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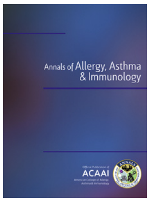

CME Review

Food Allergy Quality of Life

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INSTRUCTIONS

Credit can now be obtained, free for a limited time, by reading the review article in this issue and completing all activity components. Please note the instructions listed below:

- Review the target audience, learning objectives and all disclosures.
- Complete the pre-test online at http://www.annallergy.org (click on the CME heading).
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Release Date: November 1, 2014
Expiration Date: October 31, 2016
Estimated Time to Complete: 60 minutes
Target Audience: Physicians involved in providing patient care in the field of allergy/asthma/immunology
Learning Objectives:
At the conclusion of this activity, participants should be able to:

- Recognize that poor quality of life is a consequence of food allergy for many individuals and caretakers and identify specific attributes of food allergy that complicate the measurement of food allergy quality of life
- Evaluate the current measures of food allergy quality of life and review known associations between food allergy and quality of life

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Introduction

Food allergy is a growing public health concern, with an estimated worldwide prevalence of approximately 4% to 10%.[1,2] Food allergy is attributable to approximately 150 fatalities, 300,000 ambulatory care visits, and 200,000 emergency department encounters per year in the United States and has an estimated socioeconomic burden of approximately $25 billion per year.[1–4] There is no known Food and Drug Administration–approved cure or treatment for food allergy, and some food allergies may be lifelong. Between 1997 and 2011 there was an estimated 50% increase in the diagnosis of food allergy based on nationally representative self-reported data, although these data are not based on a criterion standard of oral challenge to verify allergy.[5] The exact increase in prevalence is hard to specify given poor disease estimates before the early 2000s. The effect of food allergy is felt in food allergic individuals (FAIs) and their caretakers. Food allergy is associated with increased anxiety and reduced quality of life (QoL). This review details the measurement of QoL, issues specific to food allergy in measuring QoL, and the effect food allergy has on generic and disease-specific QoL.

Defining QoL

The World Health Organization definition of QoL is "the individual's perception of their position in life in the context of the culture and value systems in which they live and in their relation to their goals, expectations, standards, and concerns."[6] Health-related QoL measures patients' perception of their health and how they feel.[7] QoL can be measured with a generic measurement of health status (eg, 36-Item Short Form Health Survey and Child Health Questionnaire) or with a disease-specific measure. Generic measures can be used to compare general aspects of QoL across many disease states. Most diseases also have specific QoL measures developed and tailored to better measure the problems and concepts particular to that disease.[8–10]

Measuring QoL Specific to Food Allergy

Food allergy as a chronic disease raises 2 issues in measuring QoL. The first issue is common to pediatric illness in that there are 2 different persons in whom QoL could be measured—the FAI and the caregiver. The FAI experiences an actual direct physical burden of disease in terms of symptom manifestations and potentially experiences psychological ramifications from living with food allergy (eg, bullying, anxiety, and exclusion). In contrast, caregivers only experience indirect burdens, such as the emotional burden or anxiety regarding the FAI's safety, the burden of the FAI's pain, and the frustration that unaffected individuals differentially perceive the seriousness of the FAI's allergy.[11] It is unclear whether the FAI or the caregiver is more affected by the food allergy and which individual's QoL is more important to measure as an outcome. Instruments have been specifically developed for caregivers and FAIs (including forms for FAIs of all ages).[12–17] Younger children may not reliably be able to describe their QoL, so caregiver-proxy measures have been developed for the caregiver to assess their impression of the child's QoL, although these may have validity issues regarding a caregiver's ability to accurately evaluate their child's QoL.[18,19]

The second issue is that food allergy vs. other chronic illnesses is unique. The mortality rate is low and symptoms of illness are rarely experienced.[1,20] Therefore, most FAIs rarely have large day-to-day changes in health status due to physical symptoms, and symptoms are a poor measure of food allergy QoL.[10] However, the daily burden of vigilance affects most FAIs and caregivers frequently and is a better measuring stick for QoL.[12] The burden of daily vigilance within food allergy is broad and may include the following facets: fear of and persistent vigilance for unintentional reactions, fear of hidden ingredients, fear of being able to treat a reaction, the burden lacking a disease cure or treatment, the burden of food avoidance or label reading, limitations (real or self-perceived) on activity or travel, and the social stigma of having a food allergy (social inclusion, interactions with others, bullying, and teasing).

Developing a QoL Measure

Although psychometric instrument development is beyond the scope of this review, the process can be briefly summarized.[21] Most instruments are developed through qualitative research using detailed stakeholder interviewing of patients and caregivers affected by the disease to generate a list of thematic items regarding living with the condition.[22,23] Items are converted into questions with a 4- to 7-point scale (Likert item).[24] The number of items is then reduced either mathematically (factor analysis) or based on clinical impact (clinical impact method) and tested in a disease-representative sample for reliability and validity.[25] Reliability assesses whether the instrument obtains consistent measurements (eg, the degree that respondent answers correlate with one another). Internal reliability is commonly assessed using the Cronbach α and external reliability (eg, test-retest within subjects) with the intraclass correlation coefficient (ICC). Validity assesses whether an instrument measures what it aims to do (eg, QoL or asthma control).[26] Additional testing can be performed to assess index dimensionality—do the items measure a single concept or multiple concepts (allowing for item subscales)?[27] Items are generally scored as a summarion of the individual Likert items or subscales—sometimes as a mean of the items and domains, and sometimes as a total score.[28] Of note, an index must be specifically validated for use in a different language, population type, or culture from where it was originally validated.[29]

In measuring QoL, statistical significance is not necessarily equivalent to clinical significance, and changes in scores must eclipse a threshold to affect clinical management, called the minimal clinically important difference (MCID). The MCID defines the smallest score change perceived as beneficial to the patient that would alter management.[30] In work related to chronic pulmonary and heart disease, Jaeschke et al[31] described an MCID of 0.5 for use on 7-point Likert scale instruments, which is commonly used for other 7-point scales. However, 0.5 is not an absolute value with universal applicability; MCID is index specific. MCID can be measured in several ways: through the clinical impact method, the SEM, and calculation of the number needed to treat[32] (Table 1).

Generic Measures for Food Allergy QoL

The initial studies for food allergy QoL used generic instruments and focused on defining what dysfunction existed and how that compared with other chronic disease states. These studies revealed that food allergy QoL is worse than several other prominent chronic illnesses. One of the earlier studies of QoL and food allergy found that families have greater familial-social dimension impairment and daily activity disruption in peanut allergy vs rheumatologic disorders.[33] Another early study found that food allergic families have worse health perception, emotional impact, and activity limitation than families with children with asthma, attention-deficit/hyperactivity disorder, juvenile rheumatoid arthritis, and epilepsy and that comorbid atopic disease in FAIs worsens QoL on the global health measurement domains.[34] It was also found that food allergic children have greater eating anxiety and fear of adverse events than diabetic children, that self-perceived food allergy is associated with poor QoL irrespective of a physician-verified diagnosis, that females have worse QoL than males, and that comorbid atopic disease worsens physical health-related QoL.[35,36]