

Original Article

Differences in Caregiver Food Allergy Quality of Life Between a Tertiary Care, Specialty Clinic, and a Caregiver Reported Food Allergic Populations

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What is already known about this topic? Food allergy is associated with reduced caregiver quality of life (QoL). However, little is known about how heterogeneous any deficit in QoL may be across a diverse population.

What does this article add to our knowledge? Large, significant differences in food allergy QoL exist between caregivers with children followed at referral centers versus self-selected caregivers reporting food allergic children in an online community, despite a common diagnosis.

How does this study impact current management guidelines? The food allergic population is heterogeneous, and certain segments experience a disproportionate burden of disease. Such groups may have different needs and risk profiles despite a common diagnosis, which may predispose to different long-term outcomes.

BACKGROUND: Food allergy is associated with diminished caregiver quality of life (QoL), but the heterogeneity of this effect is unknown.

OBJECTIVE: The objective of this study was to explore potential differences in caregiver QoL between self-selected caregivers reporting a child with food allergy (SS) and caregivers with children followed at a food allergy referral center clinic (RC).

METHODS: The Food Allergy Quality of Life Parental Burden (FAQL-PB) index and screening questions regarding the child's most severe food reaction were administered to caregivers of milk, egg, peanut, or tree nut allergic children. SS were recruited via the email and/or social media networks of 2 large national food allergy advocacy groups, and RC from a tertiary referral center specialty clinic.

RESULTS: Among 2003 SS and 305 RC, the mean total FAQL-PB QoL score was 2.67. Compared with SS, RC had a lower (better) mean total QoL score (1.84 vs 2.81, $P < .001$), individual FAQL-PB domain scores (mean difference range 0.51-1.93; all $P < .001$), and lower QoL scores for all allergens (mean difference range 0.89-1.32; peanut $P < .001$, tree nut $P < .001$, milk $P = .006$, egg $P = .001$). In an adjusted multiple linear regression model, RC were associated with a lower QoL score (-1.6 [95% CI, -1.91 to -1.29], $P < .001$). Factor analysis of the index revealed 2 dimensions. A minimal clinically important difference of 0.3 was calculated for the FAQL-PB using the standard error of measurement method.

CONCLUSIONS: Caregiver food allergy QoL is heterogeneous, and worse among SS versus RC. Clinically and statistically significant differences were noted in the total, domain-specific, and allergen-specific QoL scores, which indicated that the food allergic population may be segmented and have different risk profiles and/or burdens of illness, despite a common diagnosis. © 2015 American Academy of Allergy, Asthma & Immunology (J Allergy Clin Immunol Pract 2015;■:■-■)

Key words: Food allergy; Quality of life; Food Allergy Quality of Life-Parental Burden; Anaphylaxis; Epinephrine; Self-efficacy; Prevalence; Self-reported food allergy

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Food allergy is a growing public health problem that may affect up to 8% of children and 15 million Americans, though estimates may differ based on the methodology used.¹⁻⁴ Estimates of food allergy prevalence in the United States are based on a proxy report from a caregiver, serologic testing for specific IgE (sIgE), or other indirect methods of assessment such as diagnosis discharge coding, and may vary when compared with methods that use an oral food challenge to confirm diagnosis.¹⁻⁹ In particular, food allergy may be self-reported in as many as 4- to 5-fold more individuals than those in whom it can be verified.¹⁰

Abbreviations used

FAI- Food allergic individual

FAQL-PB- Food Allergy Quality of Life-Parental Burden

FASEQ- Food Allergy Self-Efficacy Questionnaire

MCID- Minimal clinically important difference

QoL- Quality of life

RC- Children followed at a food allergy referral center clinic

SEM- Standard error of measurement

sIgE- Specific IgE

SS- Self-selected caregivers reporting a child with food allergy

Food allergy is associated with reduced patient and caregiver health-related quality of life (QoL).¹¹ This has been noted with both generic pediatric QoL indices and through food allergy—specific QoL indices (in both US and international populations).¹²⁻²⁴ The degree of heterogeneity within the US food allergic population is poorly understood, but there are 2 general populations of food allergic individuals that have been studied—self-selected caregivers reporting a child with food allergy (SS), and caregivers who have children followed at referral centers (RC). Both populations strongly identify themselves as food allergic, live a food allergic lifestyle, and presumably experience the same problems and QoL reductions.^{3,16,17,21,25}

There has been no prior exploration of QoL differences between SS and RC, and there is limited prior literature exploring other potential differences in specific attributes between these 2 groups that may better explain the heterogeneity within the food allergic population. Thus, it is unknown if the problems, needs, or risk factors for poor QoL are different between these groups. Any potential difference may have significant bearing on future outcomes such as natural history of disease, utilization of health care services, or effects of treatments that may soon become available. Therefore, the purpose of this study was to better understand differences in caregiver QoL within a large food allergic population comprising distinct cohorts (SS and RC), as well as to provide further psychometric validation of the Food Allergy Quality of Life Parental Burden (FAQL-PB) index¹⁶ within this large, diverse food allergic population.

METHODS

This was a prospective, cross-sectional study of caregiver food allergy QoL, comparing 2 distinct populations. SS were recruited nationally for participation during the summer and fall of 2012 by email contact, social media feeds, and the websites of Kids with Food Allergies and the Food Allergy and Anaphylaxis Network (FAAN, since renamed FARE, Food Allergy Research and Education), 2 large national food allergy advocacy groups. Eligible participants included caregivers who identified themselves as both over the age of 18 and having at least one food allergic individual (FAI) with a physician-diagnosed food allergy. Caregivers with more than one FAI were asked to retake the survey based on their experience with each FAI independently. Analysis was restricted to those identifying a child with milk, egg, peanut, or tree nut allergy, the 4 most commonly reported allergens in the cohort.

RC patients evaluated and managed for milk, egg, peanut, or tree nut allergy at the University of Michigan Division of Allergy and Clinical Immunology clinics between 2009 and 2011 were identified by the review of a divisional food allergy patient database, and were recruited for participation in this study in clinic by mail or by phone

TABLE I. Demographic trends within the populations

Demographic trends	Self-selected caregiver report (n = 2003)	Clinic (n = 305)	P
Current age (y)	6.9	7.5	.03
Age of initial reaction (y)	2.5	1.9	<.001
Peanut	2.2	1.75	NS
Tree nut	3.6	3.3	NS
Milk	4.4	1.4	<.001
Egg	2.7	0.8	<.001
Reported history of anaphylaxis	61.9%	37.5%	<.001
White race	89.3%	79.5%	<.001
Income >\$100,000	54.6%	59.6%	NS
College graduate	83.3%	83.3%	NS
Allergist made initial diagnosis	76.9%	86.9%	<.001
Peanut/tree nut allergy	93.1%	52.8%	<.001

NS, Not significant.

TABLE II. Comparison of symptoms in the populations

Symptoms reported	Self-selected caregiver report % (n = 2003)	Clinic % (n = 305)	P
Systemic fives	49	31.5	<.001
Eczema	23.1	5.6	<.001
Other rash	10.9	7.9	NS
Oropharyngeal angioedema	57.4	28.7	<.001
Itchy throat	40.8	9.2	<.001
Throat tightness	38.1	6.3	<.001
Cough	34.4	11.6	<.001
Shortness of breath	28.4	11.6	<.001
Wheezing	26	10.2	<.001
Vomiting	41.1	33.7	.01
Abdominal pain	21.7	5.6	<.001
Hypotension	8.1	0	<.001
Syncope	7.5	5.3	.17

NS, Not significant.

between November 2011 and August 2012. These 4 allergens represented the most common food allergens seen in the practice. Caregivers were included if their child had a visit in the clinic between 2009 and 2011 and a chart-verified diagnosis of food allergy, defined by a documented, convincing clinical history of an IgE-mediated food-induced allergic reaction in the setting of confirmed IgE-mediated sensitization to the reported food (positive skin test and/or serum sIgE), or sIgE and/or a prick skin test wheal >95% positive predictive value for milk, egg, or peanut in a child with atopic dermatitis.¹⁰ A total of 1116 families with a unique visit in this 2-year time span were contacted over a year as part of a larger study to create an institutional database, with a total of 572 (51.3%) responding, of whom 92% identified an allergy to either milk, egg, peanut, or tree nut. The selection of those analyzed for chart review was blinded and at random. The data collection was halted at approximately the 300th survey because of financial constraints.²³

Caregivers in both cohorts completed separate questionnaires containing identical sections regarding symptoms of the FAI most severe reaction to the allergen, reaction treatment, perception of reaction severity, follow-up care of their food allergy, allergic and

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