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# The Psychosocial Burden of Food Allergy among Adults: A US Population-Based Study 

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#### Abstract

BACKGROUND: Food allergy (FA) affects >25 million US adults, resulting in substantial health care utilization. Data suggest that patients with FA suffer impairments in FA-related quality of life (FAQoL); however, little is known regarding psychosocial impacts of FA among US adults.

OBJECTIVE: To characterize FAQoL among a large, nationally representative adult sample, and its determinants, including sociodemographic characteristics, severity, comorbid conditions, allergic symptoms, number and type of allergens, and health care utilization.

METHODS: A survey was administered between October 2015 and September 2016 to a nationally representative sample of US households. Survey constructs included the Food Allergy Independent Measure (FAIM), which was developed to quantify adverse impacts of living with FA on patient quality of life. FAIM responses were analyzed from adults reporting current FA ( $\mathrm{N}=6207$ ). Linear regression models examined associations with sociodemographic and FA characteristics.

RESULTS: The overall estimated mean FAIM score was 2.87 ( $95 \%$ confidence interval: 2.83-2.90). FAIM scores (range = 1-7) in adjusted models were invariant by race/ethnicity, private/ public insurance status, and census division. Significant differences ( $P<.05$ ) by lower household income, lower age, and greater education emerged, resulting in higher FAIM scores indicating FAQoL impairment. Among major food allergens, wheat, soy, and milk allergies were each associated with the greatest increases in adjusted FAIM scores. Reporting a current epinephrine autoinjector (EAI) prescription, severe allergic reaction history, history of EAI use, FA-related emergency department visits, or more FAs were also associated with significantly higher FAIM scores.

CONCLUSION: The population-level psychosocial burden of adults with FA is substantial, broadly distributed, and differs by demographic and allergic disease characteristics.


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## Keywords

Food allergy; Quality of life; Psychosocial burden; Population health

Food allergies (FAs) affect over 25 million US adults and incur a substantial economic burden. ${ }^{1,2}$ At the population level, FAs arguably have their greatest impact on the quality of life (QoL) of those affected, because fatalities are rare ${ }^{3}$ and patients are generally healthy in the absence of an acute allergen exposure. However, because of the ubiquity of food throughout daily life, FA management remains challenging. ${ }^{4}$ Previous research describes how the stress of daily FA management compounded by the dearth of effective treatment options impacts mental well-being, family relationships, and often limits social activities. These impacts and limitations contribute to impaired FA-related quality of life (FAQoL). ${ }^{5}$

Accurately characterizing the distribution and determinants of FAQoL remains integral when measuring the public health impact of FAs and informing future interventions. Known predictors of greater FAQoL impairment among children include allergen type, having multiple allergies, severity, history of reported anaphylaxis, history of emergency department (ED) visits, comorbid conditions, and socioeconomic status. ${ }^{6-9}$ However, although previous studies have underscored the importance of better understanding the variability in how FAQoL may present throughout key developmental periods (ie, childhood, adolescence), remarkably little research has addressed FAQoL among US adults living with FA.

A recent US population-based survey of more than 40,000 adults estimated that $10.8 \%$ of US adults are currently food allergic, with over half of allergic adults reporting at least 1 adult-onset FA. ${ }^{2}$ Moreover, it is anticipated that this population of affected adults will continue to grow as food-allergic children transition into adulthood. ${ }^{10}$ These recent data also suggest that many adults living with food sensitivities, intolerances, or other non-IgE-mediated food-related conditions may incorrectly believe themselves to be food allergic and do not seek confirmatory physician diagnosis. Non-IgE-mediated conditions do not generally require the same level of strict allergen avoidance, and therefore many adults may be living with unnecessary restrictions-yielding unwarranted FAQoL impairment.

To date, previous FAQoL research has used small or mixed populations of children and adults, largely drawn from non-US-based convenience samples. It is therefore critical that we systematically explore the differential expression of FAQoL throughout the life course via assessment of well-characterized, population-based samples. Consequently, this study characterizes FAQL among a large, nationally representative sample of US adults, as well as its determinants, including sociodemographic characteristics, severity, comorbid conditions, allergic symptoms, number and type of allergens, and health care utilization.

## METHODS

## Sampling frame and survey administration

A population-based survey was administered between October 2015 and September 2016 to a sample of US households. Eligible study participants included adults ( $\geq 18$ years old) able to self-complete the survey in English or Spanish via web or telephone. Participants
were first recruited from NORC (formerly called the National Opinion Research Center) at the University of Chicago's probability-based AmeriSpeak Panel (completion rate $=$ $51.2 \%$ ). Respondents were assigned base, nonresponse-adjusted sampling weights, which were raked to external population totals associated with age, sex, education, race/ethnicity, housing tenure, telephone status, and Census Division. Prevalence estimates gleaned from population-weighted AmeriSpeak responses were augmented by calibration-weighted, non-probability-based responses obtained through Survey Sampling International. Detailed information regarding survey sampling, weighting, and estimation is available in previous publications. ${ }^{2,11}$ Surveys were completed by 40,443 US adults.

## Defining food allergy

For this study, analyses focused on adults meeting 3 previously used definitions of current FA. ${ }^{2,12}$ (1) Reported FA includes individuals with any self-reported current FA. (2) Convincing FA includes respondents reporting at least 1 current FA where the most severe reaction reported to that food included at least 1 stringent symptom (Figure E1, available in this article's Online Repository at www.jaci-inpractice.org). Reported allergies with reaction symptom characteristics of oral allergy syndrome or intolerances were not considered convincing (Figure E2, available in this article's Online Repository at www.jaciinpractice.org). (3) Individuals were considered to have physician-confirmed convincing FAs if they had at least 1 current FA meeting the aforementioned "convincing" criteria and for which a physician's diagnosis was also reported. For each FA, a severe reaction history was indicated by reporting 1 or more stringent symptoms across 2 or more of the following organ systems: skin or oral mucosa, gastrointestinal tract, cardiovascular, and respiratory tract. If multiple FAs were reported, each reported FA was evaluated separately using the FA categorization flowchart. Lifetime physician diagnosis of other atopic comorbidities was also assessed.

## Characterizing the psychosocial burden of food allergy

To estimate the degree of psychosocial burden experienced by adults as a result of living with FA, the Food Allergy Independent Measure (FAIM) was administered to all survey respondents reporting FA. The FAIM was designed to assess respondents' perceived risk of accidental allergen exposure and the severity of the anticipated outcome ${ }^{13}$-constructs that underlie differences in health-related QoL among food-allergic patients. The measure has been used extensively and has been found to be particularly useful in capturing change in psychosocial burden among allergen immunotherapy patients. ${ }^{14,15}$
"Expectation of Outcome" (FAIM-EO) was assessed by 4 items: How big do you think the chance is that you:

1. will accidentally eat something to which you are allergic?
2. will have a severe reaction if you accidentally eat something to which you are allergic?
3. will die if you accidentally eat something to which you are allergic?
4. cannot do the right things for your allergic reaction, should you accidentally eat something to which you are allergic?

Response options for these items were 1 (Never- $0 \%$ chance); 2 (Very small chance); 3 (Small chance); 4 (Fair chance); 5 (Big chance); 6 (Very big chance); 7 (Always- $100 \%$ chance).

The FAIM also includes the following 2 additional items that ask participants to respond on a 1- to 7-point scale.
(1) How many foods are you unable to eat because of your food allergy?

Response options were 1 (Almost none); 2 (Very few); 3 (A few); 4 (Some); 5 (Many); 6 (Very many); 7 (Almost all).
(2) How much does your food allergy affect things you do with others?

Response options were 1 (So little we don't actually notice it); 2 (Very little); 3 (A little); 4 (Moderately); 5 (A good deal); 6 (A great deal); 7 (A very great deal).

This Independent Measure (IM) subscale was designed to reflect additional aspects of the perceived severity of FA not captured by the EO questions.

## Statistical methods

The full 6-item FAIM demonstrated excellent internal consistency $\alpha=0.81$, as did both subscales $a_{\text {FAIM-EO }}=0.80 ; a_{\text {FAIM-IM }}=0.76$. Confirmatory factor analysis provided support for the separability of the FAIM-EO and FAIM-IM subscales, with a 2-factor model demonstrating excellent fit to the data (comparative fit index $=0.990$; standardized root mean residual $=0.016$; root mean squared error of approximation $=0.077)(90 \%$ confidence interval [CI]: 0.066-0.089) (L. T. Hu and P. M. Bentler, unpublished data, 1993). ${ }^{16}$ Complex survey-weighted proportions were calculated to estimate frequencies.

To estimate the magnitude of covariate-adjusted associations of interest, a series of multiple linear regression models were used to evaluate hypothesized predictors of overall FAIM scores, as well as EO and IM subscores. Models included all adults reporting a current FA. The following sociodemographic covariates were included in each model: participant race/ ethnicity, sex, age, household income, educational attainment, and whether they were born in the United States. Indicators for each of the following lifetime, physician-diagnosed atopic comorbidities were also included: asthma, atopic dermatitis, allergic rhinitis, insect sting/ venom allergy, eosinophilic esophagitis, food protein-induced enterocolitis, latex allergy, medication allergy, urticaria/chronic hives, as was an indicator for any "other" chronic conditions. Nine additional variables indicated the presence/absence of convincing FA to each of the "top 9 " foods (ie, peanut, tree nut, milk, egg, shellfish, fin fish, soy, wheat, and sesame), as well as the number of total convincing FAs (categorized as 2-3, 4-6, 7-10, and $\geq 11$ ). Indicators also included whether the participant had $\geq 1$ physician-confirmed, convincing FA, $\geq 1$ convincing allergy categorized as "severe," a current epinephrine autoinjector (EAI) prescription, a history of epinephrine use for food-induced anaphylaxis treatment, $\geq 1$ lifetime FA-related ED visit, $\geq$ FA-related ED visit within the past 12 months, $\geq 1$ adult-onset and $\geq 1$ childhood-onset FA , as well as whether the participant had only
convincing adult-onset FA (ie, no childhood-onset FA). Finally, indicators were included for the number of total and food-allergic children in the household.

Two-sided hypothesis tests with $P$ values <. 05 indicate statistical significance. Analyses were conducted using Stata 15 and accounted for complex survey sampling.

## RESULTS

## Descriptive statistics

As a result of the complex survey weighting approach used, the distributions of respondents by age, sex, and race are representative of the current food-allergic US adult population. Weighted sample demographics, including age and income distributions, are reported in Table I both for the overall study population and by current FA status. Table II reports mean US population-weighted FAIM responses among adults with reported, convincing, and physician-confirmed convincing FA.

## Sociodemographic predictors of FAQoL

Adjusted associations from multiple linear regression models are visualized in Figure 1 and presented in Table III, which reports predictors of overall FAIM, and EO/IM subdomain scores in the format of unstandardized regression coefficients and their accompanying variance estimates (eg, 95\% CI and standard errors). An unstandardized regression coefficient represents the model predicted change in a dependent variable (eg, overall FAIM scores) due to a 1 unit change in a given independent variable X, adjusting for other variables in the model. No significant demographic differences in overall FAIM scores emerged, except for significantly lower scores among adults aged $\Varangle 60$ ( $\mathrm{B}[\mathrm{SE}]=-0.10$ [0.04]) and greater scores among adults with terminal professional/doctoral degrees (B [SE] $=0.21[0.11])$.

The only significant demographic difference observed on the EO subscale was that USborn adults reported significantly reduced expectation of negative outcomes relative to foreign-born adults $(\mathrm{B}[\mathrm{SE}]=-0.12[0.06])$. With respect to the IM subscale, significant racial differences emerged with black adults reporting significantly reduced social impact and dietary restriction (B [SE] $=-0.18[0.05]$ ) relative to whites. Sex differences were also significant, with females reporting a significantly greater social impact and dietary restriction $(\mathrm{B}[\mathrm{SE}]=0.16[0.04])$, despite marginally reduced expectation of outcome relative to males $(\mathrm{B}[\mathrm{SE}]=-0.05[0.03])$. More educated adults also reported a greater social impact and dietary restriction, particularly those with terminal professional degrees (B $[\mathrm{SE}]=0.36[0.16])$. Conversely, older adults reported a significantly less social impact and dietary restriction $(B[S E]=-0.24[0.05])$ relative to young adults.

## Clinical and atopic predictors of FAQoL

When the adjusted effects of reporting specific FAs were examined, the greatest increases in FAIM scores were observed among wheat ( $\mathrm{B}[\mathrm{SE}]=0.37[0.06]$ ), milk ( $\mathrm{B}[\mathrm{SE}]=0.17$ [0.04]), soy $(\mathrm{B}[\mathrm{SE}]=0.14[0.07])$, and sesame-allergic $(\mathrm{B}[\mathrm{SE}]=0.09$ [0.12] $)$ adults. Adults with more reported FAs $\left(\mathrm{B}_{2-3} \mathrm{FAs}[\mathrm{SE}]=0.19[0.03], \mathrm{B}_{4-6} \mathrm{FAs}[\mathrm{SE}]=0.36[0.04], \mathrm{B}_{7-10}\right.$ FAs
$[\mathrm{SE}]=0.50[0.07], \mathrm{B}_{11+\mathrm{FAs}}[\mathrm{SE}]=0.67$ [0.09]) also had significantly higher FAIM scores than their monoallergic counterparts.

Reporting physician-diagnosed FA was associated with a significantly reduced burden (B $[S E]=-0.18[0.03])$. Adults reporting severe reactions $(B[S E]=0.22[0.03])$, a current EAI prescription (B $[\mathrm{SE}]=0.25[0.04])$, and especially a history of epinephrine use for FA treatment $(\mathrm{B}[\mathrm{SE}]=0.34[0.05])$ or FA-related ED visits in the last 12 months $(\mathrm{B}[\mathrm{SE}]=0.41$ [0.07]) reported substantially higher overall FAIM scores than their counterparts who did not report these experiences. With respect to atopic comorbidities, adults with eosinophilic esophagitis $(B[S E]=0.36[0.16])$ or FPIES $(B[S E]=0.26[0.15])$ also reported greater overall psychosocial impairment, compared with their counterparts without these conditions.

In general, each of the factors summarized above influenced both subscales in a similar fashion, with the following exceptions. Having a wheat allergy was very strongly associated with a greater reported social impact and dietary restriction (B [SE] $=0.99$ [0.10]), but not expectation of outcome $(B[S E]=0.05[0.06])$. Similarly, having a convincing milk (B [SE] $=0.45[0.07])$ or egg allergy $(B[S E]=0.15[0.09])$ was associated with a greater reported social impact and dietary restriction, but not expectation of outcome ( $\mathrm{B}_{\text {Milk }}[\mathrm{SE}]=0.03$ [0.05]) and $\left(\mathrm{B}_{\mathrm{Egg}}[\mathrm{SE}]=0.01[0.08]\right)$. Furthermore, reporting a recent FA-related ED visit $\left(\mathrm{B}_{\mathrm{EO}}[\mathrm{SE}]=0.55[0.08]\right.$ versus $\left.\mathrm{B}_{\mathrm{IM}}[\mathrm{SE}]=0.15[0.09]\right)$, history of EAI use $\left(\mathrm{B}_{\mathrm{EO}}[\mathrm{SE}]=\right.$ $0.43[0.06]$ versus $\left.\mathrm{B}_{\mathrm{IM}}[\mathrm{SE}]=0.18[0.06]\right)$, or severe reaction history $\left(\mathrm{B}_{\mathrm{EO}}[\mathrm{SE}]=0.26\right.$ [0.04] versus $\mathrm{B}_{\mathrm{IM}}[\mathrm{SE}]=0.16[0.05]$ ) were stronger predictors of EO subdomain scores compared with IM subdomain scores.

Notably, similar results were observed when analyzing only the 6207 individuals with "convincing" FA and the 3135 individuals with physician-confirmed convincing FA (Figure E3, available in this article's Online Repository at www.jaci-inpractice.org).

## DISCUSSION

To our knowledge, this is the first study to assess FAQoL and its determinants among a nationally representative sample of US adults with FA. Importantly, these data are not restricted to clinical populations, but rather include food-allergic adults recruited from the general US population with and without physician-diagnosed allergy. This is important because many food-allergic adults in the United States do not seek confirmatory testing of suspected FAs, and therefore those who seek treatment may be unrepresentative of the broader food-allergic population. ${ }^{12,17}$ Among US adults, the most salient factors associated with worse FAQoL pertained to health care utilization-namely receiving FA treatment in the ED, reporting a current EAI prescription, and reporting previous treatment of an allergic reaction with an EAI. In addition, the greater number of FAs and the type of FAs were important predictors of impaired FAQoL in our adult sample.

Expectation of outcome is an important predictor of health and well-being. ${ }^{19}$ The FAIM's EO subdomain assesses expectation of outcome if an allergen is accidentally ingested by the allergic individual (namely, the likelihood of ingestion, the chance of a severe reaction including death, and the chance of receiving/administering effective treatment). FAIM scores
of European adults have previously been found to explain $>50 \%$ of the total variance in their responses on the much more extensive Food Allergy Quality of Life Questionnaire (FAQLQ) -the present "gold standard" for FAQoL assessment. However, a history of anaphylaxis and having a current EAI prescription were not independent predictors of the total FAQLQ score above and beyond FAIM scores. ${ }^{6}$ In contrast, present findings indicate that reporting a severe allergic reaction history was a significant determinant of FAQoL impairment, as assessed by the FAIM. Importantly, these adverse effects of severe reaction symptomatology were of comparable magnitude ( $\mathrm{B}=0.2-0.4$ ) to the independent effects of reporting an EAI prescription and key health care utilization indicators (eg, self-reported epinephrine use, lifetime history of ED visits). Similarly, in a recent survey of young adults (aged 18-22) with FAs in the United States, respondents reporting history of anaphylaxis also perceived that their FA was more severe and exhibited greater FA-related worry. ${ }^{20}$ The authors suggested that a history of anaphylaxis may be a marker for identifying patients with FA who are at risk for developing psychological distress. This perspective is consistent with findings in other disease states that patient perceptions of illness severity are important predictors of psychological distress. ${ }^{21,22}$

The combination of perceived severity and health care utilization may contribute to the impairment of FAQoL and underscores the importance of considering patients' perceptions in relationship to FAQoL. For example, in a matched case-control study by Lange, ${ }^{23}$ the study compared FAQoL among Dutch adult patients who had experienced a severe foodallergic reaction and presented to the ED with patients who did not use health care after reaction. Both groups had similar clinical markers of severity. The patients who sought medical care after a severe reaction reported worse FAQoL than those who did not seek medical care. These results suggest that subjective perception of "severity" can moderate the impact of a severe reaction history on FAQoL and that clinical encounters may provide important opportunities to modify patient perceptions. Moreover, the nature of anaphylactic symptoms and subsequent ED experiences may be associated with psychological distress and even medical-related trauma, which warrants further exploration among adults with FA. Kazak et al's ${ }^{24} 2006$ "An integrative model of pediatric medical traumatic stress" provides a conceptual framework that considers phase I to be the potentially traumatic event (eg, anaphylaxis) and surrounding details; phase II to be medical treatment and responses (eg, EAI use, FA-related hospitalization), and phase 3 to be adjustment beyond the active medical treatment. In future work, it may be useful to explore whether these phases apply to adults who experience an anaphylactic reaction and have higher perceptions of severity of their condition (as evidenced by higher FAIM scores), as they may be at risk for experiencing medical traumatic stress. Notably, one recent study of 89 adult subjects with hymenoptera-venom allergic reactions identified significantly higher rates of probable post-traumatic stress disorder among patients reporting anaphylactic reactions versus those reporting only localized allergic responses. ${ }^{25}$ Future work may want to more explicitly characterize participants' level of anxiety and/or depression to better understand how these conditions may impact FAIM scores.

Encouragingly, even after adjustment for key covariates, adults with physician-diagnosed FA reported significantly less severe expectation of adverse FA outcomes and fewer FArelated social and dietary restrictions than their un/self-diagnosed counterparts. Although
our study did not assess whether the diagnosis was made in a primary care or specialist setting, findings suggest important aspects of clinical FA confirmation that may reduce psychosocial burden among patients. Patients who seek clinical allergy confirmation will receive counseling on effective allergen avoidance and anaphylaxis management strategies —including identification of anaphylactic signs/symptoms and appropriate treatment. ${ }^{23}$ Clinical management may help to reduce the degree of unnecessary allergen avoidance by patients (eg, a peanut- allergic patient avoiding all nuts; some milk-allergic patients avoiding baked milk). Given that much of FAQoL impairment is believed to stem from exaggerated expectation of adverse outcomes, ${ }^{28}$ engaging a trusted health professional provides an important opportunity to clarify patient misconceptions-including assuaging fears pertaining to perceived risk of "unnecessary" EAI use and ensuring that patients have realistic perspectives regarding mortality risk.

Other important predictors of impaired FAQoL in our sample include having a greater number of FAs and the presence of specific FAs-most notably wheat, milk, soy, and sesame. Previous studies of adult FA patients indicate that FAQoL may vary substantially by food allergen type. ${ }^{7}$ Here, cow's milk allergy was an important predictor of total score; however, the magnitude of this impairment was equivalent in models where we adjusted for specific reaction symptomatology, whether or not FAs were confirmed via oral food challenge, and irrespective of reported allergy onset timing. This finding suggests that FAQoL impairment may also be due to other factors-such as the relative ubiquity of milk in the food environment relative to other food allergens and associated difficulties with allergen avoidance. This may also help explain why wheat allergy had the most dramatic adverse effects on FAQoL among the "top 9" FAs, with an estimated magnitude of impairment $(B=0.37)$ more than double that of cow's milk $(B=0.17) .{ }^{29}$

Some systematic differences did emerge when examining FAIM subdomain scores, which may be attributable to cultural differences. For example, non-US-born respondents reported markedly less severe expectation of adverse FA outcomes than their US-born counterparts, despite reporting slightly higher IM subscale scores. Although these non-US-born individuals are highly heterogeneous with respect to country of origin and cultural background, these data suggest the need to cultivate a more robust support network to help ameliorate unreasonable worry about accidental ingestion or experiencing a severe/ fatal allergic reaction. These data also suggest that US-born adults may feel particularly unprepared to identify and treat food-allergic reactions.

For example, when compared with their white counterparts, black adults reported significantly less FAQoL impairment in domains assessed by the IM subscale. Further examination of this subscale, which assesses FA-related dietary limitation and social limitations, revealed that these race-related differences were driven predominantly by variation in the extent to which respondents' FA is perceived to adversely impact social activities.

As this is the first study to administer the FAIM to a large, nationally representative sample of US adults, we can compare population-level estimates with previous European work characterizing FAQoL among adults with perceived FA from the following 7 European
countries: France, Greece, Iceland, Italy, the Netherlands, Poland, and Spain. ${ }^{30}$ Swedish adults with physician-diagnosed FA were also surveyed. This study identified substantial heterogeneity in FAIM scores between countries, with mean scores ranging from 2.6 (standard deviation $[\mathrm{SD}]=1.0$ ) in Spain to $3.7(\mathrm{SD}=1.2)$ in Greece and $4.4(\mathrm{SD}=1.1)$ in Sweden. Although not measured in the study, the authors speculated that between-country differences in FAIM may be due to cross-cultural differences in cognitive coping styles, and/or dietary practices. Clinical FA management, namely the prescription and insurance coverage of EAIs, also varied substantially between countries. In contrast to the European data, geographic differences in FAIM scores across US census regions or division were minimal, with mean scores differing by a maximum of $<0.2$ points on the FAIM.

These data provide the first nationally representative estimates of the current psychosocial burden of FA among US adults, and as such, can serve as valuable inputs for updating management guidelines, developing interventions aimed at enhancing FAQoL among adults, and even contribute to the estimation of FA health state utilities. ${ }^{31}$ One recent such effort, which modeled the cost-effectiveness of emerging commercial peanut allergy immunotherapies, relied on FAQL data from just 37 untreated food-allergic residents of the Isle of Wight enrolled in an unselected longitudinal birth cohort. ${ }^{31}$ The present data, owing to the much larger sample size, not only permit more precise characterization of FAQoL among the US general adult food-allergic population, but also allow relatively precise estimation within subpopulations of interest. However, it is important to acknowledge that the present data are limited by their cross-sectional, self-report survey design, which limits the strength of causal inference. Future survey-based studies leveraging a US populationbased sampling frame should consider employing clinical FA testing on a representative subset of patients to help assess the degree of correlation between patient-reported and clinically confirmed outcomes. It may also be worthwhile for such work to administer both the FAIM and FAQLQ to compare and contrast their psychometric properties in the US context-given that extant work has been limited to European samples.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Conflicts of interest:

C. Warren has served as an epidemiological consultant for Alladapt Immunotherapeutics and Before Brands. A. Dyer and L. Lombard have no conflicts of interest to disclose. A. Dunn-Galvin serves as a consultant for DBV technologies and Aimmune Therapeutics. R. Gupta reported receiving grants from the National Institutes of Health (NIH) during the conduct of the study and from Stanford Sean N. Parker Center for Allergy Research, UnitedHealth Group, Thermo Fisher Scientific, Genentech, and the National Confectioners Association as well as personal fees from Before Brands, Kaléo Inc, Genentech, Institute for Clinical and Economic Review, Food Allergy Research \& Education, Aimmune Therapeutics, and DBV Technologies outside the submitted work.

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## Abbreviations used

CI
Confidence interval
EAI
Epinephrine autoinjector

| ED | Emergency department |
| :--- | :--- |
| EO | Expectation of Outcome |
| FA | Food allergy |
| FAIM | Food Allergy Independent Measure |
| FAQoL | Food allergy-related quality of life |
| FAQLQ | Food Allergy Quality of Life Questionnaire |
| IM | Independent Measure |
| QoL | Quality of life |
| SD | Standard deviation |

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## What is already known about this topic?

Previous studies of small clinically recruited adult allergy patients or mixed convenience samples of children and adults suggest that food allergy-related quality of life may vary by demographic, geographic, and clinical allergic disease characteristics.

## What does this article add to our knowledge?

This is the largest study evaluating food allergy-related quality of life within a nationally representative sample of US adults and establishes population-level norms for the Food Allergy Independent Measure, a commonly used patient-reported outcomes measure.

## How does this study impact current management guidelines?

This study identifies factors associated with greater psychosocial burden among US adults with food allergy and underscores the importance of clinical diagnosis and understanding patients' perceptions of severity and health care utilization to inform food allergy management.


Figure 1.
Comparing adjusted predictors of FAIM Expectation of Outcome (EO) and Independent Measure (IM) subdomain scores (unstandardized regression coefficients with 95\% confidence intervals). EAI, Epinephrine autoinjector; ED, emergency department; EoE, eosinophilic esophagitis; FA, food allergy; FAIM, Food Allergy Independent Measure; FPIES, Food Protein-Induced Enterocolitis Syndrome.

US population-weighted sample characteristics

| All adults Point estimate (95\% CI) | Adults with reported FA Point estimate ( $95 \%$ CI) | Adults with convincing FA Point estimate (95\% CI) | Adults with physician-confirmed FA Point estimate ( $\mathbf{9 5 \%}$ CI) |
| :---: | :---: | :---: | :---: |


| Race/ethnicity |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: |
| Asian | 3.9 (3.6-4.1) | 4.2 (3.8-4.8) | 4.1 (3.5-4.8) | 4.2 (3.3-5.2) |
| Black | 11.7 (11.3-12.1) | 11.2 (10.4-12.2) | 12.2 (11.1-13.3) | 12.7 (11.2-14.5) |
| White | 64.9 (64.2-65.6) | 62.3 (60.9-63.7) | 61.6 (15.2-18.2) | 60.4 (58.0-62.7) |
| Hispanic | 15.5 (14.9-16.1) | 16.8 (15.6-18.1) | 16.6 (15.2-18.2) | 17.6 (15.8-19.6) |
| Multiple/other | 4.1 (3.8-4.4) | 5.4 (4.8-6.2) | 6.0 (5.1-7.1) | 5.1 (4.1-6.3) |
| Sex |  |  |  |  |
| Female | 51.7 (51.0-52.4) | 62.6 (61.2-63.9) | 66.4 (64.8-68.1) | 64.5 (62.3-66.6) |
| Male | 48.3 (47.6-49.0) | 37.5 (36.1-38.9) | 33.6 (31.9-35.2) | 35.5 (33.4-37.7) |
| Age (y) |  |  |  |  |
| 18-29 | 21.5 (20.8-22.1) | 23.2 (22.0-24.5) | 22.6 (21.1-24.1) | 26.0 (24.0-28.2) |
| 30-39 | 17.0 (16.5-17.5) | 19.0 (17.9-20.1) | 20.1 (18.7-21.5) | 22.5 (20.6-24.5) |
| 40-49 | 16.8 (16.3-17.3) | 16.5 (15.4-17.6) | 15.6 (14.4-16.9) | 16.6 (15.0-18.3) |
| 50-59 | 18.0 (17.5-18.5) | 18.4 (17.4-19.5) | 19.9 (18.5-21.4) | 18.3 (16.5-20.2) |
| 60+ | 26.8 (26.2-27.4) | 22.9 (21.8-24.2) | 21.9 (20.4-23.3) | 16.6 (14.9-18.5) |
| Household income (\$) |  |  |  |  |
| <25,000 | 16.6 (16.2-17.1) | 15.3 (14.3-16.2) | 16.3 (15.2-17.6) | 13.7 (12.2-15.3) |
| 25,000-49,999 | 22.0 (21.4-22.5) | 21.8 (20.8-22.9) | 22.2 (20.9-23.6) | 21.1 (19.4-22.8) |
| 50,000-99,999 | 30.9 (30.3-31.5) | 32.8 (31.5-34.1) | 33.4 (31.8-35.0) | 37.2 (34.9-39.5) |
| 100,000-149,999 | 19.6 (19.0-20.2) | 20.4 (19.2-21.7) | 19.1 (17.6-20.8) | 19.3 (17.3-21.4) |
| >150,000 | 10.9 (10.4-11.5) | 9.7 (8.8-10.7) | 8.9 (7.0-9.1) | 8.8 (7.5-10.3) |
| Educational attainment |  |  |  |  |
| <High school grad | 3.8 (3.5-4.1) | 2.8 (2.3-3.5) | 3.4 (2.7-4.2) | 2.8 (2.1-3.7) |
| High school grad | 18.0 (17.4-18.6) | 14.7 (13.6-15.8) | 14.7 (13.4-16.1) | 13.4 (11.7-15.2) |
| Some college | 22.8 (22.2-23.3) | 23.2 (22.0-24.3) | 24.5 (23.1-26.0) | 22.8 (22.2-23.3) |
| Associates degree | 10.1 (9.8-10.5) | 11.0 (10.2-11.9) | 11.5 (10.5-12.7) | 10.1 (9.8-10.5) |

[^1] Some college -

TABLE I.
$C I$, Confidence interval; $F A$, food allergy
Summary FAIM scores

|  | All adults with reported FA Point estimate (95\% CI) $\mathrm{N}=9280$ | Adults with reported FA but not convincing FA Point estimate ( $95 \%$ CI) $\mathbf{N}=\mathbf{3 0 7 3}$ | All adults with convincing FA Point estimate (95\% CI) $\mathrm{N}=\mathbf{6 2 0 7}$ | All adults with physician-confirmed convincing FA Point estimate (95\% CI) $\mathrm{N}=3135$ |
| :---: | :---: | :---: | :---: | :---: |
| Overall FAIM score | 2.64 (2.61-2.67) | 2.34 (2.30-2.38) | 2.87 (2.83-2.90) | 3.15 (3.11-3.20) |
| FAIM EO subscale | 2.66 (2.63-2.69) | 2.33 (2.28-2.37) | 2.92 (2.88-2.96) | 3.19 (3.14-3.24) |
| FAIM EO Item 1 | 3.10 (3.06-3.15) | 3.06 (2.98-3.13) | 3.14 (3.09-3.19) | 3.30 (3.23-3.37) |
| FAIM EO Item 2 | 3.18 (3.13-3.22) | 2.62 (2.56-2.69) | 3.60 (3.54-3.66) | 3.91 (3.83-3.98) |
| FAIM EO Item 3 | 2.03 (2.00-2.07) | 1.61 (1.57-1.65) | 2.36 (2.31-2.40) | 2.71 (2.64-2.79) |
| FAIM EO Item 4 | 2.34 (2.30-2.38) | 2.02 (1.97-2.07) | 2.59 (2.54-2.64) | 2.84 (2.77-2.91) |
| FAIM IM subscale | 2.59 (2.55-2.63) | 2.37 (2.31-2.43) | 2.77 (2.71-2.82) | 3.08 (3.01-3.14) |
| FAIM IM Item 1 | 2.92 (2.87-2.96) | 2.70 (2.63-2.77) | 3.09 (3.03-3.15) | 3.39 (3.32-3.46) |
| FAIM IM Item 2 | 2.27 (2.22-2.31) | 2.04 (1.98-2.10) | 2.44 (2.38-2.50) | 2.76 (2.69-2.84) |

$C I$, Confidence interval; $E O$, Expectation of Outcome; FA, food allergy; FAIM, Food Allergy Independent Measure; $I M$, Independent Measure.

| Three multiple regression models predicting overall FAIM scores, EO subdomain scores, and IM subdomain scores among patients with reported FA |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Covariate | Overall FAIM score |  | EO subdomain score |  | IM subdomain score |  |
|  | $\mathrm{R}^{2}=0.26$ |  | $\mathrm{R}^{2}=0.23$ |  | $\mathrm{R}^{2}=0.19$ |  |
|  | Unstandardized coefficient | Standard error | Unstandardized coefficient | Standard error | Unstandardized coefficient | Standard error |
| Race/ethnicity (vs white NH) |  |  |  |  |  |  |
| Asian | 0.07 | 0.06 | 0.09 | 0.07 | 0.06 | 0.08 |
| Black | -0.01 | 0.04 | 0.07 | 0.04 | -0.18 * | 0.05 * |
| Hispanic | -0.01 | 0.04 | -0.004 | 0.04 | -0.01 | 0.05 |
| Multiple/other | -0.04 | 0.07 | -0.11 | 0.06 | 0.09 | 0.12 |
| Sex (vs male) |  |  |  |  |  |  |
| Female | 0.02 | 0.03 | -0.05 | 0.03 | 0.17* | 0.04 * |
| Age (y) (vs <30 y) |  |  |  |  |  |  |
| 30-39 | 0.06 | 0.04 | 0.07 | 0.04 | 0.03 | 0.06 |
| 40-49 | 0.06 | 0.04 | 0.07 | 0.05 | 0.02 | 0.06 |
| 50-59 | -0.02 | 0.04 | 0.05 | 0.04 | -0.13 * | 0.06 * |
| 60+ | -0.10 * | 0.04 * | -0.03 | 0.04 | -0.24 * | 0.05* |
| Household income (\$) (vs < $225 \mathrm{~K} / \mathrm{y}$ ) |  |  |  |  |  |  |
| 25,000-49,999 | -0.04 | 0.04 | -0.05 | 0.04 | -0.01 | 0.05 |
| 50,000-99,999 | 0.003 | 0.04 | -0.01 | 0.04 | 0.02 | 0.05 |
| 100,000-149,999 | -0.03 | 0.04 | -0.06 | 0.05 | 0.04 | 0.07 |
| >150,000 | -0.09 | 0.06 | -0.11 | 0.06 | -0.04 | 0.08 |


| Covariate | Overall FAIM score |  | EO subdomain score |  | IM subdomain score |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | $\mathrm{R}^{2}=0.26$ |  | $\mathrm{R}^{\mathbf{2}}=0.23$ |  | $\mathrm{R}^{2}=0.19$ |  |
|  | Unstandardized coefficient | Standard error | Unstandardized coefficient | Standard error | Unstandardized coefficient | Standard error |
| $1+$ physician-diagnosed FA | -0.18* | 0.03 * | -0.16 * | 0.03* | -0.23 * | 0.04 * |
| $1+$ severe FA reaction | 0.22 * | 0.03* | 0.26 * | 0.04 * | 0.16 * | 0.05 * |
| Reports current EAI prescription | 0.25 * | 0.04 * | 0.27 * | 0.05 * | 0.21 * | 0.06 * |
| Reports EAI use to $1+$ FA | 0.34 * | 0.05 * | 0.43 * | 0.06 * | 0.18* | 0.06* |
| 1+ lifetime FA-related ED visit | 0.21 * | 0.04 * | 0.23 * | 0.04 * | 0.16 * | $0.05 *$ |
| 1+ FA-related ED visit in last 12 mo | 0.41 * | 0.07 * | 0.55 * | 0.08* | 0.15 * | 0.09 * |
| Convincing childhood-onset FA only | -0.04 * | 0.03* | 0.04 | 0.04 | -0.20 * | 0.04 * |
| Convincing adult-onset FA only | 0.06 * | 0.04 * | 0.13 | 0.04 | -0.08 * | 0.05 * |
| No. of children in household | 0.02 | 0.01 | 0.02 | 0.02 | 0.02 | 0.02 |
| One food-allergic child in household (vs 0) | 0.04 | 0.07 | 0.06 | 0.07 | 0.04 | 0.10 |
| Two food-allergic children in household (vs 0) | 0.24 | 0.22 | 0.10 | 0.19 | 0.51 | 0.33 |
| 0) <br> Three food-allergic children in household (vs | 1.99* | 0.12 * | 2.36 * | 0.37 | 1.25 * | 0.49 * |

[^2][^3]
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[^1]:    Associates degree

[^2]:    $E A I$, Epinephrine autoinjector; $E D$, emergency department; $E O$, Expectation of Outcome; $F A$, food allergy; $F A I M$, Food Allergy Independent Measure; $I M$, Independent Measure.

[^3]:    *Statistically significant at a 2 -sided $P<.05$, adjusting for all covariates listed above

