

## **TITLE PAGE**

Original Article

**Title: Parental Confidence in Managing Food Allergy: Development and Validation of the Food Allergy Self-Efficacy Scale for Parents (FASE-P)**

Rebecca C Knibb<sup>1</sup>, PhD

Christopher Barnes <sup>2</sup>, PhD

Carol Stalker<sup>2</sup>, MSc

<sup>1</sup> Psychology, School of Life and Health Sciences, Aston University, Birmingham, U.K.

<sup>2</sup> Psychology, College of Life and Natural Sciences, University of Derby, Derby, U.K.

Running Head: **Development and validation of the FASE-P**

### **Corresponding Author**

Dr Rebecca Knibb

Psychology, School of Life and Health Sciences, Aston University, Aston Triangle, Birmingham, B4 7ET. Tel:0121 204 3402. Email: r.knibb@aston.ac.uk

**Word count: 4,342 Number of tables: 4**

## **ABSTRACT**

**Background:** Food allergy is often a life-long condition that requires constant vigilance in order to prevent accidental exposure and avoid potentially life-threatening symptoms. Parents' confidence in managing their child's food allergy may relate to the poor quality of life anxiety and worry reported by parents of food allergic children.

**Objective:** The aim of the current study was to develop and validate the first scale to measure parental confidence (self-efficacy) in managing food allergy in their child.

**Methods:** The Food Allergy Self-Efficacy Scale for Parents (FASE-P) was developed through interviews with 53 parents, consultation of the literature and experts in the area. The FASE-P was then completed by 434 parents of food allergic children from a general population sample in addition to the General Self-Efficacy Scale (GSES), the Food Allergy Quality of Life Parental Burden Scale (FAQL-PB), the General Health Questionnaire (GHQ12) and the Food Allergy Impact Measure (FAIM). A total of 250 parents completed the re-test of the FASE-P.

**Results:** Factor and reliability analysis resulted in a 21 item scale with 5 sub-scales. The overall scale and sub-scales has good to excellent internal consistency ( $\alpha$ 's of 0.63-0.89) and the scale is stable over time. There were low to moderate significant correlations with the GSES, FAIM and GHQ12 and strong correlations with the FAQL-PB, with better parental confidence relating to better general self-efficacy, better quality of life and better mental health in the parent. Poorer self-efficacy was related to egg and milk allergy; self-efficacy was not related to severity of allergy.

**Conclusions and clinical relevance:** The FASE-P is a reliable and valid scale for use with parents from a general population. Its application within clinical settings could aid provision of advice and improve targeted interventions by identifying areas where parents have less confidence in managing their child's food allergy.

**Key words:** Food allergy, confidence, self-efficacy, parents, quality of life

## INTRODUCTION

Food allergy affects approximately 5-10% of children worldwide [1-3]. In the U.K. hospital admissions for food allergies increased by 6.4% in the 12 months leading to February 2014 and of admissions for allergy nearly one in five were for anaphylactic reactions. This is an increase of 9.4% from the same period the previous year [4]. There is no cure for food allergy and the optimum treatment is to avoid the allergen and anything that might have come into contact with the allergen; with the administration of antihistamine or adrenaline if accidental ingestion and a reaction occurs [1]. The vigilance required to manage food allergy and avoid allergens has been reported to place a significant burden on the family which can impact on health related quality of life<sup>[5]</sup>, daily family activities and social events<sup>[6]</sup> and emotional well-being<sup>[7]</sup>. Mothers in particular have reported high levels of stress and anxiety<sup>[5,8,9]</sup>.

Confidence in managing food allergy in their child may relate to the levels of burden felt by parents. Mandell et al.<sup>[9]</sup> interviewed parents of 17 children with peanut allergy who also had a history of anaphylaxis. They found that a lack of information at diagnosis increased both anxiety and uncertainty in managing the risk of accidental ingestion of the allergen. Parents have also reported high levels of worry about their child having an anaphylactic reaction and uncertainty around what to do if their child does go into anaphylactic shock<sup>[9,10]</sup>.

Confidence and 'the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations' has been defined as self-efficacy (p. 2)<sup>[11]</sup> and is linked to how people think, feel and behave. Improving self-efficacy can lead to individuals feeling more able to master challenging problems, developing a stronger sense of commitment to dealing with these tasks and a reduction in feeling that situations are beyond their capabilities. Improving self-efficacy has been shown to be effective in improving quality of life, self-management and coping with asthma<sup>[12-14]</sup> and other long term conditions<sup>[15]</sup> through interventions which include education, training, modelling self-management using case examples and role play scenarios with feedback, encouragement and support.

Existing quality of life scales are good at identifying the extent of the impact of food allergy on various aspects of life but do provide information on areas in which confidence in being able to manage is lacking. For example a quality of life scale might tell us that checking food labels takes up a lot of someone's time but do not tell us if that person feels confident that they can identify allergens from food labels. It would therefore be extremely useful to have a means of measuring self-efficacy for food allergy management to identify areas of low self-efficacy. This may help health care practitioners to direct their advice to parents and also help the development and evaluation of interventions. At present there is no means of measuring self-efficacy for food allergy management. A widely used General Self-Efficacy Scale <sup>[16]</sup> exists however this measures a general sense of perceived self-efficacy and aims to predict coping with daily hassles and other types of stress; it does not capture the specific issues that relate to food allergy. The aim of this study was to develop and validate the first food allergy specific self-efficacy scale to measure parental confidence in managing their child's food allergy.

## **METHODS**

Ethical approval for the scale development phase of this study was provided by the Psychology Research Ethics Committee at the University of Derby (012/10/RK) and the Nottingham Trent NHS Research Ethics Committee (10/H0405/94). Ethical approval for the scale reliability and validity phase of this study was provided by the Psychology Research Ethics Committee at the University of Derby (102-13-CB). All participants gave written informed consent to take part.

### **Item Generation**

#### *Participants and procedure*

Participants were recruited for interview via allergic clinics in the Midlands for a larger study looking at knowledge and understanding of food allergy in their child, how they managed their child's food allergy and the impact it had on them. Participants had to be parents of children with a current clinical diagnosis of food allergy (diagnosed by a clinician at an allergy clinic via clinical history and either skin prick tests or blood tests). Parents were sent letters home by the clinic and they contacted the study team if they wanted to participate. Parents were mostly mothers (46 (86.8%); 7 (13.2%) fathers), with a mean age of 42.7 (range 32-59 years). Children had a mean age of 9.9 years and were allergic to peanut (60%), tree nut (54.5%), egg (12.7%) milk (12.7%), fruits and vegetables (10.9%). Symptoms included urticaria, rash or hives (62.1%), swelling of face, lips, mouth and/or tongue (57.6%), vomiting (54.6%) and respiratory (37.9%). The majority of the children had a prescribed adrenaline auto-injector (63.6%) and/or antihistamines (12.7%); 30.9% of the children had suffered one or more anaphylactic reactions as a result of their food allergy.

All parents were interviewed using a semi-structured interview schedule. Following scale development guidelines <sup>[17-19]</sup> the interview schedule was informed by discussion with experts in the area; this included two psychologists with expertise in food allergy, a psychologist with expertise in self-efficacy in parents and two paediatric allergy consultants. Relevant literature on parental management of food allergy in their child was also reviewed. Questions were

then developed to guide the interview. The schedule was not intended to be prescriptive or inclusive but acted as a guide in the interview in order to ensure the aims of the study were met. Parents were asked about how they managed food allergy in their child, what they found difficult or easy and what they felt they needed in order to be confident in managing food allergy. They were also asked what they knew about food allergy, what they did to prevent an allergic reaction, what they did/would do if their child had an allergic reaction and how food allergy had made an impact on their lives. They were also asked about where they got information about food allergy from.

The interviews were audio taped and transcribed verbatim, then analysed by content analysis using a directed approach where you start with a theory and relevant research findings for guidance, in order to identify specific issues that parents discussed concerning the management of food allergy for their child <sup>[20]</sup>. A literature review and advice from health care practitioners (detailed above) working in the area of food allergy also helped form items for inclusion in a prototype scale and items were revised to ensure there were no duplicates, unclear items or items that would not relate to the majority of parents of a child with food allergy. Based on guidelines stated by Bandura<sup>[21]</sup> items were then worded as statements and parents were asked to rate how confident they were that they could do each item on a scale of 0 to 100 with 0 being cannot do at all, 50 being moderately can do and 100 being highly certain can do. The prototype Food Allergy Self-Efficacy Scale for Parents (FASE-P) consisted of 22 items such as being able to prepare to go to a restaurant, go on holiday, check food labels and get information about food allergy from a health care professional.

### **Scale reliability and validity**

#### *Participants and procedure*

In order to assess reliability and validity of the scale on a large sample, participants were recruited from the general population via advertisement of an online survey through social media channels such as Facebook and Twitter and through the Anaphylaxis Campaign Charity's website. Emails advertising the study were also sent to all eligible members of the

Campaign although parents did not need to be members of the Campaign to take part. Inclusion criteria for the study were that the participant was a parent who had at least one child under the age of 18 years living in the family home who had a food allergy diagnosed by a clinician at an allergy clinic. Participants completed the questionnaires anonymously but were asked to provide their email address if they were happy to complete some of the questionnaires three weeks later. A total of 250 participants completed the re-test of the FASE-P.

### **Cross-sectional validation measures**

In addition to completing the FASE-P parents also completed a number of validated scales in order to assess construct validity.

General Self-Efficacy Scale <sup>[16]</sup> is a 10 item scale measuring general perceived self-efficacy. Responses are made on a 4 point scale from 1 (not at all true) to 4 (exactly true). An example item is: I can always manage to solve difficult problems if I try hard enough. Items are summed with higher scores indicating greater self-efficacy. In samples from 23 nations, Cronbach's alphas ranged from .76 to .90 with the majority in the high .80s <sup>[22]</sup>.

Food Allergy Quality of Life – Parental Burden (FAQL-PB) scale<sup>[23]</sup> has 17 items and uses a 7-point Likert scale ranging from 1 (not troubled) to 7 (extremely troubled). Questions include issues concerning going on vacation, social activities and worries and anxieties over the previous week. A higher score indicates greater parental burden. Internal validity has been reported as excellent in a U.S. sample (Cronbachs  $\alpha = 0.95$ ) <sup>[23]</sup> and in a U.K. sample ( $\alpha > 0.85$ ) <sup>[24]</sup>.

Food Allergy Independent Measure (FAIM) has 4 items which measure the severity of perceived risk of an accidental reaction to food and the risk of not being able to treat a reaction appropriately. It has been used as a means of measuring the impact of food allergy in the validation of other related questionnaires such as the Food Allergy Quality of Life

Scales <sup>[25-27]</sup>. Items are answered on a 7-point Likert scale with a greater score indicating a higher level of perceived seriousness.

General Health Questionnaire – 12 (GHQ-12) <sup>[28]</sup> is a 12 item scale of current mental health which asks individuals to state how they have felt over the last few weeks. It measures inability to carry out normal functions and also the appearance of new and distressing symptoms. It uses a 4 point Likert scale from not at all (scored 0) to much more than usual (scored 3). Scores are summed and have a range from 0 to 36. Scores over 11-12 indicate a risk of being diagnosed with a mental illness. The scale has excellent internal consistency (Cronbach's  $\alpha = 0.77-0.93$ ) and good validity <sup>[28]</sup>.

#### *Demographic and food allergy questionnaire*

In order to assess discriminative validity a questionnaire to gather demographic information from the parent and food allergy information about their child was developed based on that used in previous published studies<sup>[29]</sup>. Information collected included the type of food allergy, symptoms, how the allergy was diagnosed, medication, history of anaphylaxis and presence of other atopic conditions such as asthma, hay-fever and eczema.

#### **Statistical analysis**

Data analyses were conducted using SPSS version 21, and all tests were 2-tailed with a significance level set at  $p < 0.05$ , missing data was treated pairwise. Principle components analysis with a varimax rotation was conducted to assess internal structural validity.

Reliability analysis was conducted in order to calculate the internal consistency of the scale using Cronbach's  $\alpha$  coefficient and Guttman's split-half coefficient. Pearson's bivariate correlations were conducted between scale scores to assess construct and convergent validity. Intra-Class Correlations were conducted to assess temporal stability of the scale. Following criteria set out by Pesudov et al <sup>[18]</sup> and results reported by other similar scales such as the food allergy specific QoL scales <sup>[25-27]</sup>, a priori hypotheses were set regarding reliability and validity. We expected Cronbach's alpha of  $>0.7$  and  $<0.9$  and moderate



construct validity correlations of  $>0.3$  with sub-scales measuring similar aspects to the scale. Specifically we expected that greater food allergy self-efficacy would positively relate to greater general self-efficacy and better food allergy related quality of life. We also expected that greater food allergy self-efficacy would negatively relate to poorer mental health and greater severity of perceived risk of food allergy. Between-subjects t-tests and Pearson's correlations were performed to assess the discriminative validity of the FASE-P by comparing demographic and food allergy characteristics. Analyses of Covariance (ANCOVAs) were run to assess discriminative validity of the FASE-P controlling for possible confounders.

## **RESULTS**

Demographic information for participants in the reliability and validity phase can be found in Table 1 and food allergy information can be found in Table 2.

### **Structural validity**

Principle components analysis with a varimax rotation was conducted on the 22 items of the FASE-P. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was .83, exceeding the recommended value of .6<sup>[30]</sup> and Bartlett's Test of Sphericity (4577.90,  $df = 231$ ,  $p < 0.001$ ) reached statistical significance, supporting the factorability of the correlation matrix. Five factors with Eigenvalues over 1, explaining a total of 59.8% of the variance in the scores, were identified. All items had factor loadings greater than 0.4 and factors were labelled: precaution and prevention, allergic treatment, food allergen identification, seeking information, managing social activities (Table 3).

The item 'planning to participate in social activities with others involving food' loaded onto the sub-scale entitled managing social activities and the sub-scale entitled precaution and prevention. The highest loading was for the precaution and prevention sub-scale and as the item concerned planning it was placed there. Two other items had factor loadings above 0.4 on two subscales, but loadings were very similar and so items were placed on the factor that had the greatest face validity and made the most theoretical sense.

### **Reliability and consistency over time of the PFA-QL**

The FASE-P scale had excellent internal consistency with a Cronbach's  $\alpha$  of 0.88 overall. Split half Cronbach's  $\alpha$  for part 1 was .76 and .86 for part 2; the Guttman split-half coefficient was 0.73. Examination of the alpha levels if items were deleted revealed that removal of the item 'treat my child if they had an allergic reaction outside of the home' increased the alpha of the allergic reaction sub-scale from .29 to .80. This item was therefore removed from the scale and the item 'treat my child if they had an allergic reaction at home' was re-worded to say 'treat my child if they had an allergic reaction' to ensure this item captured allergic

reactions wherever they occurred. The alpha coefficient values decreased with deletion of any of the other items in each of the sub-scales, indicating that all items were important to the scale and so were retained. Alphas for all sub-scales can be seen in Table 4. The final scale consists of 21 items. Answers on the scale are totalled (there are no reverse items) and then divided by 21 to get a total mean score, resulting in a score range from 0 to 100. Sub-scale items are similarly totalled and divided by the number of items in each sub-scale. A higher score indicates greater self-efficacy for food allergy management.

Two hundred and fifty participants completed a re-test of the FASE-P after three weeks. Of those parents who reported no change in their own physical or mental health (n=186) there was a strong intra-class correlation of .816. For those who reported no allergic reactions in their child in the last three weeks (n=163) there was also a strong intra-class correlation of .801. There was however a slight but significant increase in the mean scores from time one to time two in parents who reported no change in their own health (mean=72.89 vs 74.30,  $t(185)=-2.86$ ,  $p=0.005$ ) and in parents who reported no allergic reaction in their child (mean=72.92 vs 74.71,  $t(162)=-3.33$ ,  $p=0.001$ ).

### **Construct Validity**

The total FASE-P score significantly correlated with the total generalised self-efficacy score ( $r=.24$ ,  $p<0.001$ ) with greater food allergy specific self-efficacy relating to greater general self-efficacy. This was in the hypothesised direction but was slightly lower than the expected correlation of around 0.3, which is probably due to the FASE-P measuring specific aspects of food allergy related self-efficacy rather than just general self-efficacy. Each item of the FASE-P also significantly correlated with the GSES with  $r$  values ranging from .10 to .22 (all  $p$  values  $<0.05$ ) apart from two items relating to the ability to get information about food allergy from the GP, nurse or family doctor ( $r=.06$ ) and from food retailers ( $r=.08$ ). These items had good factor loadings, good inter-item correlations, did not increase the alpha of the scale if deleted and were rated as important items to keep by the study team and were therefore retained in the scale.

In line with expectations, the total FASE-P score had a strong significant correlation with the FAQL-PB ( $r=-.56$ ,  $p<0.001$ ), demonstrating that greater confidence in managing their child's food allergy was related to less parental burden. The FASE-P also correlated with the GHQ12 ( $r=-.31$ ,  $p<0.001$ ) showing that greater confidence was related to better mental health (lower scores on the GHQ12).

There were negative correlations between the FASE-P and the FAIM total score ( $r=-.22$ ,  $p<0.001$ ) demonstrating that parents who rated their child's risk of a negative outcome such as an allergic reaction or death as less severe had greater confidence in managing food allergy in their child.

#### **Discriminative validity of the PFA-QL**

FASE-P scores were significantly correlated with the age of the parent ( $r=.22$ ,  $p<0.001$ ) and the child ( $r=0.26$ ,  $p<0.001$ ) indicating that older parents and parents of older children reported greater confidence in managing their child's food allergy. FASE-P scores were negatively correlated with the number of food allergies the child had ( $r=-.15$ ,  $p<0.05$ ) showing that the more allergies the child had the less confidence the parent had. FASE-P scores were not correlated to the number of times their child had reacted or to the number of children they had living at home with food allergy. There was no difference in parental self-efficacy scores between mothers and fathers, however parents of boys with food allergy had higher self-efficacy scores (mean=76.91, SD=11.07) than parent of girls with food allergy (mean=74.53, SD=11.83), ( $t(413)=2.04$ ,  $p<0.05$ ).

There was no significant difference in self-efficacy scores between parents who had children who had suffered from anaphylaxis and those who had not, or those whose child had been admitted to hospital because of food allergy and those who had not. Numbers of children carrying an adrenaline auto-injector was high ( $n=395$ ) compared to those not ( $n=19$ ); self-efficacy scores for parents were marginally greater for those with an AAI (mean=76.37,

SD=11.12) compared to those without (mean=71.93, SD=12.95) but this was not significant ( $t(412)=1.67$ ,  $p=0.09$ ).

There were no differences in self-efficacy scores for parents of children who had asthma, eczema and hay-fever or those who had allergies to peanuts or other nuts compared to those who did not. Parents of children who had allergy to cow's milk had lower self-efficacy scores ( $n=114$ , mean=73.38, SD=12.16) than those who did not ( $n=304$ , mean=77.08, SD=10.91), ( $t(416)=-2.99$ ,  $p=0.003$ ). Similarly parents of children who had allergy to egg had lower self-efficacy scores ( $n=155$ , mean=73.09, SD=12.40) than those who did not ( $n=263$ , mean=77.83, SD=10.35), ( $t(416)=-4.20$ ,  $p<0.001$ ). As there was a significant relationship between parental self-efficacy and age of child, age might be a reason for the differences seen in children with milk and egg allergy. To assess this Analyses of Covariance (ANCOVAs) were run. After controlling for age of child there was still a significant difference between parents of children with egg allergy or not ( $F=18.46$ ,  $p<0.001$ ) and also a significant difference between parents of children with milk allergy or not ( $F=15.54$ ,  $p<0.001$ ).

## DISCUSSION

The FASE-P is the first self-efficacy scale to measure confidence in parental management of their child's food allergy. It has excellent internal reliability overall, satisfactory to excellent internal reliability for the sub-scales and excellent reliability over time in parents from a general population. Scores did increase slightly from time one to time two and it may be that completing the scale itself acted as an intervention, prompting parents to think more about how they manage their child's food allergy over the following two weeks and feel more confident in doing so. The scale also had good construct validity as demonstrated by convergent validity correlations with the GSES, FAQL-PB, GHQ-12 and FAIM. Correlations were significant but slightly lower than expected with the GSES, probably reflecting the generic nature of the GSES, which does not identify the specific issues important for management of food allergy. Previous studies have also found only moderate correlations between general and parental self-efficacy, showing that generalised self-efficacy is not sensitive enough to measure behaviour specific self-efficacy <sup>[31]</sup>.

Correlations between the FASE-P and the FAQL-PB were strong demonstrating that greater food allergy specific self-efficacy seems to be an important determinant for better quality of life, although causation cannot be ascertained from this study. There was also a significant relationship between greater self-efficacy and better mental health as measured by the GHQ-12, although correlations were not as strong, probably due to mental health issues as measured by the GHQ-12 being non-specific rather than attributed to food allergy. Although correlations with the FAIM were significant they were low, which may be because parents from this general population sample view the chance of a severe reaction or death in their child differently to their ability to manage their child's condition on a daily basis. Parents have reported extreme worry and concern regarding the risk of anaphylaxis and their ability to deal with that <sup>[9, 10, 32]</sup> but parents in this sample may have felt more confident in their ability to manage other aspects of their child's food allergy.

An important and novel finding from this study was that discriminative validity of the FASE-P showed that parents had less self-efficacy when their children had milk or egg allergy. There was no difference in parents of children with peanut or nut allergy or not. This interesting finding indicates that parents may struggle to manage a food allergy where allergens are a main ingredient in a wide range of foods (such as milk and egg) rather than foods where traces of the allergen may be contained in foods (such as peanut and nut). This finding was still significant after controlling for the age of the child, demonstrating that age was not affecting the results. Much emphasis in the recent past has been placed on the significant impact of peanut and nut allergy on families rather than to other foods [e.g. 5,29]. The finding from this study highlights the importance of measuring parental confidence in managing food allergy in addition to impact on quality of life, as results may help ensure the right advice and support is offered to families who need it.

Another important finding from this study was the lack of difference in FASE-P scores on measures of the severity of food allergy such as experience of anaphylaxis and hospitalisation due to food allergy. Lack of confidence in managing food allergy is therefore just as likely in parents of children who have not had a severe reaction, which is an important consideration for health care professionals giving advice and training in food allergy management. Experience of anaphylaxis has been reported to relate to outcomes such as quality of life in some [27] but not all [33] populations. Knibb et al. [33] suggest there may be a mediating effect such as age of child or time since anaphylactic reaction that needs to be investigated in future studies. Indeed age of child did correlate with the FASE-P scores as did age of the parent showing that as parent and child got older, confidence in managing the food allergy increased. It may be that parent's life experience or food allergy management experience contributes to this finding. The scale also did not discriminate between those with an adrenaline auto-injector or not, although this might have been because almost all participants in the sample had been prescribed one of these.

A strength of this study is the large sample of parents that the scale has been validated on and in particular the large sample conducting the re-test. As with all research of this nature, the sample was self-selected and motivated to take part and may therefore be different in some way to parents of food allergic children who did not take part. Nevertheless, recruiting a large sample from a general population rather than an allergy clinic enabled us to gather data encompassing a wide range of food allergy characteristics, including parents with children who had been diagnosed for a number of years as well as those with more recent diagnoses. Although we only included parents whose child had been diagnosed by a clinician at an allergy clinic, we necessarily had to rely on self-report of parents for the reliability and validity phase of the study. Given the number of children who had been prescribed AAIs in the sample it is unlikely that a large number will have misreported the diagnosis. In addition, the wide range of scores on the FASE-P indicates that the sample consisted of parents across the spectrum and so issues such as membership of a support group should not have unduly affected the results.

Nevertheless, further validation on a sample recruited from a clinical database would be useful to ensure self-report of a clinical diagnosis in the child has not affected results. Confirmatory factor analysis is also needed to confirm the sub-scales found in the exploratory factor analysis reported here. It is also unknown whether greater self-efficacy relates to accurate knowledge and skills in food allergy management. There is evidence to suggest that better self-efficacy does correlate with better parental management of conditions such as diabetes in relation to outcomes such as glycaemic control <sup>[34]</sup>, but this needs to be investigated specifically for food allergy. Development of a short version of the scale may also be useful for use in clinical settings to identify broad areas where families are struggling to manage.

To conclude, the FASE-P is a reliable and valid tool to use with a general population of parents of children with food allergy. The relationship of parental confidence in managing food allergy to the severity of food allergy and to the foods involved has been found to be



different to previous research focusing on quality of life. It is therefore important for self-efficacy to be measured in order to direct appropriate health care advice.

**Acknowledgements**

The authors would like to thank the Anaphylaxis Campaign for their support in advertising this study and the parents who took part. This study was funded by pump priming money from the Health and Lifespan Research Group at Aston University.

**Conflicts of interest**

There are no conflicts of interest.

## REFERENCES

- (1) Sicherer SH. Epidemiology of food allergy. *J Allergy Clin Immunol* 2011; **127**:594-602.
- (2) Wasserman S, Watson W. Food allergy. *Allergy, Asthma Clin Immunol* 2011; **7**(Suppl 1): S7.
- (3) Gupta R, Sheikh A, Strachan DP, Anderson HR. Time Trends in Allergic Disorders in the UK. *Thorax* 2007; **62**:91-96.
- (4) Provisional monthly hospital episode statistics for admitted patient care, outpatients and accident and emergency data – April 2013 to February 2014. Health and Social Care Information Centre 2014. Available from <http://www.hscic.gov.uk> Accessed on 1<sup>st</sup> September, 2015.
- (5) King RM, Knibb RC, Hourihane JO. Impact of peanut allergy on quality of life, stress and anxiety in the family. *Allergy* 2009; **64**:461-8.
- (6) Bollinger ME, Dahlquist LM, Mudd K, Sonntag C, Dillinger L, McKenna K. The impact of food allergy on the daily activities of children and their families. *Ann Allergy Asthma Immunol* 2006; **96**:415-21.
- (7) Knibb RC, Semper H. Impact of suspected food allergy on emotional distress and family life of parents prior to allergy diagnosis. *Pediatr Allergy Immunol* 2013; **24**:798-803
- (8) Cummings AJ, Knibb RC, King RM, Lucas JS. The psychosocial impact of food allergy and food hypersensitivity in children, adolescents and their families: a review. *Allergy* 2010; **65**:933-945.
- (9) Mandell D, Curtis R, Gold M, Hardie S. Anaphylaxis: how do you live with it? *Health Soc Work* 2005; **30**:325-35.

- (10) Akeson N, Worth A, Sheikh A. The psychosocial impact of anaphylaxis on young people and their parents. *Clin Exp Allergy* 2007; **37**:1213-20.
- (11) Bandura A. *Self-Efficacy in Changing Societies*. Cambridge: Cambridge University Press, 1995.
- (12) Martin MA, Catrambone CD, Kee RA, Evans AT, Sharp LK. Improving asthma self-efficacy: Developing and testing a pilot community based asthma intervention for African American adults. *J Allergy Clin Immunol* 2009; **123**:153-9.
- (13) Lavoie KL, Bouchard A, Joseph M, Campbell TS, Favreau H, Bacon S. Association of asthma self-efficacy to asthma control and quality of life. *Annals Behav Med* 2008; **36**:100-106.
- (14) Kaul T. Helping African-American Children self-manage asthma: The importance of self efficacy. *J School Health* 2011; **81**:29-33.
- (15) Lorig KR. Ritter P. Stewart AL. Sobel DS. Brown BW Jr. Bandura A. Gonzalez VM. Laurent DD. Holman HR. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care* 2001; **39**:1217-23.
- (16) Schwarzer R, Jerusalem M. Generalised Self-Efficacy Scale. In: Weinman J, Wright S, Johnston M eds. *Measures in health psychology: A users portfolio*. Causal and control beliefs. Windsor UK: NFER-NELSON, 1995: 35-37.
- (17) DeVellis RF. *Scale development: Theory and Applications*. (3<sup>rd</sup> ed). London: Sage. 2012.

(18) Pesudov K, Burr JM, Harley C, Elliott CB. The development, assessment and selection of questionnaires. *Optometry Vision Sci* 2007; **84**:603-674.

(19) U.S. Department of Health and Human Services Food and Drug Administration Centre for Drug Evaluation and Research. Guidance for industry: patient-reported outcome measures: use in medical product development to support labelling claims. 2009. <http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf> Accessed on 22nd April 2015

(20) Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005; **15**:1277-88.

(21) Bandura, A. Guide for constructing self-efficacy scales. In: Pajares F, Urdan T, eds. *Self-efficacy beliefs of adolescents*. Greenwich: Information Age Publishing, 2006;307-337.

(22) Luszczynska A, Scholz U, Schwarzer R. The General Self-Efficacy Scale: Multicultural validation studies. *J of Psychol* 2005; **139**:439-57.

(23) Cohen BL, Noone S, Munoz-Furlong A, Sicherer SH. Development of a questionnaire to measure quality of life in families with a child with food allergy. *J Allergy Clin Immunol* 2004; **114**:1159-63.

(24) Knibb RC, Stalker C. Validation of the Food Allergy Quality of Life - Parental Burden Questionnaire in the U.K. *Qual Life Res*, 2013; **22**:1841-9.

(25) DunnGalvin A, de BlokFlokstra BM, Burks AW, Dubois AE, Hourihane JO. Food allergy QoL questionnaire for children aged 0-12 years: content, construct, and cross-cultural validity. *Clin Exp Allergy* 2008; **38**:977-86.

(26) Flokstra-de Blok BM, DunnGalvin A, Vlieg-Boerstra BJ, Oude Elberink JN, Duiverman EJ, Hourihane JO, et al. Development and validation of a self-administered Food Allergy Quality of Life Questionnaire for children. *Clin Exp Allergy* 2009; **39**:127-37.

(27) Flokstra-de Blok BMJ, DunnGalvin A, Vlieg-Boerstra BJ, Oude Elberink JNG, Duiverman EJ, Hourihane JO'B, Dubois AEJ. Development and validation of a self-administered Food Allergy Quality of Life Questionnaire for adolescents. *J Allergy Clin Immunol* 2008; **122**:139-144.

(28) Goldberg D, Williams P. *A User's Guide to the General Health Questionnaire*. Slough: NFER- Nelson, 1988.

(29) Cummings AJ, Knibb RC, Erlewyn-Lajeunesse M, King RM, Roberts G, Lucas JS. Management of nut allergy influences quality of life and anxiety in children and their mothers. *Pediatr Allergy Immunol* 2010; **21**:586-594.

(30) Field A. *Discovering Statistics Using IBM SPSS Statistics*. 3<sup>rd</sup> Edn. London: Sage, 2013.

(31) Coleman PK, Hildebrandt Karraker K. Parenting self-efficacy among mothers of school-age children: Conceptualization, measurement and correlates. *Family Relations* 2000; **49**:13-24.

(32) Springston EE, Smith B, Shulruff J, Pongracic J, Holl J, Gupta RS. Variations in quality of life among caregivers of food allergic children. *Annals Allergy Asthma Immunol* 2010; **105**:287-294.

(33) Knibb RC, Ibrahim NF, Petley R, Cummings A, King R, Roberts G, Erlewyn-Lajeunesse M, Lucas J. Validation of the Paediatric Food Allergy Quality of Life Questionnaire (PFA-QL). *Pediatr Allergy Immunol* 2013; **24**:288-92.

(34) Marchante AN, Pulgaron, ER, Daigre A, Patino-Fernandez AM, Sanchez J, Sanders LM, Delamater AM. Measurement of parental self-efficacy for diabetes management in young children. *Child Health Care* 2014; **43**:110-119.

Table 1. Characteristics of respondents (n %) for the reliability and validity phase of the scale development

		<b>Sample n=434</b>
		<b>n/%</b>
<b>Parents age (mean, s.d.)</b>		42.21 (6.41)
<b>Sex of Parent completing survey</b>		
	Male	19 (4.4%)
	Female	411 (94.7%)
<b>Marital status</b>		
	Married/living with partner	393 (90.5)
	Divorced	16 (3.7)
	Single	17 (3.9)
	Widowed	1 (0.2)
<b>Employment status</b>		
	Working full-time	123 (28.3)
	Working part-time	204 (47.0)
	Full-time education	3 (0.7)
	Not working or in education	102 (23.5)
<b>Country of residence</b>		
	UK	410 (94.5)
	Other EU	12 (2.8)
	Non-EU	8 (1.8)
<b>Number of children within family (mean, s.d.)</b>		2.03 (1.12)
<b>Number of children in family with a food allergy</b>		
	One	382 (88)
	Two	44 (10.1)
	Three	6 (1.4)

Where % don't add up to 100 there are missing values; where % total more than 100 parents were able to select more than one answer.



Table 2. Food allergy characteristics (n %) for the reliability and validity phase of the scale development.

		<b>Sample n=434</b>
		<b>n/%</b>
<b>Child age in years (mean, s.d.)</b>		9.47 (4.7)
<b>Child age range (years)</b>		1-18
<b>Sex of child with food allergy</b>		
	Male	282 (65)
	Female	148 (34.1)
<b>Foods reported</b>		
	Peanut	335 (77.2)
	Tree nut	287 (66.1)
	Both peanut and tree nut	265 (54.1)
	Cows Milk	119 (27.4)
	Egg	162 (37.3)
	Soya	30 (6.9)
	Fruit	54 (12.4)
	Fish	32 (7.4)
	Sesame	43 (9.9)
	Wheat	16 (3.68)
	Shellfish	34 (7.8)
<b>Symptoms reported</b>		
	Vomiting	228 (52.5)
	Abdominal Pain	155 (35.7)
	Rash, hives, urticaria	324 (74.7)
	Facial swelling	280 (64.5)
	Breathing difficulties	214 (49.3)
	Throat tightening	177 (40.8)

Table 1 continued

<b>Other allergies</b>		
	Latex	14 (3.2)
	Tree Pollen	111 (25.6)
	Grass Pollen	121 (27.9)
<b>Asthma</b>		310 (71.4)
<b>Eczema</b>		366 (84.3)
<b>Hayfever</b>		240 (55.3)
<b>History of Anaphylaxis</b>		226 (52.1)
<b>Carries Adrenaline Auto Injector</b>		411 (94.7)
<b>How allergy diagnosed</b>		
	Skin prick test	327 (75.3)
	Blood test	265 (60.8)
	Food challenge	66 (15.2)
<b>Hospitalisation due to an allergic reaction to food</b>		282 (65)

---

Where % don't add up to 100 there are missing values; where % total more than 100 parents were able to select more than one answer.

Table 3. Factor analysis for the FASE-P scale and sub-scales

	Factor Loadings				
	1	2	3	4	5
<b>MANAGING SOCIAL ACTIVITIES</b>					
Be on holiday/vacation abroad	.849				
Plan for a holiday/vacation abroad	.838				
Be on holiday/vacation in this country	.757				
Plan for a holiday/vacation in this country	.744				
Eat at a restaurant	.670				
Prepare to go to a restaurant	.621				
<b>PRECAUTION &amp; PREVENTION</b>					
Have a plan to make sure my child is safe at school or nursery		.703			
Have a plan to make sure my child is safe with a relatives, friends or a babysitter		.678			
Plan to participate in social activities with others involving food (e.g. parties)	.426	.630			
Control my child's environment to prevent an accidental exposure		.490			
Teach others about my child's food allergy		.463			
Prepare to go out of the home with my child		.424			
<b>ALLERGIC TREATMENT</b>					
Recognise an allergic reaction in my child			.755		
Treat my child if they had an allergic reaction at home			.772		
Treat my child if they had an allergic reaction outside of the home			.424		
<b>FOOD ALLERGEN IDENTIFICATION</b>					
Identify possible food cross-contamination				.759	
Check food labels				.712	
Prepare homemade meals			.501	.446	
<b>SEEKING INFORMATION ABOUT FOOD ALLERGY</b>					
Get information about my child's food allergy from:					
		G.P. nurse or family doctor			.768
		Food retailers (e.g. supermarkets, food outlets)			.724
		Websites			.623
		Paediatrician or allergy specialist at the hospital	.448		.408
<b>Eigenvalues</b>	<b>3.97</b>	<b>2.80</b>	<b>2.26</b>	<b>2.17</b>	<b>1.96</b>
<b>% variance</b>	<b>18.03</b>	<b>12.74</b>	<b>10.26</b>	<b>9.88</b>	<b>8.89</b>

Table 4. Cronbach's alphas for the FASE-P scale and sub-scales.

FASE-P	Cronbach's alphas
<b>Total Scale</b>	.88
<b>Sub-Scales</b>	
Managing Social Activities	.89
Precaution & Prevention	.74
Allergic Treatment	.80*
Food Allergen Identification	.63
Seeking Information About Food Allergy	.65

\* With the removal of the item 'treat my child if they had an allergic reaction outside of the home'.