(16)	9(31)	17(22)
Wheat		0	3(10)	3(4)
Soya		5(10)	5(17)	10(13)
Sesame		6(12)	1(3)	7(9)
Fish		2(4)	2(7)	4(5)
Shellfish		3(6)	4(14)	7(9)
Fruits		7(14)	6(21)	13(17)
Vegetables		6(12)	5(17)	11(14)
Other		7(14)	6(21)	13(17)
Sampsons score*, n (%)				
Grade 1		0	0	0
Grade 2		2(4)	0	2(3)
Grade 3		5(10)	7(24)	12(15)
Grade 4		41(84)	20(69)	61(78)
Grade 5		1(2)	2(7)	3(4)
Time since anaphylaxis, n (%)				
Very recently		4(8)	4(14)	8(10)
6-12 months		3(6)	3(10)	6(8)
1 year		2(4)	0	2(3)
2 years		5(10)	5(17)	10(13)
More than 2 years		16(33)	5(17)	21(27)
Never		19(39)	12(41)	31(40)

***Grade 1:** itching in mouth, itching lips, itchy eyes, itchy skin. **Grade 2:** hives, swelling of the skin, nausea, stomach cramps, stuffy nose, sneeze, red rash, red eyes, worsening eczema. **Grade 3:** throat tightness, itching throat, itching ears, runny nose, shortness of breath, vomiting, palpitations, tears. **Grade 4:** difficulty swallowing, hoarseness, difficulty breathing, wheezing, diarrhoea, cough, light-headedness, inability to stand. **Grade 5:** loss of consciousness. If two parents disagree on symptoms, we have chosen the parent who gave the most severe symptom.*

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Table 2. Descriptive characteristics of children with food allergy, data provided by parents

	Reported by parents					
	0-3yrs	**4-6yrs**	**7-12yrs**	**13-17yrs**	**18+yrs**	**All**
Participants, n	24	36	92	51	15	218
Participants sex (male/female)	19/5	19/17	57/35	23/28	5/10	123/95
Participants age: mean (SD)	2.5(.72)	4.78(.83)	9.80(1.72)	15.06(1.41)	21.87(4.22)	10.23(5.43)
Parent participants	36	45	139	72	25	317
Parent sex (male/female)	14/22	14/31	56/83	25/47	11/14	120/197
Type of food allergy, n (%)						
Peanut	7(29)	27(75)	79(86)	43(84)	13(87)	169(78)
Nut	12(50)	17(47)	48(52)	23(45)	8(53)	108(50)
Milk	6(25)	5(14)	11(12)	3(6)	2(13)	27(12)
Egg	18(75)	17(47)	26(28)	7(14)	4(27)	72(33)
Wheat	1(4)	1(3)	3(3)	0	1(7)	6(3)
Soya	2(8)	1(3)	8(9)	3(6)	1(7)	15(7)
Sesame	1(4)	4(11)	10(11)	6(12)	0	21(10)
Fish	1(4)	2(6)	5(5)	2(4)	0	10(5)
Shellfish	2(8)	1(3)	2(2)	4(8)	2(13)	11(5)
Fruits	1(4)	2(6)	12(13)	9(18)	3(20)	27(12)
Vegetables	0	1(3)	7(8)	5(10)	6(40)	19(9)
Other	2(8)	7(19)	15(16)	9(18)	6(40)	39(18)
Sampsons score*, **n (%)**						
Grade 1	0	0	0	0	0	0
Grade 2	5(21)	2(6)	1(1)	0	0	8(4)
Grade 3	4(17)	8(22)	21(23)	7(14)	5(33)	45(21)
Grade 4	14(58)	24(67)	67(73)	43(84)	10(67)	158(72)
Grade 5	1(4)	2(6)	3(3)	1(2)	0	7(3)
Time since anaphylaxis, n (%)						
Very recently	1(4)	4(11)	1(1)	1(2)	2(13)	9(4)
6-12 months	3(13)	1(3)	3(3)	5(10)	2(13)	14(6)
1 year	6(25)	1(3)	9(10)	3(6)	0	19(9)
2 years	4(17)	5(14)	11(12)	4(8)	2(14)	26(12)
More than 2 years	0	10(28)	37(40)	28(55)	3(20)	78(36)
Never	10(42)	15(42)	31(34)	10(20)	6(40)	72(33)

Grade 1: itching in mouth, itching lips, itchy eyes, itchy skin. Grade 2: hives, swelling of the skin, nausea, stomach cramps, stuffy nose, sneeze, red rash, red eyes, worsening eczema. Grade 3: throat tightness, itching throat, itching ears, runny nose, shortness of breath, vomiting, palpitations, tears. Grade 4: difficulty swallowing, hoarseness, difficulty breathing, wheezing, diarrhoea, cough, light-headedness, inability to stand. Grade 5: loss of consciousness. If two parents disagree on symptoms, we have chosen the parent who gave the most severe symptom.

In the cases where both parents have answered, there were some answers that were inconsistent. If one parent answers one food allergy and the other doesn't , then we chose that the couple answered that allergy. If two parents disagree on symptoms, and thus Sampson score, we have chosen the parent who gave the worst symptom to be "correct".

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Table 3. Impact of food allergy, and health-related quality of life reported by children, adolescents and adults

	Children (8-12yrs) Mean total scores (SD) Male/Female	**Adolescents (13-17yrs)** Mean total scores (SD) Male/Female	**Adults (18+yrs)** Mean total scores (SD) Male/Female
Allergen advoidance (AA)	**3.56**(1.50)/**3.84**(1.58)		
Dietary restrictions (DR)	**3.49**(1.53)/**4.15**(1.54)		
Allergen advoidance & Dietary restrictions (AADR)		**3.66**(1.62)/**4.39**(1.21)	**3.30**(1.37)/**4.00**(1.33)
Emotional impact (EI)	**4.10**(1.68)/**4.52**(1.60)	**3.90**(1.47)/**4.46**(1.21)	**3.68**(1.29)/**4.44**(1.36)
Risk accidential exposure (RAE)	**3.38**(1.55)/**3.99**(1.76)	**3.59**(1.69)/**4.03**(1.66)	**3.03**(1.69)/**4.34**(1.46)
Food Allergy related Health (FAH)			**2.21**(1.25)/**3.43**(1.38)
Quality of Life, total score	**3.64**(1.39)/**4.12**(1.51)	**3.71**(1.51)/**4.32**(1.20)	**3.06**(1.40)/**4.05**(1.38)
Food Allergy Independent Measure, total score	**3.08**(1.16)/**3.82**(1.39)	**3.42**(1.06)/**3.45**(1.22)	**3.63**(1.35)/**3.49**(.79)

Each question was scored on a 7-point scale where 1 was the best possible score (i.e. fewest problems or better HRQL).

Table 4. Parent-reported impact of food allergy on their child's health-related quality of life

	Father/Mother Mean total scores (SD)	**Father/Mother** Mean total scores (SD)	**Father/Mother** Mean total scores (SD)	**Father/Mother** Mean total scores (SD)	**Father/Mother** Mean total scores (SD)
FAQLQ-PF	**0-3yrs**	**4-6yrs**	**7-12yrs**	**13-17yrs**	**18+yrs**
Emotionel impact (EI)	**1.90**(.58)/**2.16**(.99)	**2.28**(.85)/**2.35**(.90)	**2.76**(1.06)/**2.85**(1.21)	**3.04**(1.62)/**3.18**(1.25)	**3.73**(1.67)/**3.24**(1.47)
Food Anxiety (FA)	**2.21**(1.30)/**2.12**(1.46)	**2.81**(1.10)/**2.64**(.94)	**3.24**(1.30)/**3.26**(1.38)	**3.30**(1.31)/**3.61**(1.41)	**4.17**(1.73)/**4.13**(1.66)
Social/Dietary Limitations (SDL)	**2.79**(1.45)/**2.62**(1.33)	**2.24**(.86)/**2.40**(1.03)	**2.65**(1.30)/**2.57**(1.31)	**2.43**(1.13)/**2.97**(1.49)	**3.68**(1.71)/**3.17**(1.72)
Quality of Life, total score	**2.30**(0.82)/**2.30**(1.11)	**2.48**(0.87)/**2.47**(.87)	**2.89**(1.14)/**2.89**(1.20)	**2.92**(1.13)/**3.25**(1.32)	**3.86**(1.67)/**3.52**(1.55)
FAIM*, total score	**3.75**(.77)/**3.91**(.88)	**3.82**(.73)/**3.63**(.84)	**3.89**(.84)/**4.01**(.89)	**3.97**(.58)/**4.00**(.89)	**4.27**(.77)/**4.41**(.78)

Each question was scored on a 7-point scale where 1 was the best possible score (i.e. fewest problems or better HRQL).

***FAIM: Food Allergy Independent Measure**

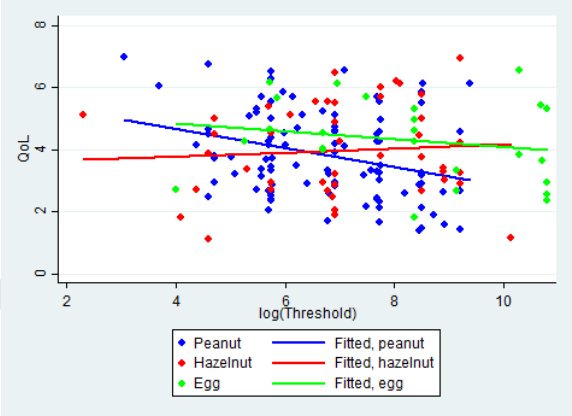
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Table 5. Regression coefficients from multivariate models of self-reported quality of life (FAQLQ) for patients with food allergy (adolescents and adults) and their mothers and fathers

	Patients			Mother			Father		
	Estimate (β)*	P-value	Confidence	Estimate (β)*	P-value	Confidence	Estimate (β)*	P-value	Confidence
Male Patient[1]	0			0			0		
Female Patient	0.14	0.310	[-0.13; 0.42]	0.31	0.008	[0.08; 0.55]	0.02	0.884	[-0.26; 0.31
Limited social life, Child	0.35	<0.001	[0.25; 0.45]	0.45	<0.001	[0.26; 0.64]	0.17	0.095	[-0.03; 0.38
Limited social life, Family				0.17	0.062	[-0.01; 0.35]	0.21	0.037	[0.01; 0.41]
Family stress				0.28	<0.001	[0.13; 0.43]	0.33	<0.001	[0.15;0.50]
Number of foods avoided	0.16	0.006	[0.05; 0.27]	0.04	0.351	[-0.05; 0.13]	-0.04	0.451	[-0.15; 0.07
Q1 FAIM	0.33	<0.001	[0.21; 0.45]	0.12	0.0041	[0.01; 0.24]	0.28	<0.001	[0.14; 0.41]
Sampson, Grad 1							0.66	0.416	[-0.95; 2.28
Sampson, Grad 2[2]				0			0		
Sampson, Grad 3				0.35	0.250	[-0.25; 0.95]	-0.07	0.827	[-0.70; 0.56
Sampson, Grad 4				0.43	0.149	[-0.15; 1.00]	0.20	0.511	[-0.41; 0.82
Sampson, Grad 5				0.04	0.942	[-0.91; 0.98]	0.26	0.629	[-0.80; 1.32

*β coefficient – higher value equals greater contribution to explaining QoL
[1]Male reference value for female
[2]Sampson severity grad 2 reference value for grad 1, 3, 4, 5

Figure 1. Mean self-reported quality of life (FAQLQ) plotted against threshold for egg, peanut, and hazelnut



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