

ORIGINAL ARTICLE

A new quality of life scale for teenagers with food hypersensitivity

Heather MacKenzie¹, Graham Roberts², Darren Van Laar³ & Taraneh Dean⁴

¹School of Health Sciences and Social Work, University of Portsmouth, Portsmouth, UK; ²David Hide Asthma and Allergy Research Centre, Isle of Wight and University of Southampton, Southampton, UK; ³Department of Psychology, University of Portsmouth, Portsmouth, UK; ⁴School of Health Sciences and Social Work, University of Portsmouth, Portsmouth and David Hide Asthma and Allergy Research Centre, Isle of Wight, UK, Portsmouth, UK

To cite this article: MacKenzie H, Roberts G, Van Laar D, Dean T. A new quality of life scale for teenagers with food hypersensitivity. *Pediatr Allergy Immunol* 2012; **00**.

Keywords

teenagers; food hypersensitivity; food allergy; health-related quality of life.

Correspondence

Taraneh Dean,
School of Health Sciences and Social Work,
University of Portsmouth, James Watson
West, 2 King Richard 1st Road,
Portsmouth, PO1 2FR, UK.
Tel.: +44 0 23 9284 4405
Fax: +44 0 23 9284 4402
E-mail: tara.dean@port.ac.uk

Accepted for publication 24 February 2012

DOI:10.1111/j.1399-3038.2012.01302.x

Abstract

Background: A disease-specific health-related quality of life (HRQL) scale enables the impact of current and new interventions on the HRQL of teenagers with food hypersensitivity (FHS) to be evaluated. No such scale exists for teenagers with FHS living in the UK. This research aimed to develop and validate a disease-specific HRQL scale for this group, thus facilitating HRQL measurement in this population.

Methods: A preliminary 51-item questionnaire was generated from interviews with 21 teenagers with FHS, the coverage and acceptability of which was refined in pre- and pilot testing (N = 102). On the basis of the field test data (N = 299), principal components analysis identified those items best measuring HRQL.

Results: The final 34-item You and Your Food Allergy scale covered five domains: social well-being and independence, support, day-to-day activities, family relations and emotional well-being. The whole scale displayed excellent internal consistency (Cronbach's $\alpha = 0.92$) and test-retest reliability (ICC = 0.87). The scale correlated as hypothesised with a generic HRQL scale (PedsQL) and discriminated by disease severity, providing evidence for its construct validity.

Conclusions: The You and Your Food Allergy scale is the first HRQL scale to have been developed and validated with UK teenagers with FHS. Subject to further evaluation of its psychometric properties, its development has important applications in future research into the HRQL of teenagers with FHS. Short and easy-to-complete, the scale has been designed to appeal to teenagers and is likely to be useful to facilitate discussion of HRQL issues.

In the field of allergy, the importance of measuring health-related quality of life (HRQL) in research and clinical practice has been recognised (1). This is particularly salient in teenagers with food hypersensitivity (FHS). The constant vigilance required to manage FHS may affect many aspects of the sufferer's life (2), and the aspects of the HRQL of teenagers with FHS (who are coping with increasing responsibility for their FHS) have been found to have been impaired compared with teenagers without FHS (3, 4). Such findings have been supported by qualitative research (5–8). Hence, it is clear that, in addition to ensuring that teenagers are able to manage their FHS safely, it is also important to monitor the impact of FHS on teenagers' HRQL and to evaluate the effectiveness of interventions designed to improve it. Disease-specific HRQL scales are required for this purpose; they are sensitive to the particular aspects of HRQL affected by a

disease and are therefore more clinically relevant than generic HRQL scales (9). Two such scales exist for teenagers with FHS: one developed for use with a Dutch and the other with a US population, the FAQLQ-TF (10) and FAQL-teen, respectively (11). However, no scale exists to measure the HRQL of UK teenagers with FHS.

While it might appear that one of the existing scales could be used in the UK, there are two key reasons why this may not be appropriate. Firstly, it is not sound practice to use scales developed in other countries without conducting extensive work not only to translate the content of the measure but also to establish its reliability and validity in the new context (12). Secondly, the influence of culture on what individuals consider important for their HRQL (13) can compromise the cross-country transferability of HRQL scales as items of significant importance to the HRQL of the new

population may not be present if such issues were not relevant in the country in which it was developed (14). This study therefore aims to develop a disease-specific HRQL scale developed on and for teenagers with FHS living in the UK, and to assess the reliability and validity of the resultant scale. This approach will additionally enable a cross-country comparison of the domains underlying the HRQL of teenagers with FHS living in the UK, the United States and the Netherlands.

Methods

Development of the You and Your Food Allergy scale

The HRQL scale was developed in stages as follows (Fig. 1 provides further detail about the objectives and methods for each stage):

Stage 1 – Developing a preliminary HRQL scale: Item generation was informed by qualitative data from a previous study involving 21 interviews with teenagers (aged 13–18 yr) with FHS (8), a literature review and the following working definition of HRQL: *HRQL is an individual's perception of the impact of any aspect of their health (including disease, treatments and healthcare interventions) on important aspects of their life.*

Stage 2 – Pre-testing the preliminary measure: Teenagers with and without FHS (recruited from an allergy clinic in the South of England and a local High School respectively), health professionals working with teenagers with FHS (at an allergy clinic in the South of England) and other professionals working with teenagers (from a local High School) checked the general presentation, readability and tone of the preliminary scale, and made suggestions for improvements.

Stage 3 – To test the pilot scale to identify any problematic items: 102 teenage members (13–18 yr) of the Anaphylaxis Campaign (a national charity which aims to help people with food allergies) from across the UK completed the pilot measure.

Stage 4 – To reduce the number of items in the field test scale to those best measuring HRQL (item reduction): 800 teenage members of the Anaphylaxis Campaign from across the UK (who had not previously been approached via the Anaphylaxis Campaign to take part in a research study) were invited to take part.

Ethical approval was granted by the Southampton and South West Hampshire Research Ethics Committee (A) (07/Q1702/60). Data were stored in accordance with the Data Protection Act.

Recruitment

In all stages, parents of teenagers were sent an information pack, including parent and teenager information sheets, questionnaires and a stamped return envelope. They were asked to pass this to their son or daughter should they be happy for them to be invited to take part. In stage 4, the packs also contained a reply slip for the test–retest study. Teenagers were told that they did not have to participate and were free to withdraw at any time. A reminder letter was sent after 2 wk. Returned questionnaires indicated consent. In stage 3, teenagers were also able to complete the questionnaire online. In stage 2, participants with FHS were recruited from an allergy clinic and had a confirmed clinical diagnosis of FHS. In stage 4, participants were recruited via a support organisation from which it was not possible to confirm whether participants had a clinical diagnosis of FHS. However, 98.6% of these participants reported having been prescribed an adrenaline autoinjector, which suggests that the vast majority had been given a clinical diagnosis.

Approach to item reduction

Factor analysis is a common approach to item reduction which examines inter-item correlations to determine which items best measure HRQL and empirically identify the number and content of underlying domains of HRQL (15). An

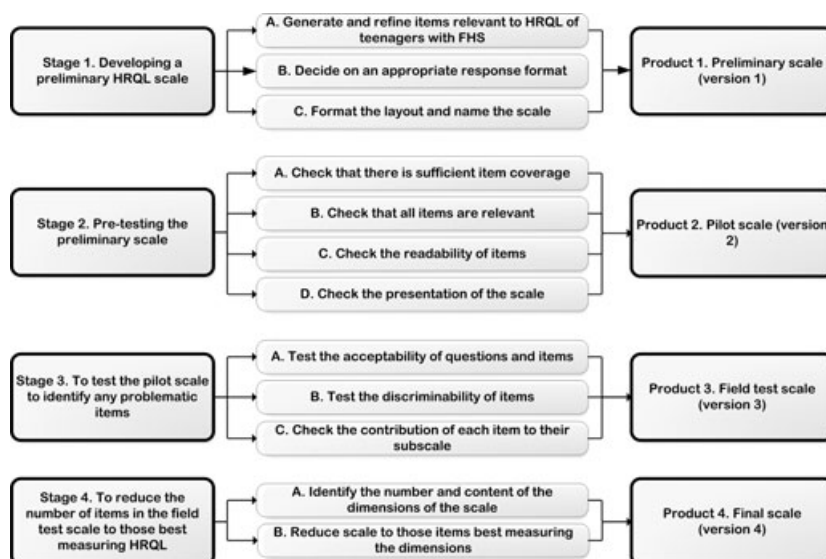


Figure 1 Further information about the objectives and methods for each stage.

alternative is the clinical impact method, which scores items for 'impact' according to a combination of the proportion of respondents experiencing the HRQL issue and the degree to which they found it troublesome; items falling below a cut-off point for 'impact' are excluded from the scale (16). In practice, both approaches appear to give very similar results (16–18). Proponents of the clinical impact method argue that its key benefit is that it includes only those items identified by patients as most important to their HRQL. However, the clinical impact method is not able to provide evidence to support the construct validity of the resultant scale, empirically identify the number and content of underlying subscales or provide evidence of the legitimacy of summing scores on the whole- and subscales. Hence, a factor analytic approach was chosen. The relevance of items to teenagers with FHS was ensured by alternative means: generating the initial item pool from qualitative research with patients (and relevant literature) to reflect salient issues, piloting the items with patients and relevant professionals, and excluding any items to which >95% of patients failed to reply or replied that it never affects them (i.e. items with low 'impact', although no items were excluded on this basis).

Hence, a principal components analysis (PCA, a type of factor analysis) was used to determine the number and type of domains underlying the HRQL of teenagers with FHS and reduce the number of items in the scale to those best measuring this. After testing for correlations between components (≥ 0.32) (19), PCA was conducted using an oblique rotation. The number of components extracted was determined by parallel analysis (20). PCA was conducted in an iterative manner, excluding items that failed to load and conducting further analyses until a simple structure was achieved (19).

Evaluating the reliability and validity of the You and Your Food Allergy scale

Various aspects of the reliability and validity of the You and Your Food Allergy scale were evaluated as follows, using the data from the field test sample:

Internal consistency measures the degree to which items on a scale measure the same underlying concept and provides evidence for the validity of producing summative scores from a scale (15). Cronbach's alpha was calculated for the whole scale and each subscale. Most authors agree that more than 0.7 is acceptable, >0.8 good and >0.9 excellent (15).

Test-retest reliability concerns the stability of a scale over time and provides evidence that score changes reflect real changes in HRQL (21). Participants in the field test sample were asked to complete the You and Your Food Allergy scale a second time (after 4 wk). Participants who indicated no change in HRQL were included in the test-retest reliability analysis. Intraclass correlations were calculated as follows: <0.4 was considered poor, 0.4–0.59 fair to moderate, 0.6–0.74 good and more than 0.75 excellent (22).

Construct validity assesses the evidence that a scale measures what it intends to and is investigated by testing hypotheses derived from the theoretical construct on which the scale is based (21). Hypotheses were proposed to test convergent and divergent validity (respectively, whether the You and Your Food Allergy scale correlates with validated (sub)scales designed to measure similar or related constructs and does not correlate with (sub)scales designed to measure unrelated constructs) (23) and known-groups validity (the ability of the scale to discriminate between groups expected to have differing levels of HRQL) (23). These are summarised in Table 1.

To test hypotheses 1 and 2, participants in the field test were asked to respond to two questions measuring the overall quality of life (At the moment would you say your quality of life was...?: very poor/quite poor/neither poor nor good/quite good/very good) and the impact of FHS on this (Overall, how much do you think your food allergy affects your quality of life?: makes my life...much worse/a bit worse/doesn't affect my life/a bit better/much better). To test hypotheses 2–5, participants were also asked to complete a generic HRQL measure; the PedsQL teenager report (24). Pearson's correlation coefficients were calculated between the whole You and Your Food Allergy scale score, the two QL items and the PedsQL whole scale score; and between the You and Your

Table 1 Hypotheses for testing the construct validity of the You and Your Food Allergy scale

Hypothesis
Convergent validity
1. The You and Your Food Allergy whole scale score will correlate more highly with ratings of the impact of FHS on an individual's QL than with their rating of their overall QL.
2. The You and Your Food Allergy whole scale score will correlate moderately with a generic HRQL scale – the PedsQL teenager report (a 23-item scale composed of 4 subscales; Physical, Emotional, Social and School Functioning; 18).
3. There will be moderate correlations between the Emotional Well-Being and Social Well-Being subscales of the You and Your Food Allergy and equivalent PedsQL scales; Emotional Functioning and Social Functioning, and also between the Day-to-Day subscale and PedsQL Emotional Functioning subscale.
Divergent validity
4. There will be no/small correlations between the Support and Family Relations subscales and the PedsQL subscales (as the PedsQL has no equivalent subscales).
5. There will be no/small correlations between all subscales and the Physical Functioning PedsQL subscale (as the You and Your Food Allergy scale has no equivalent subscale).
Known-groups validity
6. The scale will be able to distinguish between those who were allergic to ≤ 2 foods and those who were allergic to >2 foods.

Food Allergy subscales, the subscales of the PedsQL and the global QL items. Correlations more than 0.5 were taken to indicate a high correlation between the scales: 0.5–0.31, moderate and ≤ 0.3 , small (23). To test the known-groups validity, participants were asked to report the number of foods to which they were allergic. An independent t-test was conducted to compare the whole scale scores of those allergic to ≤ 2 foods ($n = 198$) and those allergic to > 2 foods ($n = 91$).

Data screening

Respondents were asked to rate, on a five-point Likert scale (Never; Not often; Sometimes; Often; All the time), how often in the previous 4 wk issues had affected them. Responses were coded, entered into Microsoft Excel, and imported into SPSS for Windows 16.0 for analysis (SPSS Inc., Chicago, IL, USA). Prior to analysis, data were checked for accuracy, frequencies of endorsement (proportion of participants selecting a particular response to each item; this should not be $> 95\%$ of the sample) (26) and the level and type of missing data assessed. Appropriate screening was conducted for the univariate and multivariate analyses, and outliers treated by replacement by the next valid value where necessary.

Results

Field test response rate and sample characteristics

In total, 364 questionnaires were returned. Of these, 14 were not suitable for use; they had either been completed incorrectly, returned after the cut-off date, the individual had moved or the recipient was unable to complete them. Three hundred and fifty measures were suitable for analysis (44.5% response rate). Sample characteristics are presented in Table 2.

For the test–retest data, 216 participants agreed to participate for a second time: 85 questionnaires were returned, eight of which were after the cut-off date (37.0% response rate; 23.4% of those returning the original questionnaire). Participants whose HRQL had not changed in the intervening period were included ($N = 58$).

Results of data screening

No items had $> 95\%$ frequency of endorsement. Data were missing completely at random, and only one item had $> 5\%$ missing data (marginally so at 5.1%). Missing data were imputed using the prior knowledge method for cases with only one missing data point (21). Other cases were excluded (21). There were no significant deviations from normality or skew, and all relationships were linear.

Development of the scale

After data screening, 299 cases were available for analysis. Five components were extracted in the final PCA (Table 3). Of the original 51 items, 17 items were removed to produce a simple structure.

Table 2 Characteristics of the field test sample

Characteristics	
Gender, n (%)	
Male: Female	186 (53.1):154 (44.0)
Missing	10 (2.9)
Age (yr): Mean (s.d.)	15.10 (1.46)
Ethnic background, n (%)	
White British	314 (89.7)
Other	36 (10.3)
Living situation, n (%)	
Live with both parents	306 (87.4)
Other	35 (10.0)
Missing	9 (2.6)
Mother's: Father's qualifications, n (%)	
None	5 (1.4):6 (1.7)
High school	65 (18.6):60 (17.1)
Further education	107 (30.6):63 (17.9)
Higher education	141 (40.3):181 (51.7)
Don't know	21 (6.0):29 (8.3)
Missing	11 (3.1):11 (3.1)
Food(s) allergic to, n (%)	
Peanut	314 (89.7)
Tree nuts	233 (66.6)
Egg	49 (14.0)
Fruits	49 (14.0)
Sesame	43 (12.3)
Milk	29 (8.3)
Shellfish	25 (7.1)
Fish	18 (5.1)
Legumes	17 (4.9)
Soya	11 (3.1)
Wheat	8 (2.3)
Vegetables	2 (0.6)
Lupin	2 (0.6)
Other	13 (3.7)
Missing	3 (0.9)
Other allergic diseases, n (%)	
Hay fever	239 (68.3)
Asthma	232 (66.3)
Eczema	228 (65.1)
Pet allergy	185 (52.9)
House dust mite	112 (32.0)
Food allergies now outgrown	17 (4.9)
Drug allergy	12 (3.4)
Bee or wasp sting allergy	6 (1.7)
Latex	5 (1.4)
Missing	12 (3.4)
Have adrenaline, n (%)	
Yes:No	345 (98.6):4 (1.1)
Missing	1 (0.3)

The final version of the You and Your Food Allergy scale consists of 34 items across five subscales: Social Well-being and Independence; Support; Day-to-day; Family Relations; Emotional Well-being. The full scale and scoring instructions can be obtained by contacting the authors, although it should be noted that higher scores indicate better HRQL.

Table 3 Factor loadings for all items of the final extracted components

Item	Component				
	1 (Social Well-being and Independence)	2 (Support)	3 (Day to Day)	4 (Family Relations)	5 (Emotional Well-being)
In the past 4 wk how often have you...					
Felt that food allergy has stopped you having the social life you would like?	0.840	–	–	–	–
Felt that food allergy has stopped you from doing normal things others your age do?	0.812	–	–	–	–
Missed out on spending time with friends because of your food allergy?	0.747	–	–	–	–
Missed out on taking part in activities or hobbies because of your food allergy?	0.731	–	–	–	–
Felt that your food allergy has affected your relationships with boy/girlfriends?	0.577	–	–	–	–
Felt that you can't do as many things without your parents as you would like because of your food allergy?	0.572	–	–	–	–
Felt that you can do anything you want to in life in spite of food allergy? (Reversed)	0.512	–	–	–	–
Felt left out because of your food allergy?	0.475	–	–	–	–
Been able to do everything that you want to do in spite of your food allergy? (Reversed)	0.458	–	–	–	–
In the past 4 wk how often have you...					
Felt that other people have made it easier for you to live with food allergy? (Reversed)	–	0.706	–	–	–
Felt that others have been sympathetic about your food allergy? (reversed)	–	0.670	–	–	–
Felt that you have enough support for your food allergy? (reversed)	–	0.654	–	–	–
Felt you have someone to talk to when you are upset or worried about food allergy? (reversed)	–	0.647	–	–	–
Made it easier for you to live with your food allergy? (Reversed)	–	0.460	–	–	–
In the past 4 wk how often have you...					
Found it a pain having to take precautions over your food allergy?	–	–	0.703	–	–
Found it annoying checking to make sure food is safe for you to eat?	–	–	0.687	–	–
Felt annoyed about having food allergy?	–	–	0.671	–	–
Felt annoyed about carrying medication?	–	–	0.588	–	–
Felt that you have been unable to eat all the food you would like to because of food allergy?	–	–	0.571	–	–
Felt that food allergy has had a good effect on your life? (reversed)	–	–	0.545	–	–
Felt frustrated because of food allergy?	–	–	0.515	–	–
Felt you have missed out on food because of your food allergy?	–	–	0.491	–	–
Felt sad that you have a food allergy?	–	–	0.455	–	–
Found it difficult to communicate about your dietary needs?	–	–	0.424	–	–
In the past 4 wk how often have your parents...					
Worried about you more than you would like because of your food allergy?	–	–	–	0.823	–
And you argued more than you would like about your food allergy?	–	–	–	0.761	–
Been more upset than you would like because of your food allergy?	–	–	–	0.746	–

Table 3 (Continued)

Item	Component				
	1 (Social Well-being and Independence)	2 (Support)	3 (Day to Day)	4 (Family Relations)	5 (Emotional Well-being)>
Been more protective of you than you would like because of your food allergy?	–	–	–	0.720	–
In the past 4 wk how often have you...					
Worried about dying because of your food allergy?	–	–	–	–	–0.760
Worried about having an allergic reaction to food?	–	–	–	–	–0.635
Worried about using medication for your food allergy?	–	–	–	–	–0.634
Felt confident about managing your food allergy? (reversed)	–	–	–	–	–0.598
Felt confident about managing your food allergy in the future? (reversed)	–	–	–	–	–0.559
Felt safe when you have been away from your parents? (reversed)	–	–	–	–	–0.544

Principal components analysis groups items into components based on the inter-item correlations. Items are given factor loadings, which are the correlation between an item and each of the components. Since all items will load (to a lesser or greater degree) on all components, factor loadings ≥ 0.4 are usually taken to indicate that an item is of importance to a particular component. Hence, only factor loadings ≥ 0.4 are presented here, so that the groupings of items according to components can be clearly seen.

The factor loadings for component five have negative signs as a result of the oblique rotation of the factors and do not have any interpretative meaning (21).

Evaluating the reliability and validity of the You and Your Food Allergy scale

The whole scale score demonstrated excellent internal consistency and test–retest reliability. All subscales except the ‘Support’ subscale displayed at least acceptable internal consistency and excellent test–retest reliability (Table 4).

With regard to convergent and divergent validity, most hypothesised relationships between the subscales of the You and Your Food Allergy and the PedsQL were evident (although three were not, and an additional relationship was found between the Emotional Well-Being and Social Functioning subscales), supporting the hypothesis that the scale does measure HRQL (Table 5). Moreover, the whole scale score correlated more highly with participants’ rating of the

overall impact of FHS on their QL ($r = 0.504$, $p < 0.01$) than with participants’ rating of their overall QL ($r = 0.430$, $p < 0.01$) and correlated moderately with the whole PedsQL scale ($r = 0.486$, $p < 0.01$). This indicates that the You and Your Food Allergy more closely measures FHS-specific HRQL than general HRQL.

For the known-groups analysis, there was a significant difference between the whole scale scores of those allergic to ≤ 2 foods [mean (s.d.) = 71.7(13.1)] and those allergic to > 2 foods [mean (s.d.) = 67.5(14.1)], supporting the scale’s ability to distinguish between groups hypothesised to have differing HRQL ($t = 2.459$, $df = 287$, $p < 0.05$).

Discussion

This study used a psychometric approach to develop the first self-report HRQL scale for teenagers with FHS in the UK: the You and Your Food Allergy scale. Importantly, this new scale displayed excellent internal consistency and test–retest reliability, and support was provided for its construct validity. The low level of missing data also supports the acceptability of the scale. Hence, the You and Your Food Allergy enables clinicians and researchers in the UK to reliably monitor (and facilitate discussion about) relevant HRQL issues for teenage patients and to seek teenagers’ perspectives when evaluating the impact of interventions on their HRQL (23).

HRQL issues for teenagers with FHS

The content of the You and Your Food Allergy (when compared with that of related disease-specific HRQL scales; 10, 11, 27, 28) may indicate which HRQL issues are specific to teenagers with FHS. Teenage-specific issues appear to include

Table 4 Results of internal consistency and test–retest reliability analyses

Scale	Internal consistency Cronbach’s α (judgement)	Test–retest reliability intraclass correlation (judgement)
Whole scale	0.918 (Excellent)	0.867 (Excellent)
Social Well-being and Independence	0.884 (Good)	0.855 (Excellent)
Support	0.631 (Not acceptable)	0.485 (Fair to moderate)
Day to day	0.883 (Good)	0.828 (Excellent)
Family relations	0.817 (Good)	0.771 (Excellent)
Emotional Well-being	0.787 (Acceptable)	0.766 (Excellent)

Table 5 Results of convergent validity analyses comparing the subscales of the You and Your Food Allergy and PedsQL (those Pearson's correlation coefficients that support hypothesized relationships are presented in bold)

You and Your Food Allergy scales	PedsQL scales			
	Physical functioning	Social functioning	Emotional functioning	School functioning
Whole scale	N/A	N/A	N/A	N/A
Social Well-being and Independence	0.215** (Low)	0.496** (Moderate)	0.466** (Moderate)	0.291** (Low)
Support	0.045 (Low)	0.129** (Low)	0.049 (Low)	0.098 (Low)
Day to day	0.220** (Low)	0.367** (Moderate)	0.443** (Moderate)	0.282** (Low)
Family Relations	0.051 (Low)	0.253** (Low)	0.256** (Low)	0.167** (Low)
Emotional Well-being	0.224** (Low)	0.354** (Moderate)	0.486** (Moderate)	0.299** (Low)

**p < 0.01.

the impact of FHS on family relationships, general annoyance at having FHS and having to carry self-injectable adrenaline. Most strikingly, and in contrast to other age groups, the foremost HRQL issue for teenagers with FHS was the impact on their social well-being and independence (explaining the largest amount of variance in HRQL scores). This is, perhaps, not surprising given that social activities form a central feature of teenagers' lives, who increasingly prefer to spend time with their friends rather than their parents (29). Hence, while the safety of teenagers is a key concern, it is also important to consider the impact of managing FHS on teenagers' social activities and independence. The You and Your Food Allergy scale will enable clinicians to monitor the impact of FHS on teenagers' social well-being during this critical period of increasing independence.

Cross-cultural comparisons of salient HRQL issues

Comparing the content of the You and Your Food Allergy scale with those developed for Dutch (FAQLQ-TF) and American (FAQL-teen) teenagers (10, 11), it appears that the impact of FHS on day-to-day activities and emotional well-being is important to all three populations. However, while the impact of FHS on social activities was of primary importance to UK and US teenagers, this does not appear to be the case for the Dutch teenagers. US teenagers reported feeling a burden to others, but this was not reported by UK and Dutch teenagers. Also of interest is that although support with managing FHS was important to the HRQL of UK teenagers, this does not appear to be so important for US and Dutch teenagers. Similarly, while the risk of accidental exposure was an important component of the HRQL of Dutch teenagers with FHS, it does not feature in the US and UK scales. However, it may be that in these scales, the effect of this risk is reflected in its impact on the day-to-day management of FHS, for example, 'may contain' labelling poses a risk of accidental exposure the impact of which may be felt in restricted product choice. It should be noted, however, that there may be other explanations for inter-scale variation. For example, different approaches to item reduction (the FAQLQ-TF and FAQL-teen used the clinical impact method) may have produced different resultant scales, although, as previously discussed, studies suggest that the

method of item reduction has minimal impact on the items included in the resultant scales (16–18).

Strengths and limitations

A key strength of this new scale is that the perspectives of teenagers with FHS were sought throughout its development, ensuring that it is salient, appropriate and appealing to a British teenage audience. The final You and Your Food Allergy consists of items generated from interviews with teenagers with FHS retained based on the responses of a large nationwide sample. This increases the scale's generalizability and ensures that its items both directly reflect, and best measure, the HRQL of teenagers with FHS (15). However, taking into account the sample composition, its transferability cannot be guaranteed in some populations.

For example, participants were predominantly White British [89.7% compared with $\approx$ 84% of the general UK population (30)] and lived with both parents, the majority of whom were educated to at least degree level. Furthermore, a substantial majority of the sample reported being allergic to peanut (89.7%), and while the scale is therefore transferable to the vast majority of UK food-allergic teenagers (31), it may be less so for the minority allergic only to rarer food allergens. Additionally, 98.6% of participants had an adrenaline autoinjector, and the HRQL scores of the sample were not statistically significantly different from a hospital-recruited sample (N = 26). Hence, those with milder symptoms may be underrepresented, and the transferability of the scale may be reduced for these groups.

Consequently, further research is needed to establish the applicability of the You and Your Food Allergy scale to a more diverse demographic. Further studies may also be necessary to evaluate the inclusion of the support subscale in future versions of the You and Your Food Allergy scale. It should also be noted that the response rate for the test–retest reliability was small, which may have introduced a bias into this aspect of the scale's evaluation.

Conclusion

The You and Your Food Allergy scale is the first HRQL scale developed and validated for UK teenagers with FHS.

This scale has the potential to open up future research into the HRQL of teenagers with FHS, enabling the impact of current and new interventions on the HRQL of this population to be evaluated.

Acknowledgments

We would like to thank the participants and their parents for their time, and the staff from The David Hide Asthma and

Allergy Research Centre at the St Mary's Hospital, Isle of Wight, Southampton Universities Hospital Trust and The Anaphylaxis Campaign for their generosity and invaluable help in recruitment. This study was supported by a PhD studentship grant from University of Portsmouth.

Conflict of interest

The authors have no conflicts of interest to declare.

References

1. Van Wijk RG. Quality of life, should we bother? *Allergy* 2003; **58**: 284–6.
2. Monks H, Gowland MH, Mackenzie H, et al. How do teenagers manage their food allergies? *Clin Exp Allergy* 2010; **40**: 1533–40.
3. Lyons AC, Forde EME. Food allergy in young adults: perceptions and psychological effects. *J Health Psychol* 2004; **9**: 497–504.
4. Marklund B, Ahlstedt S, Nordström G. Health-related quality of life among adolescents with allergy-like conditions – with emphasis on food hypersensitivity. *Health Qual Life Outcomes* 2004; **2**: 65.
5. Marklund B, Wilde-Larsson B, Ahlstedt S, Nordström G. Adolescents' experiences of being food-hypersensitive: a qualitative study. *BMC Nurs* 2007; **6**: 8.
6. Akeson N, Worth A, Sheikh A. The psychosocial impact of anaphylaxis on young people and their parents. *Clin Exp Allergy* 2007; **37**: 1213–20.
7. Mandell D, Curtis R, Gold M, Hardie S. Anaphylaxis: how do you live with it? *Health Soc Work* 2005; **30**: 325–35.
8. Mackenzie H, Roberts G, Van Laar D, Dean T. Teenagers' experiences of living with food hypersensitivity: a qualitative study. *Pediatr Allergy Immunol* 2009; **21**: 595–602.
9. Eiser C, Morse JM. Quality-of-life measures in chronic diseases of childhood. *Health Technol Assess* 2001; **5**: 1–157.
10. Flokstra-de Blok BMJ, DunnGalvin A, Vlieg-Boerstra BJ, et al. Development and validation of the self-administered Food Allergy Quality of Life Questionnaire for adolescents. *J Allergy Clin Immunol* 2008; **122**: 139–44.
11. Resnick ES, Pieretti MM, Maloney J, Noone S, Muñoz-Furlong A, Sicherer SH. Development of a questionnaire to measure quality of life in adolescents with food allergy: the FAQL-teen. *Ann Allergy Asthma Immunol* 2010; **105**: 364–8.
12. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine* 2000; **25**: 3186–91.
13. Schmidt S, Bullinger M. Current issues in cross-cultural quality of life instrument development. *Arch Phys Med Rehabil* 2003; **84** (4 Suppl 2): S29–34.
14. Corless IB, Nicholas PK, Nokes KM. Issues in cross-cultural quality-of-life research. *J Nurs Scholarsh* 2001; **33**: 15–20.
15. DeVellis RF. Scale Development: Theory and Applications, 2nd edn. London: Thousand Oaks, 2003.
16. Juniper EF, Guyatt GH, Streiner DL, King DR. Clinical impact versus factor analysis for quality of life questionnaire construction. *J Clin Epidemiol* 1997; **50**: 233–8.
17. Marx RG, Bombardier C, Hogg-Johnson S, Wright JG. Clinimetric and psychometric strategies for development of a health measurement scale. *J Clin Epidemiol* 1999; **52**: 105–11.
18. Newcombe PA, Sheffield JK, Juniper EF, et al. Development of a parent-proxy quality-of-life chronic cough-specific questionnaire. *Chest* 2008; **133**: 386–95.
19. Tabachnick BG, Fidell LS. Using Multivariate Statistics, 5th edn. London: Pearson, 2007.
20. Hayton JC, Allen DG, Scarpello V. Factor retention decisions in exploratory factor analysis: a tutorial on parallel analysis. *Organ Res Methods* 2004; **7**: 191–205.
21. Kline P. The Handbook of Psychological Testing, 2nd edn. London: Routledge, 2000.
22. Cicchetti DV, Sparrow SA. Developing criteria for establishing interrater reliability of specific items: applications to assessment of adaptive behavior. *Am J Ment Defic* 1981; **86**: 127–37.
23. Fayers PM, Machin D. Quality of Life: Assessment, Analysis and Interpretation. Chichester: John Wiley & Sons Ltd, 2000.
24. Varni JW, Seid M, Kurtin P. PedsQL(TM) 4.0: reliability and validity of the pediatric quality of life inventory(TM) Version 4.0 generic core scales in healthy and patient populations. *Med Care* 2001; **39**: 800–12.
25. Streiner DL, Norman GR. Health Measurement Scales: A Practical Guide to Their Development and Use, 2nd edn. Oxford: Oxford University Press, 1995.
26. Flokstra-de Blok BMJ, DunnGalvin A, Vlieg-Boerstra BJ, 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, van der Meulen GN, DunnGalvin A, et al. Development and validation of the Food Allergy Quality of Life Questionnaire – Adult Form. *Allergy* 2009; **64**: 1209–17.
28. Steinberg L, Morris AS. Adolescent development. *Annu Rev Psychol* 2001; **52**: 83–110.
29. Office for National Statistics. Population Estimates by Ethnic Group 2002–2009. Newport: Office for National Statistics, 2011.
30. Pereira B, Venter C, Grundy J, Clayton B, Hasan Arshad S, Dean T. Prevalence of sensitization to food allergens, reported adverse reactions to foods, food avoidance, and food hypersensitivity among teenagers. *J Allergy Clin Immunol* 2005; **116**: 884–92.