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FOOD ALLERGY (T GREEN, SECTION EDITOR)

Quality of Life Among Food Allergic Patients and Their Caregivers

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Abstract Food allergy is increasing in prevalence worldwide. This review summarizes progress made studying relationships between food allergy and quality of life (QOL), with an emphasis on recent work in the field. Early work examining QOL among food allergy patients established that stress and anxiety associated with continuous allergen avoidance and the looming threat of anaphylaxis were associated with significantly impaired food allergy quality of life (FAQOL) for children with food allergy and their caregivers. Recent clinical studies suggest that undergoing oral food challenge to confirm food allergy and oral immunotherapy to treat food allergy may each improve FAQOL among both patients and their caregivers. Other intervention modalities, such as nurse-facilitated counseling and educational workshops, also hold promise, but additional work is needed. Future work must strive to recruit more representative, population-based samples, including adult patients, in order to improve the generalizability and clinical relevance of findings.

Keywords Food allergy · Quality of life · Pediatrics · Food hypersensitivity · Anaphylaxis

Abbreviations

FAIM	Food Allergy Independent Measure
FAQLQ	Food Allergy Quality of Life Questionnaire
FAQLQ-AF	Food Allergy Quality of Life Questionnaire—Adult Form
FAQLQ-CF	Food Allergy Quality of Life Questionnaire—Child Form
FAQLQ-PF	Food Allergy Quality of Life Questionnaire—Parent Form
FAQLQ-TF	Food Allergy Quality of Life Questionnaire—Teen Form
FAQOL	Food Allergy-related Quality of Life
FAQOL-PB	Food Allergy-related Quality of Life—Parental Burden Questionnaire
HQOL	Health-related Quality of Life
QOL	Quality of Life

Introduction

Food allergy is increasing in prevalence worldwide [1] and currently affects an estimated 8 % of children [2] and 5 % of adults in the USA [3•]. Food allergy is a relatively unique chronic condition in that patients are generally in good health in the absence of allergen exposure. While food allergy can be severe and even fatal, at the population level, its greatest public health impact is arguably that on the quality of life (QOL) of affected individuals and their caregivers. Given that

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treatment options for food allergy are limited, QOL research is particularly important, as it represents a tangible outcome that may be amenable to intervention in both the clinical and policy arenas [4]. The growing interest in studying QOL among food-allergic patients parallels trends across a variety of clinical research domains advocating the increased assessment of patient-reported [5] or patient-centered [6] outcomes. This review summarizes progress made over the past two decades in evaluating relationships between food allergy and quality of life, with an emphasis on recent work in the field and suggestions for future work.

Quality of Life and Health-Related Quality of Life

Quality of life refers to an individual's subjective perception of his or her position in life [7]. It is a multidimensional construct influenced by the complex interactions of an individual's life conditions, personal experiences, and personal values [7, 8]. Each of these dimensions in turn may be influenced by a variety of external and internal factors, including one's physical environment, socioeconomic status, material security, physical and mental health, and social and emotional well-being. The relationship between an individual's QOL and health status is, likewise, complex; just as the presence of health or disease may affect a patient's QOL, specific dimensions of QOL (e.g., physical safety, nutritional status, environmental exposures) may have profound effects on physical health. Health-related QOL (HQOL) refers to the functional effect(s) of both a disease or disability and its treatment(s) on a patient's quality of life [9]; it is a measure of the *experience* of illness rather than the severity [10]. Given their subjective nature, QOL and HQOL are most often assessed by patient report in the form of questionnaires. Both general HQOL and disease-specific instruments may be used to measure HQOL in patients with chronic illness [11].

Quality of Life Assessment in Food Allergy

Early work examining QOL among food allergy patients established that the stress and anxiety associated with both the need for continuous allergen avoidance and the looming threat of anaphylaxis are associated with significantly impaired QOL for children with food allergy. This work found QOL in children with food allergy to be significantly impaired relative to both healthy children [12] and to children with other chronic illnesses such as diabetes [13, 14] and rheumatologic disease [15]. These studies used general health-related QOL (HQOL) scales, such as the Pediatric Quality of Life Inventory [16] or World Health Organization Quality of Life-BREF assessment [17]; however, because food allergy impacts HQOL in relatively specific contexts, with few physical symptoms in the absence of allergen exposure, general HQOL scales may not be sufficiently sensitive or domain-specific to capture the unique QOL impairments associated with food allergy. Therefore, numerous food allergy-specific QOL (FAQOL) measures have been developed (Table 1). Of these instruments, the most well-validated and frequently utilized is the Food Allergy Quality of Life Questionnaire, which has self-report versions for adults [18], teens [19], and children [20] as well as a parent-report version for children [21]. Another frequently used instrument is the Food Allergy Quality of Life—Parental Burden Questionnaire [22], which is a caregiver-report measure of QOL related to caring for a child with food allergy. The Food Allergy Independent Measure (FAIM) is a short (5–6 items) instrument validated for the assessment of FAQOL in children, teenagers, and adults [23]. Specifically, the FAIM assesses patients' expectations of adverse food allergy-related outcomes and has been shown to correlate significantly with longer FAQOL questionnaires.

Factors Affecting FAQOL

Number of Food Allergies and Dietary Restrictiveness

Food-allergic children with severely restricted diets report poor QOL; similar findings are seen among their caregivers. For example, several studies have shown that children with greater numbers of food allergies report reduced QOL [24–26] relative to children with fewer allergies. Similarly, a study of tree nut- and peanut-allergic children found that FAQOL was better among children who reported eating foods that "may contain" their allergen(s) relative to children who did not report eating foods with the "may contain" label; mothers of children who eat foods that "may contain" their allergen(s) also report better FAQOL than mothers of children who do not [12]. Furthermore, children with allergies to ubiquitous foods such as milk and egg report worse QOL relative to children with more easily avoidable allergens such as peanut and tree nut [27•, 28] even though reactions to the latter comprise a larger proportion of fatal anaphylaxis cases [29].

Food Allergy Severity and Management Practices

While one might expect the degree of severity of previous food-allergic reactions to correlate with QOL among food-allergic children and their caregivers, some early studies found that this was not the case [12, 30, 31]. However, many of these early studies did not specifically assess FAQOL nor did they incorporate stringent clinical criteria to categorize reaction severity. Subsequent work incorporating more rigorous classification of food allergy severity has found FAQOL to be significantly reduced among parents of children who had previously experienced anaphylaxis relative to parents of children who had not [27]. Additionally, a history of severe food-allergic reactions (including those requiring an emergency department visit or hospitalization), previous epinephrine use, and greater

Table 1 Overview of common food allergy-specific quality of life instruments

Questionnaire name	Abbreviation	Number of items	Sample survey items
Patient self-report			
Food Allergy Quality of Life Questionnaire			*-Because of food allergy, I feel frustrated by dietary restrictions:* *-Because of food allergy, my social environment is restricted because of limitations on restaurants I can safely go to:* Responses are on a seven-point scale from "not at all" to "extremely"
Child form (ages 8–12)	FAQLQ-CF	24	
Teenager form (ages 13–17)	FAQLQ-TF	28	
Adult form (ages 18+)	FAQLQ-AF	29	
Food Allergy Independent Measure			*-How great do you think the chance is that you will have a severe reaction if you accidentally eat something to which you are allergic?* *-How great do you think the chance is that you cannot effectively deal with an allergic reaction should you accidentally eat something to which you are allergic?* Responses are on a seven-point scale from "0 % chance" to "100 % chance"
Child form (ages 8–12)	FAIM-CF	6	
Teenager form (ages 13–17)	FAIM-TF	5	
Adult form (ages 18+)	FAIM-AF	6	
Caregiver proxy-report			
Food Allergy Independent Measure—Parent Form	FAIM-PF	6	*-How great do you think the chance is that your child will die if he/she eats something to which he/she is allergic?* *-How great do you think the chance is that your child will accidentally eat something to which he/she is allergic?* Responses are on a seven-point scale from "0% chance" to "100% chance"
Food Allergy Quality of Life Questionnaire—Parent Form	FAQLQ-PF		*-Because of food allergy, my child experiences emotional distress:* *-Because of food allergy my child has been negatively affected by his/her environment being more restricted than other children of his/her age:* Responses are on a seven-point scale from "not at all" to "extremely"
Ages 0–3 version		14	
Ages 4–6 version		26	
Ages 7–12 version		30	
Caregiver self-report			
Food Allergy Quality of Life—Parental Burden	FAQoL-PB	17	*-In the past week, how troubled have you been by the possibility of or actually leaving your child in the care of others because of their food allergy?* *-In the past week, how troubled have you been by sadness regarding the burden your child carries because of their food allergy?* Responses are on an eight-point scale from "not troubled" to "extremely troubled"

numbers of symptoms during previous food-allergic reactions are associated with worse FAQOL among both children and caregivers [24, 26, 32, 33]. A recent large European study of both adults and children with food allergy found that a history of anaphylaxis was not associated with worse HQOL [34]; however, perceived disease severity was a significant predictor of QOL among both adults and children.

Given that emergency administration of epinephrine is the only effective treatment for a severe food-allergic reaction, a recent study investigated the effects of epinephrine auto-injector prescription and carrying practices on QOL [12]. This study of peanut- and tree nut-allergic children and their mothers found that the prescription of an epinephrine auto-injector significantly reduced anxiety among mothers but not among food-allergic children themselves. Whether the child reported carrying an auto-injector was not significantly associated with impaired QOL for mother or child. There has been a substantial push to expand the availability of "stock" or "undesignated" epinephrine auto-injectors in schools and other public spaces so that these devices are readily available in the event of a severe food-allergic reaction [35]. However, the effect of these policies on the QOL of patients with food allergy and their caregivers remains unknown.

A study evaluating relationships between epinephrine auto-injector carrying practices and QOL found that higher levels of anxiety among mothers and children did not increase the likelihood that children carried their auto-injectors or reported avoiding foods labeled that they "may contain" their allergen(s). This is inconsistent with earlier studies [13, 15] suggesting that high levels of stress in families with peanut-allergic children may positively influence coping strategies by promoting stricter avoidance of allergens. These apparently

conflicting findings suggest that the relationship between anxiety and QOL may follow a U-shaped curve, in keeping with the so-called Goldilocks principle[36], which is represented by (Fig. 1). This principle posits the existence of an optimal level of anxiety that facilitates adaptive coping and effective disease management while minimizing maladaptive hypervigilance and potentially dangerous risk-taking behavior. This attitude has been referred to in previous qualitative work as "relaxed readiness" [37]. To this point, a recent study found that relationships between food allergy severity and children's caregiver reported FAQOL were stronger among children of highly stressed mothers relative to less stressed mothers [33]. The authors also reported that greater maternal overprotection was associated with lower child QOL as well as greater dietary and social limitations independent of food allergy outcomes. This is consistent with studies in other fields suggesting that inappropriate maternal stress and overprotective parenting practices can lead to increased anxiety and other adverse outcomes in children [38]. However, one might argue that overprotection of food-allergic children, particularly those with a history of severe reactions, may be justified in light of the potentially fatal consequences of allergen exposure. An optimal balance between vigilance and risk is likely to be beneficial for FAQOL, but given the heterogeneity of food allergy phenotypes, additional research is needed to determine where this "sweet spot" may lie and how to most effectively and safely help patients achieve it.

Oral Food Challenge

Oral food challenges (OFC), wherein patients intentionally ingest suspected allergens and are clinically observed for subsequent reactions, are often required to establish definitive diagnoses of food allergy. Double-blinded, placebo-controlled food challenges (DBPCFC) are the gold standard for diagnosing food allergy. In DBPCFC, bias is minimized, relative to open and single-blinded OFC, as the potential impact of patient or clinician anxiety on the patient's observed reaction to the food is reduced [39]. Participation in a DBPCFC has been shown to improve FAQOL in children, teenagers, and adults [40]. Improvement has been demonstrated in children and their caregivers regardless of OFC outcome, whereas adults and teenagers experience improved QOL only when the result of the OFC was to rule out the presence of food allergy [41] [42••]. However, this improvement has not been shown to reliably persist beyond 6 months post-OFC [43••]. A recent prospective study found no difference in FAQOL between children with suspected food allergies and children with diagnoses confirmed by OFC or skin prick test [44] at 10-year follow-up.

Oral Immunotherapy

The only widely accepted and widely available management strategy for food allergy is allergen avoidance and the use of injectable epinephrine for accidental exposures. Clinical trials of novel therapeutics aimed at retraining the immune system to tolerate food allergens and preventing anaphylaxis [45] are ongoing. The potential therapy most frequently studied is oral immunotherapy (OIT), which involves deliberate exposure to a food allergen in order to establish desensitization or tolerance. During OIT, patients consume increasing amounts of their allergen(s) until maximum tolerated doses (MTD) are reached. Despite the potential risk associated with such

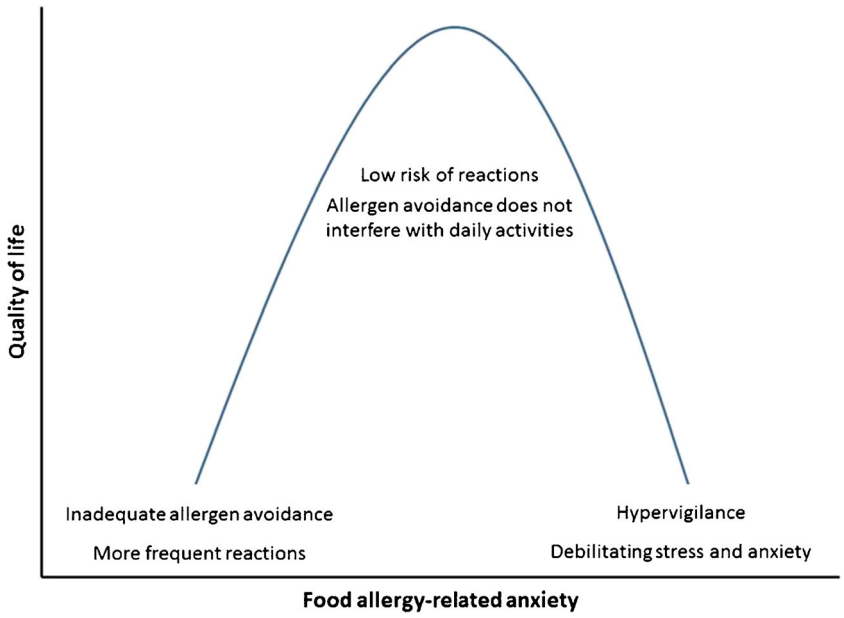

Fig. 1 Hypothesized relationships between food allergy-related quality of life and anxiety according to "The Goldilocks Principle"

exposure, multiple studies have found that OIT significantly improves both child and caregiver HQOL and FAQOL [46, 47••, 48, 49]. A recent study of children aged 4–12 undergoing OIT for milk, peanut, or egg allergy found that QOL was significantly influenced not only by allergy severity but also by the patient's MTD, as older children with lower MTD demonstrated significantly worsened FAQOL relative to those with higher MTD [46]. Lower MTD has been previously shown to correspond to increased risk of severe reactions and poor response to OIT in food-allergic children [50]. Considerably less is known regarding the impact of OIT on QOL among adult food allergy patients.

Interventions to Improve QOL

Relatively few studies have examined specific interventions to improve QOL among food-allergic patients and their caregivers; however, a number of approaches appear promising. One recent study found that a half-day group workshop consisting of food allergy education and skills training for children aged 5–7 and their caregivers significantly improved caregiver QOL [51]. The impact on the children's QOL was not reported. Similarly, a study of nurse-facilitated counseling sessions for caregivers using the framework of self-regulation for chronic disease management found that the intervention was associated with a significant improvement in caregiver QOL [52]. A randomized, controlled trial found that children of caregivers provided access to a 24-h telephone hotline staffed by food allergy specialists experienced significantly improved FAQOL over a 6-month period compared to children receiving usual care [53]; this improvement persisted at 6-month follow-up.

Limitations of Food Allergy QOL Studies and Suggestions for Future Research

Self vs. Proxy Report

Most studies of FAQOL among children have used parent-report measures as proxies for the children's QOL. The relative underuse of child-report measures may be a source of bias, as parents of food-allergic children tend to underestimate the degree of QOL impairment experienced by their children, relative to their children's self-reported QOL [54]. Future work on pediatric FAQOL should therefore attempt to assess both child- and caregiver-reported QOL. The use of latent variable approaches, which combine child- and caregiver-reported QOL into a single latent outcome while statistically accounting for the inherent correlation and measurement error, may reduce the aforementioned bias. Latent variable models can also include multiple indicators for child and/or caregiver-reported FAQOL simultaneously. Despite these advantages, latent variable frameworks like structural equation modeling have been underutilized in epidemiological [55] and clinical research studies [56] in general and particularly within the FAQOL literature.

Overrepresentation of Mothers

Research into the impact of childhood food allergy on QOL has disproportionately surveyed mothers. One of the few studies to distinguish between maternal and paternal QOL assessed the impact of childhood peanut allergy on anxiety, stress, and QOL among families in the UK [57] and found that relative to fathers, mothers of food-allergic children experienced reduced QOL and increased stress and anxiety. Mothers also perceived their children's peanut allergies as more adversely impacting their children's HQOL than did fathers, siblings, or food-allergic children themselves. Another study of mothers and fathers of children with peanut, tree nut, cow's milk, and egg allergies found that maternal FAQOL was significantly worse than paternal, irrespective of allergy type, severity, or the presence of comorbidities, despite the fact that mothers reported greater empowerment to effectively manage their child's allergy than did fathers [27]. While greater perceived social support was predictive of improved quality of life among both mothers and fathers, it was a stronger predictor among mothers, suggesting that efforts to increase social support may hold promise as a way to improve caregiver FAQOL, particularly among mothers. Further study of the effects of pediatric food allergy on the QOL of fathers and other male caregivers is needed, both to define the scope of the problem in this population and to guide the development of evidence-based interventions aimed at improving QOL and FAQOL.

Other Sources of Sampling Bias

Studies of FAQOL may also be limited by other types of sampling bias, including self-selection and pre-screening. A recent study examining differences in caregiver FAQOL between a sample recruited from an allergy clinic and a self-selected sample recruited through national food allergy advocacy groups found significantly greater impairment in the self-selected sample [58••]. Future studies would benefit from the utilization of a variety of recruitment methods and venues in an effort to include a population representative of the food allergy population as a whole.

Predominance of Cross-Sectional Data

To date, most studies of QOL among patients with food allergy, particularly in children, have utilized cross-sectional designs; such studies often fail to capture the dynamic natures of both QOL, which can change depending on a patient's social

and environmental context, and food allergy, which often manifests as general wellness with infrequent and/or brief periods of active disease in the form of allergic reactions. A recent study of food-allergic adults highlighted the utility of non-cross-sectional study design in this field by employing a daily diary method to evaluate the impact of common food allergy issues, such as problems finding suitable foods to eat when away from home and extra financial cost due to higher food prices for safe food, on participants' daily psychological functioning [59•]. The study found that participants experienced greater overall stress and negative mood on days with more food allergy issues and that these relationships were stronger among older participants. This and similar near-real-time approaches to data collection have multiple advantages over common cross-sectional survey methods. One such advantage is that they permit the examination of associations between food allergy issues and psychological functioning both between- and within-subjects. Additionally, they are generally less subject to recall bias as subjects report events the same day they occur. Given these advantages and the ubiquity and computational power of smartphones, researchers are increasingly leveraging smartphones to deliver the so-called ecological momentary assessments, which aim to capture detailed data about the co-variation between variables of interest throughout the day [60]. For example, a recent study used repeated cell phone-based assessments to test how within-day variability in stress and social context leads to asthma exacerbations among minority adolescents with chronic asthma [61]. These within-subject sampling methods not only improve statistical power to detect associations of interest but also allow the variability of participants' responses to be examined as a separate outcome. These methods are well suited to discover momentary predictors of food allergy-related anxiety or QOL as well as predictors of increased moment-to-moment variation in these constructs. Rising rates of smartphone ownership among teenagers and young adults make ecological momentary assessment an attractive research method in the field of FAQOL in these relatively understudied age groups, which are at the highest risk of fatal food-induced anaphylaxis [62].

Conclusions

This review summarized a substantial body of research demonstrating that QOL is significantly impaired in children with food allergy and their caregivers. However, additional work is needed to evaluate the impact of food allergy on the QOL of adult patients, who are managing their disease in a different context than children and have been understudied relative to pediatric populations. Similarly, while OIT and OFC have been shown to improve QOL outcomes in pediatric populations, their effects on adult QOL have been relatively understudied, as have other interventions. Furthermore, future epidemiological work should strive to move beyond convenience samples recruited from single clinics or advocacy groups to larger, more broadly generalizable population-based samples. Such work will likely be facilitated by the recent development and validation of short-forms of FAQOL assessments such as the FAQLQ-PF10 [63] which can be administered more quickly and with less participant burden than the full versions. Finally, the next generation of work in FAQOL should consider greater utilization of prospective designs, which can provide much-needed information about both longitudinal and day-to-day variability in FAQOL and how they may differ among key clinical subpopulations. Such work has the potential to inform clinical practice and policy, as well as improve the lives of the millions of patients with food allergy worldwide.

Compliance with Ethical Standards

Conflict of Interest Drs. Warren, Otto, Walkner, and Gupta declare no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- • Of importance
- •• Of major importance

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