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Validation of the Food Allergy Quality of Life—Parental Burden Questionnaire in the UK

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Abstract
Purpose Food allergy can have a profound effect on quality of life (QoL) of the family. The Food Allergy Quality of Life—Parental Burden Questionnaire (FAQL-PB) was developed on a US sample to assess the QoL of parents with food allergic children. The aim of this study was to examine the reliability and validity of the FAQL-PB in a UK sample and to assess the effect of asking about parental burden in the last week compared with parental burden in general, with no time limit for recall given.
Methods A total of 1,200 parents who had at least one child with food allergy were sent the FAQL-PB and the Child Health Questionnaire (CHQ-PF50); of whom only 63 % responded.
Results Factor analysis of the FAQL-PB revealed two factors: limitations on life and emotional distress. The total scale and the two sub-scales had high internal reliability (all $\alpha > 0.85$). There were small to moderate but significant correlations between total FAQL-PB scores and health and parental impact measures on the CHQ-PF50 ($p < 0.01$). Significantly greater parental burden was reported for the no-time limited compared with the time-limited version ($p < 0.01$).
Conclusions The FAQL-PB is a reliable and valid measure for use in the UK. The scale could be used in clinic to assess the physical and emotional quality of life in addition to the impact on total quality of life.

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Abbreviations

FAQL-PB	Food Allergy Quality of Life—Parental Burden Scale
QoL	Quality of life
CHQ-PF50	Child Health Questionnaire—Parent Form

Introduction

Food allergy is an immunologically mediated adverse reaction to food, with the majority of reactions from milk, eggs, peanuts, tree nuts and shellfish [1]. There is no cure for food allergies, and the only way to prevent an allergic reaction is constant vigilance and strict avoidance of the particular food. Symptoms can range from mild itching or a rash, treated with antihistamine, to anaphylactic shock which includes swelling of airways, difficulty breathing, loss of consciousness and death if not promptly treated with adrenaline [1]. The prevalence of food allergies appears to be increasing and is currently thought to affect between 2 and 10 % of the population in the UK [1–3].

Research has identified that those suffering from food allergy as well as those caring for food allergic children have a poorer quality of life (QoL) than either healthy controls or those suffering from other chronic conditions [4–10]. Sicherer et al. [4] reported parents of children with nut allergy reported lower scores than a healthy norm group for general health perception, had greater distress and worry for their child's condition and felt there were greater limitations and interruptions to family life. Marklund et al. [6] compared parents of food hypersensitive school children with parents of children with no allergic disease and found that the former reported a significantly greater impact on parental emotions, parental time and family activities. A study in the UK [7] demonstrated that having a child with peanut allergy particularly affected the mothers, who had poorer quality of life and higher stress and anxiety levels than fathers. More recently, a study also found that mothers of food allergic children reported poorer overall quality of life and had poorer social relationships than mothers of healthy children [10].

The majority of these studies used generic QoL measures, and recently, validated food allergy-specific quality of life measures have been published [11–14]. Gerth van Wijk [15] has suggested that this is an area that would benefit from the development and validation of more specific measurements, particularly for the effect of a child's food allergy. In order to address this, Cohen et al. [16] developed the Food Allergy Quality of Life—Parent Burden Questionnaire (FAQL-PB), which was validated on a sample of 352 parent participants from the USA. This process highlighted that further development was needed to overcome the methodological issues and validation was also needed on other populations. The aim of the present study was to validate the FAQL-PB in a sample of parent participants from the UK. As the scale was developed in the United States, there may be environmental or cultural differences or differences in health care regarding food allergy which means that the items developed are not valid in other countries [17]. By establishing whether the FAQL-PB is a valid measure in the UK, it will ensure it can be utilised in further studies and interventions which aim to improve QoL in parents of children with food allergies.

In addition, Cohen et al. [16] noted that it may be useful to look at whether the time span participants are given to report the burden of food allergy has an effect on the results. Therefore, in this study, a proportion of participants were asked to respond to how their child's food allergy had affected their life in general (with no time span given) and other participants were asked to record impact they had experienced over the previous week (as stated in the original version of the scale).

Methods

Design

This was a questionnaire-based cross-sectional design and involved the administration of a questionnaire pack consisting of questions designed to ascertain demographic information, the Food Allergy Quality of Life—Parental Burden Questionnaire (FAQL-PB) to identify levels of parental burden and the Child Health Questionnaire—Parent Form (CHQ-PF50) to measure child's health.

Materials

The Food Allergy Quality of Life—Parental Burden Scale (FAQL-PB) [16]

The Food Allergy Quality of Life—Parental Burden (FAQL-PB) Scale is a 17-item instrument. It utilises 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. The number circled for each question is summed to provide a total continuous score with a higher score indicating greater burden on the family. Scores can range from 17 to 119 or can be divided by 17 to obtain a mean total score from 1 to 7. Internal validity has been reported as strong (Cronbach α, 0.95) [17].

In the present study, the FAQL-PB Scale was modified, for a sample of participants, to look at how the child's food allergy affects parents when no time limit for recall is given. For example, a question with a time limit stated 'In the past week, how troubled have you been that your child may not overcome their allergy?' For the modified version, the words 'In the past week…' were removed and parents were asked to rate each item based on how they felt each item affected them in general. This allowed participants to answer without being restricted to just recalling what had happened in the past week. This is in line with issues identified by Cohen et al. [16] who noted that participants mentioned that sometimes their results were affected by what they had been doing in the previous week, and if that was not typical of their normal routine, then that may not accurately reflect the parental burden. In all versions, the word 'holiday' was used instead of the word 'vacation' as the former is a term more generally used in the UK.

The Children's Health Questionnaire—PF50 (CHQ-PF50) [18]

The Child Health Questionnaire—Parent Form—50 is a frequently used basic generic health measurement tool, which is used to examine the physical and psychosocial functioning in children; it has been validated for parents of children aged 5–18 years and was used by Cohen et al. [13] in their validation study. It consists of 15 sub-scales (with 1–6 items in each sub-scale) that measure functioning on a range of physical and psychosocial dimensions. Items are rated on 4–6 point Likert scales with responses typically ranging from limited a lot to not limited at all. Scores are summed and then divided by the number of items within the scale to obtain a mean score for each sub-scale; a lower score indicates poorer child health. It has been validated on both clinical and non-clinical samples and has excellent reliability with Cronbach's $\alpha > 0.85$ for child and parent normal sub-sample groups and >0.84 for an asthma clinic population [18]. Internal consistency for this sample of UK parents was good with alphas ranging from 0.76 to 0.92, apart from two sub-scales measuring parental impact-emotional ($\alpha = 0.67$) and general health perceptions ($\alpha = 0.63$).

Demographic and food allergy questionnaire

A demographic questionnaire consisted of a series of closed response questions to gather details about the foods, symptoms and severity of food allergy suffered by each child and demographic information about the child and parent completing the scales. This questionnaire was designed by the researcher, based on questionnaires used in previous published research [19].

Parents also answered two expectations of outcome questions, following what had been used by Cohen et al. [16]. These were ‘How great do you think your child’s chance is of having a serious reaction upon ingesting the food(s) to which s/he is allergic?’ and ‘How great do you think your child’s chance is of dying if your child should ingest food(s) to which s/he is allergic?’ These were answered on a 7-point Likert scale (no chance, very small chance, small chance, moderate chance, large chance, very large chance and always).

Participants

Participants were all parents of children with food allergy, identified through the Anaphylaxis Campaign, UK. This is a charity that offers support predominantly to parents of children with food allergy. In order to comply with data protection, ethical and confidentiality guidelines, the charity was provided with the questionnaire packs to distribute; this ensured that the researchers had no access to identifiable personal information about the sample. The charity was responsible for selecting 1,200 of their members from their database to whom they sent packs out, of which 754 were returned (a response rate of 63 %).

Procedure

Questionnaire packs were sent to 6 members of The Anaphylaxis Campaign for pilot testing, and all participants stated the instructions and questions were clear. The Anaphylaxis Campaign UK was then asked to post questionnaire packs out to a random sample of 1,200 members, which equates to approximately 20 % of their members. Questionnaire packs were delivered to The Anaphylaxis Campaign with the two versions of the questionnaire placed in the packs in a random order, and the Campaign was asked to send these to a random selection of 1,200 parents from their database of parents who had children with food allergy. The packs included a cover letter explaining how to take part in the study, ethical considerations and how to return the questionnaires. Participants were asked to complete the questionnaires and place them in a postage paid envelope addressed to the lead researcher. As the study was anonymous, no follow-up of non-responders was conducted.

Ethical considerations

The study was conducted in accordance with the British Psychological Society’s Code of Ethics and Conduct [20] and was approved by the Department’s Psychology Research Ethics Committee and the Medical Advisory Board of the Anaphylaxis Campaign. All participants gave their informed consent to take part in the study.

Data analysis

Data were analysed using SPSS version 18.0. There were no floor or ceiling effects for any of the items in the FAQL-PB. Kolmogorov–Smirnov tests were run to assess normality, which revealed most scale scores were not normally distributed, although the FAQL-PB total score was within accepted levels for skewness. Nonparametric tests were, therefore, conducted. Chi-square and Mann–Whitney *U* tests were conducted to assess the differences between demographic information in the two groups of participants. Principle components factor analysis with an orthogonal varimax rotation was conducted on the FAQL-PB. This exploratory method was chosen as factor analysis had not previously been applied to this scale, and so, there were no hypotheses regarding the presence of sub-scales. The determinant for the correlation matrix was 0.2 showing that there was no multicollinearity in the data. The Kaiser–Meyer–Olkin measure of sampling adequacy was 0.955 and the Bartlett’s test was significant ($\chi^2(136) = 9{,}520.48$, $p < 0.001$), indicating that patterns of correlations are relatively compact and factor analysis should produce distinct, reliable and meaningful factors [21].

Reliability analysis was conducted on the FAQL-PB in order to ascertain Cronbach’s α coefficient for each version of the scale. In order to assess convergent validity, Spearman’s bivariate correlations were conducted between the FAQL-PB questionnaire mean total score and the CHQ-P50 mean sub-scale scores and with the expectation of outcome mean scores. A priori hypotheses were set regarding reliability and validity of the scale, following criteria set out by Pesudovs et al. [22] and the results reported by Cohen et al. [16]. We expected Cronbach’s alpha of >0.7 and <0.9 and moderate convergent validity correlations of >0.3 with sub-scales measuring similar aspects to the scale, including affects on parent’s time, emotions, activities and general health.

We expected low correlations <0.3 with the other subscales. Mann–Whitney *U* tests were conducted to determine whether there were different total burden scores for the FAQL-PB and the modified FAQL-PB. Due to the number of comparisons run, Bonferonni corrections were applied to reduce Type I errors which reduced the accepted alpha level to 0.01.

Results

Characteristics of respondents

A total of 444 parents returned the time-limited questionnaire (63.4 % response rate) and 310 with no time limit (62 %) were returned. The majority (92.5 %) were completed by the mothers of children with food allergy. Demographics and food allergy characteristics of the time-limited and no-time-limited groups were not significantly different apart from children with allergy being slightly younger in the no-time limit group and number of children in the family being slightly higher in the time limit group (Table 1). Almost all respondents stated that their child's food allergy had been clinically diagnosed by skin prick, blood test or food challenge (98.7 %). The remainder stated their child's allergy had been diagnosed by clinical history only (Table 1). Children suffered mainly from an allergy to peanut and tree nuts (37 %), peanut only (14.8 %), tree nut only (1.9 %), dairy (9.4 %), egg (15.6 %), fish (4.2 %), fruit (6.8 %) and sesame (0.4 %). Symptoms included facial swelling (25.5 %), hives (14.9 %), itching or a rash (20.9 %), breathing difficulties (15.8 %), and 22.9 % had suffered anaphylactic symptoms.

Factor structure of the FAQL-PB

Principal Components Factor Analysis with varimax rotation was conducted to look at the factor structure of the FAQL-PB with and without a time limit and on the overall group. All analyses provided the same solution; therefore, results of the whole group are reported here. The analysis revealed two factors with eigenvalues over one. The component transformation matrix was symmetrical showing that the two factors were not correlated. An oblique rotation was run and produced factor loadings that were virtually identical. As the transformation matrix was symmetrical, the varimax-rotated solution was retained.

Table 2 shows both factors with factor loadings, eigenvalues and the variance explained. All items had factor loadings of >0.4 apart from item 15: 'How troubled have you been about concerns for your child's nutrition because of their food allergy?' This item also had the

Table 1 Characteristics of respondents in the time-limited and no-time-limited groups and the whole group

	Whole group	Time-limited group	No-time-limited group	*P* values
Gender of respondent mother	699 (92.5)	412 (92.8)	286 (92.3)	0.79
Married/co-habiting	645 (85.3)	377 (84.9)	268 (86.5)	0.56
Single/divorced/widowed	85 (11.3)	53 (11.9)	31 (10.0)	0.41
Work status				
Working full-time or part-time	533 (70.5)	320 (72.0)	213 (68.8)	0.32
Homemaker/unemployed/retired	195 (25.7)	108 (24.3)	86 (27.7)	0.30
Children in family (mean *N*)	2.1	2.2	2.0	0.01
Children in family with food allergy (mean *N*)	1.1	1.1	1.1	0.98
Food allergic children's age (mean years)	8.9	9.5	8.2	<0.001
Gender of child with food allergy				
Male	500 (60.9)	303 (62.6)	196 (58.5)	0.24
Female	321 (39.1)	181 (37.4)	139 (41.5)	0.24
Number of food allergies reported				
1 allergy	402 (49.1)	246 (51.0)	155 (46.3)	0.20
>1 allergy	417 (50.9)	236 (49.0)	180 (53.7)	0.16
Allergy diagnosed clinically	810 (98.7)	483 (99.8)	327 (97.6)	0.12
Suffers from anaphylaxis	474 (57.7)	275 (56.8)	197 (58.9)	0.57
Has medication	790 (96.2)	465 (96.1)	323 (96.4)	0.80
Carries EpiPen/AnaPen	749 (91.2)	442 (91.3)	306 (91.3)	0.95
Has eczema/asthma/hay fever	580 (76.7)	340 (76.6)	239 (77.1)	0.59

Values given as number (%)

Table 2 Factor analysis loadings, eigenvalues and % variance explained for FAQL-PB

Item (abbreviated wording)	Factor one emotional distress	Factor two limitations on life
Frightened by thought child will have a reaction	0.828	
Worry won't be able to help child if they have allergic reaction	0.812	
Worry that child may not overcome their food allergy	0.808	
Sadness regarding burden child carries because of food allergy	0.796	
Troubled by concerns over child's health	0.785	
Troubled by child attending school, camp or daycare	0.769	
Anxiety related to child's food allergy	0.756	
Troubled by leaving child in care of others	0.751	
Concern over child being near others while eating	0.710	
Frustration over others lack of appreciation of seriousness of allergy	0.695	
Worry child will not have normal upbringing	0.683	
Choices limited when planning a holiday		0.837
Choices limited when going to a restaurant		0.835
Limited when participating in social activities		0.800
Have to spend extra time preparing meals	(0.426)	0.625
Take special precautions before leaving the house	(0.497)	0.585
Concern over child's nutrition		0.392
Eigenvalue	7.21	3.99
Percentage of variance explained	42.39	23.48

lowest corrected item-total correlation (0.50) and inter-item correlation (0.28). However, the loading for this was adequate at 0.39. Two items had cross-loadings (loadings in brackets in Table 2) and were assigned to the factor with the highest loading. The first factor consists of 11 items and relates to emotional distress with questions such as 'How troubled have you been by sadness regarding the burden your child carries because of their food allergy?' The second factor consists of 6 items and refers to limitations on life such as 'If you and your family were planning a holiday/vacation, how much would your choice of holiday/vacation be limited by your child's food allergy?'

Internal reliability of the questionnaire

Cronbach's alphas were excellent for the overall scale for the whole group and for the time-limited and no-time-limited groups (all $\alpha > 0.94$), although the very high alpha indicates some possible redundancy within the scale. Internal consistency was also good for the two domains revealed in the factor analysis (Table 3). Alphas in all versions dropped if any items were deleted (apart from item 15, although this only increased alpha by 0.03), demonstrating all items were important to the scale. Inter-item correlations were above 0.30 for all items (apart from item 15 which was 0.28). Corrected item-total correlations were above 0.50 for all items. Guttman split half-coefficients were >0.90 for both versions of the scale and for the whole group.

Convergent validity of the scale

The total mean score for the FAQL-PB was significantly negatively correlated with all sub-scales of the CHQ-PF50, apart from changes in health and family cohesion (Table 4). As expected, correlations were small to moderate. The same pattern was found for the time-limited and no-time-limited versions of the scale, except in addition, the time-limited version did not correlate with self-esteem and the no-time-limited version did not correlate with global behaviour. Total FAQL-PB mean score also correlated significantly with both expectation of outcome questions and the mean of the expectation of outcome questions, demonstrating food allergy-specific construct validity (Table 4).

Discriminative validity of the scale

The whole group

There was a significant difference between mean FAQL-PB scores depending on whether you were married/co-habiting or single/divorced/widowed, with the latter having a significantly higher burden score ($p < 0.001$) (Table 5). Employed parents had significantly lower scores than unemployed parents ($p = 0.003$), and parents of children with only one food allergy scored lower than parents of children with more than one food allergy ($p = 0.006$). Parents of children who suffered from anaphylaxis also

Table 3 Cronbach's α for FAQL-PB Scale and the two sub-scales

	Factor one limitations on life	Factor two emotional distress	Overall scale
Whole group	0.952	0.860	0.952
Time-limited group	0.950	0.860	0.952
No-time-limited group	0.930	0.857	0.941

scored higher than parents of children who did not ($p = 0.002$) (Table 5).

Time and no-time-limited version of the scale

The time-limited version of the scale discriminated along marital status with married parents scoring significantly lower than those not married, divorced or widowed ($p = 0.01$). Parents who worked scored significantly lower than parents who did not work ($p = 0.01$) (Table 5). There were no other significant differences at the $p < 0.01$ level for this version of the scale. The no-time-limited version only discriminated along marital status ($p = 0.002$) (Table 5). Neither version of the scale differentiated between gender of child, number of children with food allergy, number of allergies and the presence or not of atopy and anaphylaxis. Comparisons for carrying medication could not be made due to low number of those who did not.

Parental burden with and without a time limit

The mean FAQL-PB score for the whole group was 69.99 (SD = 23.17). It has been suggested [23] that a score difference of 0.5 in a questionnaire with a 7-point Likert scale is the smallest difference in score which patients would perceive as beneficial and would mandate a change in the patient's management [24]. Mean item scores ranged from 1.12 to 7, indicating that all parents in this sample were over the threshold for minimal important difference, although caution should be exercised as this measure is more often used in longitudinal studies to measure change after an intervention [25]. Mann–Whitney *U* test showed that participants in the no-time-limited group reported significantly poorer quality of life (total mean score = 79.9; SD = 20.0) than those in the time-limited group (mean = 63.3; SD = 22.9) ($p < 0.001$). Total mean scores in the no-time-limited group were significantly higher than the time-limited group along a number of demographic and food allergy parameters (Table 5) (all $p < 0.001$).

Discussion

The FAQL-PB has previously been shown to be a reliable and valid tool to use in a US sample of parents. The aim of the present study was to investigate the generalizability of

Table 4 Correlations between the FAQL-PB mean total score with the CHQ-PF50 mean sub-scale scores and expectation of outcome questions

CHQ-PF50	Whole group	Time-limited group	No-time-limited group
Global health (GGH)	−0.260**	−0.243**	−0.360**
Physical functioning (PF)	−0.205**	−0.223**	−0.208**
Role/social limitations—emotional-behavioural (REB)	−0.238**	−0.270**	−0.231**
Role/social limitations—physical (RP)	−0.256**	−0.216**	−0.341**
Bodily pain (BP)	−0.169**	−0.139**	−0.235**
General behaviour (BE)	−0.155**	−0.172**	−0.150*
Global behaviour (GBE)	−0.102*	−0.148**	−0.085
Mental health (MH)	−0.251**	−0.267**	−0.240**
Self-esteem (SE)	−0.109**	−0.059	−0.193**
General health perceptions (GH)	−0.408**	−0.373**	−0.540**
Changes in health (CH)	0.070	0.095	0.040
Parental impact-emotional (PE)	−0.314**	−0.351**	−0.348**
Parental impact-time (PT)	−0.419**	−0.466**	−0.450**
Family activities (FA)	−0.390**	−0.446**	−0.411**
Family cohesion (FC)	−0.031	−0.009	−0.054
Expectation of outcome			
Serious reaction on ingestion of food	0.218**	0.189**	0.255**
Dying on ingestion of food	0.361**	0.317**	0.455**
Expectation of outcome mean score	0.344**	0.301**	0.418**

* $p < 0.05$; ** $p < 0.01$

Table 5 Mean (SD) FAQL-PB total scale scores for the time-limited group, no-time-limited group and the whole group, split by respondent characteristics

	Whole group	Time-limited group	No-time limited group	*p* values[a]
Parent gender				
Male	66.69 (17.74)	61.83 (17.02)	72.93 (17.23)	0.18
Female	69.88 (23.62)	63.10 (23.38)	79.71 (20.33)	<0.001
Marital status				
Married	69.00 (23.27)[b]	62.42 (22.85)[c]	78.29 (20.58)[d]	<0.001
Single/divorced/widowed	75.56 (21.87)[b]	68.30 (22.98)[c]	86.46 (14.39)[d]	<0.001
Work status				
Working	68.19 (23.55)[b]	61.50 (23.09)[c]	78.31 (20.47)	<0.001
Not working	73.96 (22.33)[b]	67.57 (22.70)[c]	82.00 (19.27)	<0.001
Gender of child with allergy				
Male	69.94 (23.23)	64.09 (23.32)	78.73 (20.08)	<0.001
Female	70.07 (23.12)	62.02 (22.28)	80.43 (19.97)	<0.001
N of children with food allergy				
1 child	69.30 (23.30)	62.33 (22.93)	79.27 (20.02)	<0.001
>1 child	75.24 (24.05)	71.11 (24.88)	80.74 (22.15)	0.53
N of allergies				
1 allergy	67.47 (22.58)[b]	61.36 (22.86)	76.68 (18.51)	<0.001
>1 allergy	72.37 (23.51)[b]	65.33 (22.91)	81.70 (21.02)	<0.001
Child atopic				
Yes	70.82 (23.36)	64.10 (23.21)	80.33 (20.11)	<0.001
No	67.28 (22.41)	60.88 (21.99)	76.37 (19.53)	<0.001
Child suffers from anaphylaxis				
Yes	72.23 (23.37)[b]	64.30 (23.35)	83.04 (18.59)[d]	<0.001
No	66.55 (22.73)[b]	62.10 (22.56)	73.37 (21.33)[d]	<0.001

Values given as mean (SD)

[a] *p* values for comparisons between time-limited and no-time-limited groups

[b] $p < 0.01$ for comparisons between the participant characteristic for the whole group

[c] $p < 0.01$ for comparisons between the participant characteristic for the time-limited group

[d] $p < 0.01$ for comparisons between the participant characteristic for the no-time-limited group

the scale to a UK sample, using support group parents of children with food allergy. The study also aimed to investigate whether the length of time a parent is asked about the burden of food allergy has an impact on the level of burden they report. The results demonstrated the scale to have excellent internal consistency with high alpha levels in both the time-limited and no-time-limited versions and across the whole group. The high Cronbach's α for the scale does suggest there may be some redundancy in the scale and a shorter one, more ideal for clinical use, could be developed while retaining the overall reliability and validity of the scale. Factor analysis demonstrated that the scale may be measuring two types of parental burden: limitations on life and emotional distress. Both of these domains had excellent internal reliability in both versions of the scale. It may, therefore, be possible to adapt the scale to incorporate 2 sub-scale scores as well as an overall score in order to provide more information on the type of parental burden that is most salient, particularly as factor analysis revealed that these two latent variables were not correlated and so measured different aspects of the parent burden construct. Similar results have been found in a study assessing QoL in Chinese families [26]. Leung et al's factor analysis of the FAQL-PB also resulted in two factors with broadly the same items loading onto each factor. They found a smaller number of items loading onto factor two, but identified that one factor concerned social limitations and the other concerned emotional impact and food anxiety, similar to the present study. Confirmatory factor analysis will need to be conducted on the scale before the factor structure of the scale can be confirmed.

The scale demonstrated good cross-sectional convergent validity with significant correlations with most of the sub-scales of the CHQ-PF50. In most cases, the strength of the correlations was weak to moderate; this was expected and suggests the scale is not merely measuring parental burden associated with general health. The strongest correlations were with general health perceptions, parental impact-time and parental impact-emotional and family activities, areas found to significantly correlate with the original US sample [16]. Interestingly, no version of the FAQL-PB Scale correlated with changes in health or family cohesion, which is different to findings of other studies. Marklund et al. [6] found that food hypersensitive children with food-induced breathing difficulties reported improved family cohesion. Similarly, Sicherer et al. [4] found family cohesion to be stronger in families with a peanut allergic child compared to healthy norm population scores. This may be because changes in health and family cohesion are measured using only one item in the CHQ-PF50 which can reduce reliability or because the present study was not restricted to children with peanut allergy or breathing difficulties. Changes in general health may also not be sensitive to differences in burden associated with food allergy. More recent studies have also failed to find an association between quality of life and family cohesion [13], and so, further research is needed to understand its relationship with families with food allergy.

The scale demonstrated good convergent disease-specific validity with significant correlations with the expectation of outcome questions. The strength of the correlations were similar to that found previously by Cohen et al. [16] although was slightly less strong than correlations found in the development of other health-related quality of life scales using these expectation of outcome questions [27]. The scale was able to discriminate between some demographic characteristics; however, despite previous research highlighting the importance of gender in food allergy [4], there were no differences in scores depending on gender of food allergic child or gender of parent. This is probably due to the very low number of fathers completing the scale and due to the FAQL-PB measuring burden on the whole family, rather than the QoL of the child (which is where gender differences have been found in previous studies). This may mean that burden on family is not influenced by the gender of the child.

Removing the time limit had a significant impact on the level of burden reported. This version of the scale may, therefore, be useful to gauge how the child's food allergy affects all areas of family life as it is not restricted to just looking at what has occurred over the previous week and would be relevant for a first time use in clinic or for research purposes. This idea was supported in that some parents who returned the time-limited version of the questionnaire stated that they felt restricted reporting how they had felt over the past week and that this did not give a accurate representation of their levels of parental burden. Having a time limit of one week could affect results gained from the scale in two ways. Parents may have an untypical week and be planning a holiday or a social outing in the week preceding completion of the scale, possibly increasing burden scores, or may not be doing something they usually do, thus reducing their burden scores. Completing the scale over school holidays may also affect the scores. So looking at burden in the previous week may be a useful clinical tool to assess the burden felt at that moment in time but may not accurately reflect the benefits of any interventions that may be put in place. Interventions may focus on better coping and food allergy management skills across a range of areas, and so a scale that asks about the burden parents feel in general may better reflect changes in their perceived ability to cope and the burden they feel. Having two versions gives more choice for clinicians and researchers to choose the most appropriate depending on their aims for administering the scale.

There are a number of limitations of this study. Although parents represented a range of demographics, they were also predominantly white and mothers of food allergic children. This is very typical of members of the Anaphylaxis Campaign, and foods reported were fairly representative of the pattern of food allergy reported in the UK [1, 3]; however, there may be a response bias, as we were not able to ascertain characteristics of members of the Campaign who were not selected or did not return their questionnaires. These parents may represent parents of highly allergic children who, therefore, report a greater burden of food allergy. Or they may feel they suffer less burden, as they have the help and support of the Anaphylaxis Campaign, who run a website, a helpline and a small number of parent workshops each year. It would, therefore, be useful to validate this scale on clinic populations and parents who do not belong to a support group.

Conclusions

This study has demonstrated that the FAQL-PB (with a time limit or without) is reliable and valid for a UK population. Factor analysis revealed two distinct domains: emotional distress and limitations on life. Gaining information on which type of parental burden is more salient may be useful in order to appropriately direct support for parents. Having versions of the scale with and without time limits increases the choice for clinical and research use and can be utilised to measure short- and longer-term changes over time or effects of an intervention. Validation using a range of different time frames and on clinic and non-support group populations is now needed.

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