
Variations in quality of life among caregivers of food allergic children

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Background: Pediatric food allergy is a serious health problem in the United States. As the number of affected children increases, more caregivers are charged with the responsibility of managing their child's food allergy.

Objective: To better understand the impact of pediatric food allergy on caregiver quality of life.

Methods: As part of a larger project examining the knowledge, attitudes, and beliefs of caregivers with food allergic children, the Food Allergy Quality of Life–Parental Burden questionnaire was administered to a large sample of caregivers across the United States from January 1, 2008, to January 31, 2009. Findings were analyzed to describe caregiver quality of life and to examine the impact of the manifestation of food allergy on participant response.

Results: Data were collected from 1,126 caregivers. The impact of food allergy on caregiver quality of life varied widely with 1 exception: caregivers consistently reported being troubled by social limitations resulting from their child's food allergy. Poor quality of life was significantly more likely on a number of survey items among caregivers more knowledgeable about food allergy and among caregivers whose children had been to the emergency department for food allergy in the past year, had multiple food allergies, or were allergic to specific foods.

Conclusions: Previous research has emphasized the negative impact of food allergy on caregiver quality of life. This study illustrates the diverse experience of caring for a child with food allergy and the importance of considering the manifestation of disease when evaluating parental burden.

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INTRODUCTION

Pediatric food allergy is a serious health problem in the United States, affecting an estimated 4% to 6% of children.^{1,2} Recent data suggest that the prevalence of caregiver-reported food allergy has increased significantly during the last decade, as has the number of children discharged from the hospital with a food allergy–related diagnosis.³ It is well documented that children with food allergy are more likely to experience asthma, eczema, and respiratory allergy than their non-food allergic peers.⁴ Moreover, there is evidence that hospitalizations for anaphylaxis have increased more than 4-fold among patients younger than 20 years, with food-induced anaphylaxis the most common cause.⁵

Multiple studies have documented the negative effect of food allergy on quality of life (QoL).^{6–9} Negative outcomes are often compounded by limited treatment options, the absence of a cure, and the social ubiquity of food. Allergen avoidance currently remains the primary course of action for food allergic children.¹⁰ Unintentional exposure is not uncommon: food is a central aspect of many social interactions, food labels can be difficult to decipher, and food is often prepared and consumed outside the home. As a result, food allergy can have a profound psychological and social effect on the daily lives of affected children and their families.¹¹

Several studies indicate that QoL among those with subjective food hypersensitivity and those with physician-diagnosed food allergy is similarly impaired,^{7,12} suggesting the anxiety of allergen avoidance may affect QoL to a far greater degree than the physical manifestation of the allergy itself.¹³ However, although the negative effect of pediatric food allergy on QoL has been documented, the relationship between caregiver QoL and the extent of disease has not been adequately examined, with data limited to a handful of small studies presenting incongruous findings.^{9,13–16}

To further evaluate the impact of food allergy on QoL, Cohen et al¹⁷ developed and validated the Food Allergy Quality of Life–Parental Burden questionnaire (FAQL-PB). As part of a larger project examining the knowledge, attitudes, and beliefs of caregivers with food allergic children, we administered the FAQL-PB to a large sample of caregivers across the United States to better understand the

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relationship between caregiver QoL and a child's history of food allergy.

METHODS

Study Design

Caregivers of children with food allergy were recruited anonymously to complete the Web-based FAQL-PB survey from January 1, 2008, to January 31, 2009. Participants were recruited via targeted Web posts on food allergy resource pages and social media sites. In addition, support groups nationwide were contacted to recruit caregivers of children with food allergy. Eligible participants had at least 1 child with a physician-diagnosed food allergy and resided inside the United States. A small honorarium was provided to the first 1,500 participants. For further details on the study methods, refer to the article by Gupta et al.¹⁸

The study protocol was approved by the institutional review boards of Children's Memorial Hospital and Northwestern University in Chicago, Illinois. Caregiver consent to participate was implicit in the return of completed surveys, which did not include personal identifiers.

Survey Instrument

The FAQL-PB was developed to measure the effect of pediatric food allergy on health-related QoL among caregivers. The final instrument included items investigating high effect areas of food allergy (eg, effect on family/social activities, health concerns, and emotional issues) using a 7-point Likert scale. Validation of the instrument suggested strong internal and cross-sectional validity. For further details on survey development, refer to Cohen et al.¹⁷ In addition to the FAQL-PB, caregivers were asked to complete the validated Chicago Food Allergy Research Survey for Parents, which included an assessment of food allergy knowledge and a brief evaluation of a child's clinical history of food allergy, including report of anaphylaxis, food allergy-related visits to the emergency department (ED), comorbid conditions, and identification of allergenic food(s).¹⁸ Sociodemographic data on child and caregiver were also collected, and an open-ended item was added to the survey in which caregivers were given the opportunity to share additional information regarding experiences with food allergy.

Statistical Analysis

Descriptive statistics were used to characterize survey respondents. To describe the degree of trouble caregivers experienced with different aspects of QoL, responses were collapsed into 3 categories: minimally troubled (not troubled/limited and hardly troubled/limited), moderately troubled (somewhat troubled/limited and moderately troubled/limited), and extremely troubled (quite a bit troubled/limited, very troubled/limited, and extremely troubled/limited). Relative risk ratios were estimated using Poisson regression models with robust error variances¹⁹ to evaluate associations between demographic and clinical data with caregiver report of QoL. Separate models adjusting for demographic charac-

teristics of the caregiver and child and data detailing the child's history of food allergy were estimated for each survey item. Income was imputed for 46 participants in these models because of missing data. All statistical analyses were performed using STATA statistical software, version 10 (Stata-Corp LP, College Station, Texas).

Qualitative analyses were conducted to evaluate comments received from caregivers. A constant comparative method was used to identify emerging themes.^{20,21} Comments were coded into 1 of 5 content domains: emotional burden, stigma/normalecy, health/nutrition, daily burden, and social activities/limitations. At least 2 reviewers (E.S. and J.S.) independently coded the data. Discrepancies were reconciled based on comment language and code definitions until complete agreement of the assigned code was met.

RESULTS

Data were analyzed for 1,126 caregivers. Participants were well distributed across US geographic regions but were primarily white (90.1%), female (95.0%), and well educated (75.3% with a 4-year college degree or more) (Table 1).

Most participants had only 1 food allergic child (83.4%), although that child frequently had multiple food allergies (77.6%). Food-induced anaphylaxis (based on parent report and interpretation of the term) occurred in 42.6% of children, with 16.9% of caregivers reporting a food-related ED visit in the past year. Eczema was the most common comorbid condition (71.1%), followed by environmental allergy (70.7%) and asthma (47.4%) (Table 2).

Participant response to the FAQL-PB was well distributed across the Likert scale. Caregivers were most frequently troubled by items assessing social interaction/limitations. Report of being at least moderately troubled in this content domain ranged from 78.7% to 91.2%. Items assessing health/nutrition were least troublesome, ranging from 51.5% to 59.4% for moderately or extremely troubled (Table 3).

Multiple regression models suggested that demographic characteristics of participants had little effect on caregiver QoL. Only sex and education were significantly associated with QoL and only on singular items. Men were less likely than women to be concerned with a food allergic child's nutrition, and those with at least some college education were more likely to be burdened by precautions associated with their child's food allergy. Food allergy-specific knowledge was a better predictor of burden. Risk of being extremely troubled was significantly higher on multiple items for caregivers with a food allergy knowledge score higher than 90% and caregivers familiar with epinephrine administration. A child's clinical history of food allergy was most frequently associated with reported QoL. Specifically, the risk of being extremely troubled by items on the FAQL-PB was most often significantly higher among caregivers whose children had a food allergy-related ED visit in the past year or had multiple food allergies. By allergen, impaired QoL was more likely among caregivers with vs without a milk or wheat allergic child (Table 4).

Table 1. Demographic Characteristics of Caregivers With Food Allergic Children

Characteristic	No. (%) of caregivers (N = 1,126)
Sex	
Male	56 (5.0)
Female	1,070 (95.0)
Race/ethnicity ^a	
White	1,014 (90.1)
Black	23 (2.0)
Asian	69 (6.1)
Hispanic/Latino	43 (3.8)
Other	7 (0.6)
Geographic region	
Northeast	282 (25.0)
Midwest	377 (33.5)
South	265 (23.5)
West	202 (17.9)
Education (degree)	
High school	111 (9.9)
Associate	167 (14.8)
Bachelor's	474 (42.1)
Graduate	374 (33.2)
Income, \$ ^b	
<25,000	39 (3.6)
25,000–49,999	122 (11.3)
50,000–99,999	460 (42.6)
100,000–199,999	345 (31.9)
200,000–299,999	67 (6.2)
≥300,000	47 (4.4)
No. of children <18 years old	
1	274 (24.3)
2	619 (55.0)
3	167 (14.8)
4	50 (4.4)
≥5	16 (1.4)
Food allergy knowledge score >90% ^c	264 (23.5)

^a Sum does not equal 100% because multiple selections were allowed.

^b Data were missing for 46 caregivers.

^c On the basis of 15 food allergy knowledge items completed as part of the Chicago Food Allergy Research Survey for Parents.¹⁶

Consistent with the wide distribution of participant response to the FAQL-PB, caregivers submitted a wealth of comments regarding their experience of having a child with food allergy. Comments are highlighted below by content domain and presented in [eTable 1](#).

Emotional Burden

Participants' comments best illustrate the diverse emotional experience of raising food allergic children:

Why focus on all these negatives? Food allergies only rule your life if you allow them to. My son leads a perfectly normal life because we don't treat him like he needs to be in a bubble.

These worries are constant. They don't ever go away and can sometimes become so overwhelming that I feel

paralyzed with fear. It is a daily struggle to provide a "normal" life for my son while keeping him safe from the food allergens that are so dangerous for him.

Stigma/Normalcy

A large proportion of participants expressed frustration with others' inability to appreciate the seriousness of their child's food allergy. This sentiment was echoed by participants' comments:

I'm always surprised at how little the general population knows about food allergies—people don't even know that flour is made from wheat.

Many caregivers were also concerned about their child's ability to lead a normal life.

My children are singled out, they are different. I feel badly for them; I do not wish this hurdle on anyone.

Others reported taking action to ensure their child had a normal upbringing:

My husband and I work very hard to make our daughter's milk/dairy allergy a "nonissue" in her life. We provide alternate food at birthday parties, etc, so she doesn't miss out on anything.

Table 2. Characteristics of Caregivers' Food Allergic Children (N = 1125)

Characteristic	No. (%) of caregivers
No. of food allergic children <18 years old	
1	938 (83.4)
2	168 (14.9)
3	16 (1.4)
4	2 (0.2)
≥5	1 (0.1)
≥1 Child with multiple food allergies	874 (77.6)
≥1 Male child with food allergies	788 (70.0)
Age of food allergic child(ren), y ^a	
0–5	601 (53.4)
6–10	481 (42.7)
11–17	166 (14.7)
≥1 Food allergic child with history of anaphylaxis	480 (42.6)
≥1 Food allergic child with food allergy–related ED visit in past year	190 (16.9)
≥1 Food allergic child with eczema	801 (71.1)
≥1 Food allergic child with asthma	534 (47.4)
≥1 Food allergic child with environmental allergy	796 (70.7)
≥1 Egg allergic child	529 (47.0)
≥1 Fin fish allergic child	82 (7.3)
≥1 Milk allergic child	570 (50.6)
≥1 Peanut allergic child	815 (72.4)
≥1 Shellfish allergic child	151 (13.4)
≥1 Soy allergic child	109 (9.7)
≥1 Tree nut allergic child	496 (44.1)
≥1 Wheat allergic child	164 (14.6)

Abbreviation: ED, emergency department.

^a Sum does not equal 100% because multiple selections were allowed.

Table 3. Degree of Trouble Experienced by Caregivers as a Result of a Child's Food Allergy During the Week Before Survey Administration

Item	Minimally troubled, ^a %	Moderately troubled, ^b %	Extremely troubled, ^c %
Emotional burden			
Anxiety relating to child's food allergy	33.8	40.1	26.1
Concern child may not overcome food allergy	29.9	40.5	29.6
Sadness for child's burden	31.3	38.5	30.2
Frightened that child will have reaction	34.8	38.6	26.6
Stigma/normalcy			
Frustration over others' lack of food allergy awareness	30.0	34.1	35.9
Worry that child will not have normal upbringing	41.6	35.5	22.9
Health/nutrition			
Concern for child's health	30.6	39.9	29.5
Concern for child's nutrition	48.5	29.2	22.3
Daily burden			
Extra time preparing meals	35.3	40.4	24.3
Precautions before leaving home with child	40.1	43.3	16.5
Social interaction/limitations			
Choice of vacation	21.3	34.8	43.9
Choice of restaurant	8.8	26.3	64.9
Social activities involving food	16.9	43.2	39.9

^a Participant selected 1 of the following options: not troubled/limited or hardly troubled/limited.

^b Participant selected 1 of the following options: somewhat troubled/limited or moderately troubled/limited.

^c Participant selected 1 of the following options: quite a bit troubled/limited, very troubled/limited, or extremely troubled/limited.

Health/Nutrition

Although caregivers frequently reported concern about their child's health as a result of food allergy, concern regarding nutrition was less common. However, several caregivers were worried about nutritional deficiencies as a result of allergen avoidance.

My son experiences anxiety when eating foods out of the house and has limited his food choices as a result. He is an extremely picky eater, and I believe that his food allergies have affected the range of foods that he feels comfortable eating and therefore his nutritional intake.

Others described unexpected benefits of living with food allergy:

I also don't worry about my child's nutrition. It is quite the opposite, in fact. We are more likely to avoid

processed and packaged foods now, because of the allergies.

Daily Burden

Many participants indicated some degree of trouble regarding time required for meal preparation and the need to take special precautions before leaving home. To this end, several caregivers pointed to the value of developing routines over time.

Since we have been dealing with food allergies for many years now, our day-to-day living is not too problematic. The first year or two after diagnosis was very difficult.

Social Interaction/Limitations

Social interaction appeared to impart the greatest burden among caregivers of food allergic children. To this end, though not directly addressed by the survey itself, caregivers frequently commented on their consternation or discomfort in dealing with schools and daycare.

My son is starting kindergarten in the fall and the fear is overwhelming. I want him to feel normal and confident with managing his allergies. He is young and I worry about his care being in the hands of the school.

DISCUSSION

To our knowledge, this is the largest study to evaluate the impact of pediatric food allergy on the lives of caregivers in the United States. Findings illustrate the diverse experience of caregivers with food allergic children. The impact of food allergy on QoL varied widely among participants with the exception that most participants were at least moderately troubled by all items assessing social interaction/limitations. That being said, significant associations in burden were observed. Specifically, poor QoL was significantly more likely among caregivers more knowledgeable about food allergy and among caregivers whose children had been to the ED for food allergy in the past year, had multiple food allergies, or were allergic to specific foods. Demographic characteristics of the caregiver (eg, sex, income) infrequently affected QoL, although further study is needed to determine whether this observation holds true in a more diverse sample.

Multiple studies have established food allergy as a burden that can negatively affect an individual's QoL but have infrequently considered the extent to which the manifestation of food allergy influences outcomes.^{6,8,9} In fact, it has been suggested that QoL is similarly impaired among those with subjective food hypersensitivity and those with physician-diagnosed food allergy.^{7,12} Such findings imply that it is the perception of disease rather than its manifestation that affects QoL. Our findings suggest the contrary. Caregiver QoL varied widely and, to a large extent, was dependent on the severity of the child's food allergy.

Past studies accounting for the manifestation of food allergy also found its effect on QoL to vary in relationship to severity. However, these studies were relatively small, and consensus has yet to be reached in the literature. For example,

Table 4. Variables Significantly Associated With Risk of Caregiver Being Extremely Troubled During the Week Before Survey Administration^a

Variable	QoL content domain	Relative RR (95% CI) ^b
Caregiver is male vs female		
Concern for child's nutrition	Health/nutrition	0.29 (0.10–0.81)
Caregiver has at least some college education		
Precautions before leaving home with child	Daily burden	1.43 (1.00–2.04)
Caregiver food allergy knowledge score >90%		
Anxiety relating to child's food allergy	Emotional burden	1.25 (1.00–1.55)
Worry that child will not have normal upbringing	Stigma/normalcy	1.36 (1.07–1.72)
Choice of vacation	Social interaction/limitations	1.32 (1.17–1.50)
Choice of restaurant	Social interaction/limitations	1.15 (1.06–1.24)
Social activities involving food	Social interaction/limitations	1.27 (1.09–1.48)
Caregiver aware epinephrine administered in thigh		
Frustration over others' lack of food allergy awareness	Stigma/normalcy	2.15 (1.39–3.33)
Choice of vacation	Social interaction/limitations	2.01 (1.30–3.12)
Choice of restaurant	Social interaction/limitations	1.75 (1.32–2.33)
Social activities involving food	Social interaction/limitations	2.21 (1.32–3.42)
≥1 Child with multiple food allergy		
Anxiety relating to child's food allergy	Emotional burden	1.53 (1.03–2.26)
Worry that child will not have normal upbringing	Stigma/normalcy	1.55 (1.02–2.33)
Concern for child's health	Health/nutrition	1.49 (1.05–2.13)
Concern for child's nutrition	Health/nutrition	1.70 (1.03–2.78)
Extra time preparing meals	Daily burden	1.95 (1.25–3.04)
Precautions before leaving home with child	Daily burden	2.30 (1.29–4.12)
Choice of vacation	Social interaction/limitations	1.35 (1.02–1.78)
≥1 Male child with food allergy		
Frustration over others' lack of food allergy awareness	Stigma/normalcy	0.83 (0.71–0.98)
Food allergic child is 6–10 vs 0–5 years old		
Choice of vacation	Social interaction/limitations	1.18 (1.04–1.35)
Food allergic child is ≥11 vs 0–5 years old		
Anxiety relating to child's food allergy	Emotional burden	0.56 (0.37–0.84)
Frightened that child will have reaction	Emotional burden	0.52 (0.34–0.79)
Frustration over others' lack of food allergy awareness	Stigma/normalcy	0.58 (0.42–0.81)
Concern for child's health	Health/nutrition	0.61 (0.43–0.88)
Extra time preparing meals	Daily burden	1.40 (1.05–1.86)
≥1 Food allergic child with history of anaphylaxis		
Choice of vacation	Social interactions/limitations	1.23 (1.08–1.41)
Choice of restaurant	Social interactions/limitations	1.20 (1.10–1.31)
Social activities involving food	Social interactions/limitations	1.24 (1.07–1.45)
≥1 Child with food allergy–related ED visit in past year		
Anxiety relating to child's food allergy	Emotional burden	1.70 (1.36–2.13)
Concern child may not overcome food allergy	Emotional burden	1.34 (1.08–1.66)
Sadness for child's burden	Emotional burden	1.45 (1.19–1.78)
Frightened that child will have reaction	Emotional burden	1.56 (1.25–1.95)
Frustration over others' lack of food allergy awareness	Stigma/normalcy	1.27 (1.06–1.53)
Worry that child will not have normal upbringing	Stigma/normalcy	1.42 (1.10–1.82)
Concern for child's health	Health/nutrition	1.52 (1.23–1.87)
Concern for child's nutrition	Health/nutrition	1.46 (1.16–1.85)
Extra time preparing meals	Daily burden	1.74 (1.40–2.19)
Precautions before leaving home w/child	Daily burden	1.45 (1.06–1.96)
Social activities involving food	Social interaction/limitations	1.20 (1.02–1.42)
≥1 Food allergic child has eczema		
Concern for child's nutrition	Health/nutrition	1.61 (1.19–2.18)
≥1 Child is egg allergic vs not		
Concern child may not overcome food allergy	Emotional burden	1.24 (1.00–1.54)

Table 4. Continued

Variable	QoL content domain	Relative RR (95% CI) ^b
Extra time preparing meals	Daily burden	1.30 (1.01–1.68)
Choice of vacation	Social interaction/limitations	1.31 (1.12–1.68)
Choice of restaurant	Social interaction/limitations	1.13 (1.02–1.25)
≥1 Child is fin fish allergic vs not		
Choice of vacation	Social interactions/limitations	1.33 (1.13–1.56)
Choice of restaurant	Social interactions/limitations	1.16 (1.04–1.29)
≥1 Child is milk allergic vs not		
Concern for child's nutrition	Health/nutrition	2.71 (2.00–3.66)
Extra time preparing meals	Daily burden	1.70 (1.32–2.17)
Precautions before leaving home w/child	Daily burden	1.46 (1.06–2.00)
Choice of vacation	Social interaction/limitations	1.26 (1.09–1.46)
Choice of restaurant	Social interaction/limitations	1.14 (1.03–1.26)
≥1 Child is peanut allergic vs not		
Choice of vacation	Social interaction/limitations	1.20 (1.01–1.43)
Choice of restaurant	Social interaction/limitations	1.13 (1.01–1.26)
≥1 Child is shellfish allergic vs not		
Worry that child will not have normal upbringing	Stigma/normalcy	1.38 (1.05–1.81)
Concern for child's nutrition	Health/nutrition	1.39 (1.09–1.77)
≥1 Child is soy allergic vs not		
Extra time preparing meals	Daily burden	1.40 (1.10–1.78)
≥1 Child is wheat allergic vs not		
Anxiety relating to child's food allergy	Emotional burden	1.29 (1.02–1.65)
Concern child may not overcome food allergy	Emotional burden	1.52 (1.22–1.88)
Precautions before leaving home with child	Daily burden	1.36 (1.02–1.82)
Choice of vacation	Social interaction/limitations	1.28 (1.11–1.47)
Social activities involving food	Social Interaction/limitations	1.31 (1.11–1.56)

Abbreviations: CI, confidence interval; ED, emergency department; QoL, quality of life; RR, risk ratio.

^a Participant selected 1 of the following options: quite a bit troubled/limited, very troubled/limited, or extremely troubled/limited.

^b Relative RR for all variables listed in Tables 1 through 3 were estimated; only statistically significant associations are shown. All estimates were adjusted for variables listed in Tables 1 and 2 as well as food allergy tolerance (any child) and familiarity with epinephrine administration.

having multiple food allergies or other allergic disorders has been reported both to impair^{13–16} and to leave unchanged^{12,13} caregiver QoL.

Our study suggests that the burden is greatest among caregivers whose children went to the ED in the past year for food allergy. Risk of impaired QoL was significantly higher among these caregivers on 11 of the 13 survey items. History of anaphylaxis, however, was only associated with impaired QoL on items assessing social interaction/limitations. This is surprising because the adverse effect of pediatric anaphylaxis on QoL has been frequently reported.^{9,22} Our findings suggest that it is not the experience of anaphylaxis as much as the recency of an adverse food allergic event that results in the greatest impediment. This distinction becomes more obvious when one recalls that associations with anaphylaxis were adjusted for ED visits in the past year.

Strengthening past studies,^{13,14,16} caregivers whose children had multiple food allergies were also significantly more likely to report being extremely troubled by their child's food allergy on 7 of the 13 survey items. Comorbid presentation of asthma, eczema, and environmental allergy, however, was not strongly tied to QoL. An association was observed only between eczema and heightened concern for a child's nutri-

tion. No statistically significant associations were found between asthma or environmental allergies and impaired QoL. The former finding is particularly surprising because it is known that asthma increases the risk of experiencing fatal food-induced anaphylaxis.²³

Type of food allergy was frequently associated with caregiver QoL as well. Specifically, caregivers with vs without milk, wheat, or egg allergic children were more likely to report poor QoL on a number of survey items. Associations between peanut allergy and caregiver QoL were less common. There are several ways to interpret these findings. It is notable that more than half of all caregivers had children younger than 5 years. In this age range, milk and egg allergy may be more of an issue than peanut allergy largely as a result of the child's diet. It is also possible that avoidance of milk, wheat, and egg at any age, because of their omnipresence in prepared foods, requires more vigilance and therefore more anxiety than peanut avoidance. Finally, given the high frequency with which peanut allergy was reported, the sample may have had insufficient power to detect variation among those with vs without peanut allergic children.

Most participants reported being at least moderately troubled by all items related to social limitations resulting

from a child's food allergy. This finding is consistent with a number of studies that have demonstrated the burden of food allergy in social settings.^{8,13,16} Avoidance remains the primary means of managing a child's food allergy, which is apt to create challenges in social situations. Indeed, food-induced reactions most often occur outside the home.²⁴ It is likely that most caregivers of children with food allergy, regardless of disease severity, feel at least somewhat obligated to guard against unintentional exposure during activities away from home.

Participants' comments tended to focus on one social situation in particular—school/daycare. A number of responses demonstrated the limitations caregivers face in this setting, which has previously been shown to be a source of increased caregiver burden.⁸ Recent studies lend legitimacy to caregivers' concerns. It has been reported that only 36% of nut allergic children have medication available at school and only 56% of schools have staff trained to administer allergy-related medications.²⁵ Moreover, among children carrying an epinephrine autoinjector at school, only 54% are believed to have a plan for use in place with faculty and staff.²⁶ It is well documented that timely recognition of adverse reactions and prompt administration of epinephrine are critical in the prevention of fatal anaphylaxis.²⁷ Regardless of specific actions taken, it is clear that uniform food allergy policies in schools are needed to keep affected children safe.

This study has several limitations. Although data represent responses from more than 1,000 caregivers in the United States, those unable to complete the survey in English and without access to the Internet are not represented. The sample was also composed of primarily white, upper-income, well-educated female participants. It is unclear whether these demographic characteristics are representative of the primary caregivers in families most frequently affected by food allergy or whether sampling was skewed toward this distribution. In addition, the sample represented a large number of caregivers of children with severe food allergy. However, even within this severely food allergic sample, a wide spectrum of caregiver QoL was observed. Finally, although Web-based surveys have been shown to be a valid and reliable means of data collection, potential difficulties have been highlighted, such as multiple entries for a given individual and poor sample representation due to limited Internet access.²⁸ Responses were carefully monitored to avoid duplicate entries, and the survey was deployed in a controlled and secure online environment.

This study highlights the diversity of experience among caregivers of children with food allergy in the United States. Previous research has emphasized the negative impact of food allergy on caregiver QoL without taking into account the severity of disease, even suggesting that *perceived* and *actual* food allergy similarly impair QoL. However, our study found that the manifestation of food allergy largely dictates caregiver burden, with high caregiver knowledge of food allergy, recent ED visits, having a child with multiple food allergies, and specific allergenic foods associated with lower QoL. One

exception to this observation is the social limitation experienced by caregivers of food allergic children, particularly in the school and daycare settings. Caregivers consistently reported being troubled by food allergy during activities away from home.

It is thus imperative that health care professionals, public health officials, and educational faculty and staff be cognizant of the potential for impaired QoL among caregivers of food allergic children. Well-conceived and well-communicated food allergy management and treatment plans in addition to increased public awareness efforts are needed to lessen caregiver burden and to keep affected children safe.

SUPPLEMENTARY DATA

Additional tables accompany the on-line version of this article (available at <http://www.annallergy.org>).

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eTable 1. Comments Submitted by Caregivers After Completing the Food Allergy Quality of Life–Parental Burden Survey

Domain	Comment
Emotional burden	<i>Anxiety</i> ■ My daughter is now 7 years old, and she is severely allergic to peanuts, tree nuts, and sesame seeds. She understands what can happen to her, and she has developed anxiety with her allergies. Sometimes she does not even eat in school because now she eats in the cafeteria with other children. Even though she sits on the peanut free table, she is worried about other people eating PB sandwiches. We have seen a children psychologist for the anxiety as well. Especially if there is a new situation (ie, like summer camp), it's very stressful. ■ . . . we have had food allergies for almost 5 years, so over time, management, coping skills, and support groups all decrease anxiety. ■ Neither of my children have life-threatening reactions, so that relieves a lot of stress about how to deal with going out or leaving them with others.. <i>Fear</i> ■ Food allergies take everything that is frightening about being a parent and magnify them a million times. ■ I live in fear each day. A constant fear that my daughter will lose her life to her food allergies. The fear consumes me. Sometimes it is unbearable. ■ The accidental exposures that cause anaphylaxis are almost too much to bear as a mother. It is such a difficult life to live. <i>Significant others</i> ■ I worry the most when she is with her father. He doesn't believe that she is allergic ■ My husband is an optimist and avoids pain and would probably say much lower "troubled" scores, but he is not the primary caregiver and does not always label his feelings like I would. He would say that he is constantly aware or something like that but would not voluntarily choose the word troubled. For me, it is a "trouble" because I am always having the burden of wondering if I am "handling" it correctly, from both a physical protection view, to a nutritional, to a social interaction, to a parent/child development level, and on and on.
Stigma/normalcy	<i>Identity</i> ■ I think it is really important that we remember that these are children who have food allergies rather than let food allergies define our children. ■ I am careful about my daughter's food allergies, but I feel some media/parent groups promote quite a bit of fear and focus on the allergies. It is important to remember your whole child, not just their allergies. I try to be as careful as I can, and then just enjoy my child and let the rest go. <i>Isolation</i> ■ I know he feels very alone with his condition on campus. <i>Normalcy</i> ■ My child is sad and feels different than his peers. He gets anxious around others because he does not know what they have eaten and if he will have a reaction. ■ I just want him to be a typical little boy, who doesn't have to worry about getting sick if someone touches him after eating. ■ He has been at 2 birthday parties in the past week. At one his right eye got red and swollen; he took Benadryl and was fine. The mom called me, I let him stay because I don't want to make him feel even more "different" but I was at home, nervous—car keys in my hand. It made me so sad. ■ My son is now 14. We travel and eat out a lot, but it is always a huge concern. We try very hard to live a "normal" life but there are always incidents that bring us back to the reality that this is a life-long issue.
Health/nutrition	<i>Anticipatory guidance</i> ■ I definitely would like more education on having, carrying, and using an EpiPen and anaphylaxis. Just because the doctor prescribes it and you carry it does not mean you can feel equipped to know when it needs to be used and when not to. ■ My child was tested for food allergies and was positive for eggs and peanuts. I do not know the degree or severity of the allergy, and that causes some anxiety. I do now know what will happen if that food is ingested. <i>Dietary restrictions</i> ■ We are more worried about the ketotic hypoglycemia they have due to their restricted diets from their allergies.

eTable 1. Continued

Domain	Comment
	■ The one positive aspect of our daughter's allergies to peanuts, tree nuts, soy, and shellfish is she in general eats very healthy foods. Since soy is in practically every manufactured food, and we can't depend on fast food restaurant staff to be knowledgeable about ingredients and prep practices, she does not eat any fast food or junk food, and very little processed food. I know that she would be eating a ton of this crap if she didn't have any allergies. <i>Knowledge of health care professionals</i> ■ Even my pediatrician and pediatric dermatologist have provided me with misinformation. ■ My son was hospitalized (age 2) with respiratory distress, etc, and even the hospital could not meet his special needs as far as food and Neocate One Plus. We had to bring stuff from home.
Daily burden	<i>Awareness of others</i> ■ People can also complicate our situation a lot with ignorance and just plain old disinterest. ■ My child's school is very uneducated and unwilling to learn about food allergies. I have a horrible feeling in my stomach all day, every day, until I see her when I pick her up after I get out of work. ■ My child has a peanut allergy. Her school, friends, and extended family are all aware of it. She has an EpiPen in her backpack and in the office at school. I am comforted by a high level of awareness around her. <i>Expenses</i> ■ Our biggest stresses are the costs of feeding our children certain foods that don't make them sick and not being able to attend social functions that serve food. ■ Life is very challenging because I take his care as a full-time job. I haven't gone back to work since having him and that wasn't the initial plan. ■ Due to my son's peanut allergy we are forced to place him in a peanut-free private school at a significant cost to us. ■ We have created a very safe environment for our child, involving constant supervision and extensive child care. We are concerned that most other families could not afford this support. <i>Food labeling</i> ■ Premade items are also time-consuming to research and manufacturers aren't always the most gracious or understanding, which makes the task even more upsetting. <i>Meal preparation</i> ■ I prepare snack items and freeze them for birthday parties or school events where food will be served. This helps take away some of the stress on both our family and the family having the function. ■ Still, after 7 years, I find myself still struggling daily with meal preparation. It's easier than at first, but still a struggle that takes extra time, energy, and thought at every meal. <i>Ubiquity of burden</i> ■ This stress affects my work, my marriage, my parenting skills, and my outlook on life. ■ Sometimes you can't put a number on the "trouble" or sad or concerned feelings. It's something we deal with everyday that is not fully understood by others. It impacts EVERYTHING, EVERYDAY. ■ It is tiring to have to always be on the alert for any food situations involving my child. ■ We've been living with this allergy for so long that it has become a way of life and we don't look at it as a burden, just a fact of life.
Social interaction/limitations	<i>Childcare</i> ■ At this time I am the primary caregiver of my child, and when we do use a sitter it is only at our peanut-free home. Next year my son will start to attend daycare so I can go to school full time, which is very frightening to me. ■ When he is not in my care I am somewhat troubled over his babysitter's ability to quickly recognize anaphylaxis and also just her understanding of the danger of my son coming in contact with foods he is allergic to even though I have educated her. <i>Education (pre-K)</i> ■ My child had an unexplained reaction (for the fourth time) at preschool due to an unidentified cause. I am extremely frustrated and maddened at the fact that we can't figure out what caused the reaction and how to prevent it from recurring. I grapple with the feelings of wanting to never take her there again but of wanting her to have a "normal" and fun preschool experience. <i>Education (elementary)</i> ■ My child cannot attend after-school activities because there is no nurse present after school. She is only able to do those activities or go on field trips if I accompany her (again, because the nurse does not go on field trips). Her teacher does not carry an EpiPen, only the nurse or me.

eTable 1. Continued

Domain	Comment
	■ I have set up my 3-year-old's life so that I don't have to worry daily—she attends peanut-free school and we have extra precautions just in case (her class is learning to be peanut police and "reading" labels, eating more veggies/fruit)
	<i>Education (high school/college)</i>
	■ I worry more about when they enter the teenage years and may engage in riskier behavior and when they go to college. ■ It is like speaking but not having a voice . . . you get silence . . . stares . . . and the general impression they are not ready to fully understand what is needed on campus in the way of protocol . . . they don't want to hear . . . and I know someone is going to die on that campus in the coming years . . . they are not ready for the students that will follow my child . . . he has been there 7 months and has had his own lessons with the 3 reactions . . . but the response to his reactions show no communication among the groups, ignorance in the nurse, ignorance in the EMS [emergency medical services] department, and a level of risk in dining hall that remains . . .
	<i>Education (homeschooled)</i>
	■ My children are home with me during the day and are homeschooled. I VERY RARELY leave them with ANYONE! ■ I work out of the home and home school our children because of food allergies. I do not feel schools are adequately trained to handle children with life-threatening allergies.
	<i>Family activities</i>
	■ I find the communication with friends and family more stressful than strangers. I feel like friends and family are quick to put me at ease so they say they understand it yet don't change their behavior and are careless with food prep simply because they aren't looking at whole peanuts or eggs, etc. ■ Most troubling is that my family doesn't seem to understand the seriousness. We've had several family members choose foods with nuts and even serve foods with nuts at family gatherings, making avoidance extremely difficult.
	<i>Leaving the home</i>
	■ The only place I know she's truly safe is in our home but that isn't living, it's surviving. ■ I don't leave my house. It is his safe place. No one comes here. It's like we are hiding from the world. ■ Since my child's food allergies reactions are also caused by touch of the allergic items, it makes it extremely difficult to go to the park, grocery shopping, or even feel comfortable with anyone else touching him.
	<i>Restaurants</i>
	■ We rarely eat out. I've actually been refused service at a restaurant that didn't want to be responsible for cross-contamination. ■ Holidays, restaurants, etc, aren't limited but require a lot of work because we have to bring all of her food with her. She simply cannot eat anything they offer.
	<i>Social activities</i>
	■ I'm somewhat troubled by the social implications. My 6-year-old son rarely gets invited to play dates . . . I think other parents don't want to make an effort to be responsible for managing his allergy while in their home. School friends do not join him at the allergy table at lunch . . . I would imagine it's too much trouble for other parents to make a special lunch at times for their child so as to foster friendships during the school day. It seems to boil down to a common thought . . . "if it's not my child, it's not my problem and I don't have to make any effort on your child's behalf" ■ We are lucky to have a wonderful support system in our neighborhood, so play dates among the 3 families are worrisome free.
	<i>Vacations</i>
	■ We don't go on vacations . . . We can't safely. ■ Our daughter flew by herself for the first time this week and is attending a national music conference where meals will be provided. I was extremely worried about her safety. I had to make numerous phone calls to make sure everything from her air flight to her eating arrangements would be safe.