
Development of a questionnaire to measure quality of life in adolescents with food allergy: the FAQL-teen

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Background: Living with food allergies affects quality of life (QOL) and may be particularly problematic for teenagers.

Objective: To develop a validated food allergy QOL assessment tool for US adolescents (FAQL-teen).

Methods: Initial items were developed through expert opinion, literature review, and adolescent focus groups, resulting in an 88-question impact assessment questionnaire. This questionnaire was completed by 52 adolescents for effect scoring; final instrument questions were determined through analysis of effect scores. The final 17-item instrument was completed by 203 participants aged 13 to 19 years via an Internet link on the Food Allergy & Anaphylaxis Network Web site and via paper surveys distributed at a Food Allergy & Anaphylaxis Network conference. Items were scored on a 7-point Likert scale: 0 corresponded to “not troubled/limited,” 3 to “moderately troubled/limited,” and 6 to “extremely troubled/limited.”

Results: Areas most troubling included limitations on social activities (score, 2.7), not being able to eat what others were eating (score, 2.7), and limited choice of restaurants (score, 3.9). Instrument validation steps showed strong internal validity (Cronbach $\alpha = .9$). The instrument discriminated by disease severity: adolescents with a history of anaphylaxis had significantly lower QOL (higher scores) than did those without a history of anaphylaxis ($P = .003$).

Conclusions: While developing a food allergy QOL assessment tool for US adolescents (FAQL-teen), we identified multiple social and emotional concerns that could be targeted for adolescent counseling. This instrument is internally valid and has the ability to discriminate, making it a useful tool in adolescent food allergy studies.

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INTRODUCTION

Food allergies are increasing in prevalence, disproportionately affect children and adolescents, and have no currently available cure.¹ Avoidance is the mainstay of food allergy treatment; however, accidental exposures may occur and may cause physical and emotional harm.² Food allergen avoidance can be onerous and can interfere with activities of daily life.³ Health-related quality of life (HRQOL) is an important end point in patients with food allergy.⁴ It is estimated that 2.3% of adolescents may have food allergies,⁵ and adolescents have the highest risk of death from a food-related allergic reaction.⁶ We hypothesize that adolescents with food allergy may have different factors affecting HRQOL compared with adults or children with food allergy or parents of children with food allergy.

Only a few studies^{7–15} have examined food allergy–related QOL. The first validated food allergy disease-specific HRQOL questionnaire was published in 2004 and assessed the parental burden associated with having a food-allergic child.¹¹ Several studies were subsequently performed to assess HRQOL in children and adults with food allergy. To our knowledge, only 2 studies have assessed the HRQOL of adolescents with food allergy. The first studied adolescents with “self-reported allergylike conditions,” with a focus on food hypersensitivity.¹⁶ The second created a validated Dutch-language instrument for adolescents with food allergy.⁹ No instrument exists to measure HRQOL in American adolescents with food allergy. The objective of this study was to create a food allergy–specific QOL assessment tool explicitly for adolescents in the United States. Information gathered using this instrument can be used to improve the quality of interventions and the treatment of adolescent food allergy.

METHODS

Item Generation and Reduction

All steps were undertaken with the approval of the Mount Sinai Medical Center institutional review board. No identifiable personal health information was collected on any participant. In an effort to develop a food allergy–specific QOL assessment tool for adolescents, focus groups were held with food-allergic adolescents in Baltimore (Maryland), Chicago (Illinois), and New York (New York). Using this information

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and information from literature reviews and the experience of the authors, experts in food allergy created an 88-question impact assessment questionnaire. The questionnaire was distributed to 52 adolescents for effect scoring. Patients rated how troubling the item was on a 5-point scale: 1 corresponded to very little and 5 corresponded to very much.¹⁷ The maximum possible effect for an item was 5.0, and the items with the highest effect scores became the final 17-item questionnaire. Item similarity (face validity) and Pearson correlations were performed to eliminate high-scoring but redundant items. Items selected for the final questionnaire were converted to questions with a 7-point worded response scale. Seventeen families at a Food Allergy & Anaphylaxis Network (FAAN) conference were asked to evaluate the final questions for clarity.

The final survey (FAQL-teen) was then posted on SurveyMonkey (<http://www.surveymonkey.com>), and patients aged 13 to 19 years were eligible to complete it. A link to the survey was posted on the FAAN Web site (<http://www.food-allergy.org/>), and paper surveys were also distributed at a FAAN conference. Items were scored on a 7-point worded-response scale: 0 indicated “not troubled/limited”; 1, “hardly troubled/limited at all”; 2, “somewhat troubled/limited”; 3, “moderately troubled/limited”; 4, “quite a bit troubled/limited”; 5, “very troubled/limited”; and 6, “extremely troubled/limited.” Thus, a higher score on the FAQL-teen indicates a greater perception of trouble/limitations due to food allergies.

Validation

Validations steps were adapted from previous studies.¹¹ Survey respondents were asked to answer 2 questions regarding expectations of future reactions (expectation of outcome): (1) “How great do you think your chance is of having a serious reaction on ingesting the food(s) to which you are allergic?” and (2) “How great do you think your chance of dying is if you ingest the food(s) to which you are allergic?” Responses were scored on a 7-point scale: 0 indicated no chance; 1, very small chance; 2, small chance; 3, moderate chance; 4, large chance; 5, very large chance; and 6, always. This allowed comparison of the food allergy-specific questionnaire with the expectation of outcome questions.

Survey respondents answered not only the FAQL-teen but also the Pediatric Quality of Life Teen Report (PedsQL), a generic, validated health status tool.¹⁸ Sixteen control patients with atopic disease (asthma, allergic rhinitis, or atopic dermatitis) but no history of food allergy were also asked to take the generic PedsQL. This allowed comparison of generic QOL measures in food-allergic vs non-food-allergic adolescents.

Eleven control patients with atopic disease but no history of food allergy were asked to complete the PedsQL and the FAQL-teen. This allowed for comparison of food-allergic adolescents vs controls with the expectation that teens without food allergies would have little or no effect scored on the FAQL-teen.

Comparisons were made between adolescents with a history of anaphylaxis and those without a history of anaphy-

laxis and between adolescents with 2 or fewer food allergies and those with 3 or more food allergies. The expectation was that teens with a history of anaphylaxis and those with more food allergies would have higher scores on the FAQL-teen. Cronbach α was used to assess the consistency of the FAQL-teen. Previous studies¹⁹ have identified an acceptable Cronbach α as being greater than .7.

RESULTS

Item Generation and Reduction

An 88-question impact assessment questionnaire developed using focus groups and author experience was distributed to 52 adolescents for effect scoring (described previously herein). Items with the highest effect scores were used to create the final questionnaire; items with similar face validity or Pearson correlations greater than 0.85 were eliminated. The final instrument was a 17-item questionnaire. The final questions were reviewed by 17 participants at a FAAN conference. Items selected for the final questionnaire were converted to questions with a 7-point Likert response scale as described previously herein.

Validation

Subjects. The survey was posted on SurveyMonkey, and adolescents aged 13 to 19 years were eligible to complete it. A total of 248 adolescents completed the demographic information, 209 respondents went on to begin the FAQL-teen survey (84%), and 203 completed the FAQL-teen (97% of those who initiated it). Demographic information is found in Table 1. Of note, 91.9% of subjects reported that their food allergy was diagnosed by a physician, 8.1% reported that their food allergy was self-diagnosed, and 12.1% reported that their food allergy was diagnosed by both themselves and their physician.

Validation. Intrinsic validity was assessed using the Cronbach α coefficient, which was determined to be .9, indicating excellent agreement between the individual questions in the survey. The discriminative ability of the survey was also evaluated. Studies²⁰ have shown that the minimum clinically important difference for measurements of QOL using 7-point Likert scales is 0.5. Adolescents were divided among those who had experienced an anaphylactic reaction ($n = 133$) and those who had not ($n = 70$). The mean FAQL-teen score for those with anaphylaxis was 2.5 vs 2.0 in those without anaphylaxis ($P = .003$). This discriminative ability was not observed in adolescents with 2 or fewer food allergies ($n = 95$; mean score, 2.2) vs those with greater than 2 food allergies ($n = 108$; mean score, 2.5).

Cross-sectional validity was assessed using expectation of outcome questions. There was a statistically significant difference between the responses of adolescents to these expectation of outcome questions. Adolescents who believed that they had a small chance of allergic reaction ($n = 71$; mean score, 2.0) had a significantly lower score on the FAQL-teen than did those who believed that they had a large chance of allergic reaction ($n = 132$; mean score, 2.5) ($P = .002$).

Table 1. Characteristics of the 203 Survey Respondents

	Respondents, %
Sex	
Male	27.4
Female	72.6
Ethnicity	
Hispanic/Latino	3.2
Non-Hispanic/Latino	96.8
Race	
Asian	4.4
Hawaiian/Pacific Islander	0.8
Black	4.8
White	87.5
Alaska Native/American Indian	0
Other	2.4
Specific food allergies	
Peanut	71.4
Tree nuts	65.7
Milk	28.6
Shellfish	27.4
Egg	27.4
Soy	17.7
Fish	16.9
Wheat	12.1
Other	42.7
Food allergy diagnosed by physician	91.9
Other atopic conditions	
Eczema (atopic dermatitis)	45.4
Seasonal allergies (allergic rhinitis)	84.3
Asthma	65.1
Allergic reactions in the past 5 y, No.	
0	27
1–5	47.2
>5	25.8
Epinephrine use	
None	35.1
1–5 times	54.8
>5 times	10.1
Last allergic reaction	
<1 mo ago	24.6
1–6 mo ago	20.2
>6 mo ago	55.2

Similarly, adolescents who believed that they had a small chance of dying if ingesting a food to which they were allergic ($n = 138$; mean score, 2.1) had significantly lower scores than did those who believed that they had a large chance of dying on ingestion of an allergen ($n = 65$; mean score, 2.8) ($P = .001$).

Finally, control subjects with atopic disease (allergic rhinitis, atopic dermatitis, or asthma) but not food allergies were asked to complete the generic PedsQL and the FAQL-teen. Food-allergic subjects had significantly worse QOL on the generic PedsQL than did atopic controls ($P = .002$). All atopic controls asked to complete the FAQL-teen scored 0 (no effect), indicating that these questions are specific for adolescents with food allergy.

Survey Results

Question average ratings ranged from 1.3 to 3.9 (Fig 1). The questions with the highest average ratings were those most troubling to the respondents. Teens were most troubled by food allergies placing limitations on their social activities (score, 2.7), by not being able to eat what others were eating (score, 2.7), by the thought of being a burden to others because of food allergies (score, 2.8), and by the thought that their school does not adequately educate others about food allergies (score, 2.7). Teens felt most limited by food allergies affecting their choice of restaurant (score, 3.9) and vacation destination (score, 2.9). In contrast, adolescents were less troubled by the idea of wearing a MedicAlert bracelet (score, 1.3), by carrying self-injectable epinephrine (score, 1.4), and by parents being overbearing or bringing attention to their food allergies (score, 1.6).

DISCUSSION

Food allergies are increasing in prevalence and disproportionately affect children and adolescents. We developed a brief self-administered instrument to measure QOL in adolescents with food allergy: the FAQL-teen. This instrument is internally valid (Cronbach $\alpha = .9$) and discriminates based on disease severity: adolescents with a history of anaphylaxis had significantly lower QOL (higher scores) than did those without a history of anaphylaxis ($P = .003$). Responses to expectation of outcome questions indicate cross-sectional validity of this instrument. It is also specific for adolescents with food allergy; atopic control subjects without food allergies had scores of 0 on the FAQL-teen. This makes the instrument useful in further studies of food-allergic adolescents. To our knowledge, this is the first QOL measure for American adolescents with food allergy.

A limitation of this instrument is that it was validated on a population from the FAAN, a patient support network whose members are primarily of white race and of higher-than-average socioeconomic status. This population may also have a greater severity of food allergies than the general population. Ideally, this instrument will be used by other groups to assess QOL in food-allergic teens across many diverse cultural and socioeconomic backgrounds.

We hypothesized that adolescents with food allergy would have distinct areas of impact on HRQOL compared with children with food allergy or parents of children with food allergy. Parents of food-allergic children, for example, have health and nutritional concerns for their children as well as worries about the time affected for meal preparation and precautions when leaving home.¹¹ Children with food allergies are concerned about having to explain to others that they have a food allergy.⁸ In contrast, adolescents in this study were most concerned about food allergies placing limitations on their social activities, not being able to eat what others were eating, and the thought of being a burden to others owing to food allergies. Surprisingly, adolescents were much less troubled by parents being overbearing or bringing attention to their food allergies. Thus, this instrument can be used

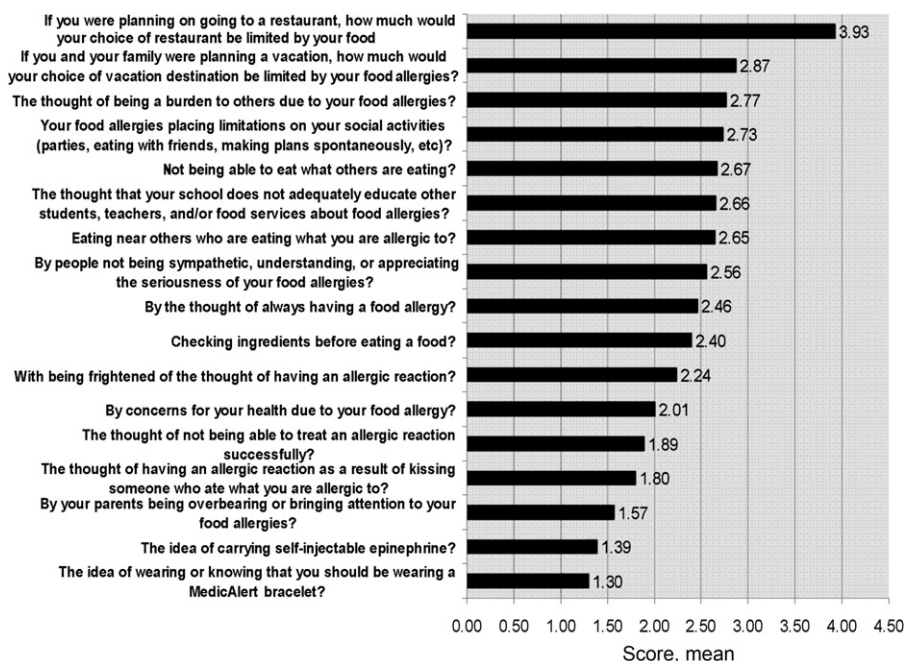


Figure 1. FAQL-teen questions and responses. Adolescents scored items from 0 to 6: 0 = not troubled/limited; 1 = hardly troubled/limited at all; 2 = somewhat troubled/limited; 3 = moderately troubled/limited; 4 = quite a bit troubled/limited; 5 = very troubled/limited; and 6 = extremely troubled/limited.

to identify social and emotional concerns that could be targeted for adolescent counseling. Other studies²¹ have shown that adolescents take risks for a variety of reasons; this instrument may be useful in identifying food-allergic teens with significant impact on HRQOL, who, therefore, may be at risk for reckless behavior. Interventions could be undertaken for at-risk teens before adverse consequences arise.

In summary, we developed a food allergy-specific instrument to assess QOL in American food-allergic adolescents. This instrument can be used in further food-allergy studies involving adolescents.

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