

Food Security, Utilization of Food Assistance Programs, and Caregiver Perceptions of Food-Induced Anaphylaxis Risk in Children with Food Allergies

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This study provides a preliminary investigation of food insecurity (FIS), food assistance program utilization (Supplemental Nutrition Assistance Program [SNAP], food banks), and history of food-induced anaphylaxis (FIA) in children with Food Allergy (FA). Pediatric FA affects 4% to 8% of US children. FIS is the uncertainty or inability to meet family food requirements. We expected that children of FIS families would be more likely to have history of FIA due to limited control over food selection. Caregivers ($n = 183$; 50% mothers) of children with history of physician-diagnosed FA (57% male; $M_{\text{Age}} = 7.5$ years; 67% white, 22% black, and 21% Latino) completed an online survey. Key variables included demographics, perceptions about FIS, and history of child FIA. Caregivers classified as FIS reported increased perceived risk of accidental ingestion ($\chi^2 = 11.99$, $P = 0.001$, $\phi = 0.27$; 41% versus 17%), severe reaction ($\chi^2 = 6.24$, $P = 0.01$, $\phi = 0.20$; 45% versus 24%), and death ($\chi^2 = 22.55$, $P < 0.001$, $\phi = 0.36$; 38% versus 12%). FIS status was associated with child history of FIA ($\chi^2 = 5.54$, $P = 0.02$, $\phi = 0.19$) and utilization of food assistance programs ($\chi^2 = 39.31$, $P < 0.01$, $\phi = 0.46$; 52% versus 8%) and food banks ($\chi^2 = 183$) = 37.99, $P < 0.01$, $\phi = 0.46$; 74% versus 28%). No differences between FIS and non-FIS caregivers were observed for income, ethnicity, or age. Surprisingly, no associations were observed between FIS status and demographics. Differences in perceptions of FA-related risks may reflect the challenges these families face to meet basic nutritional needs. Findings may also reflect experiences specific to FA, such as the economic burden of obtaining FA-safe foods; access to FA-safe foods; and FA-related anxiety. Future research is needed to examine FA risks and the impact of FIS on nutritional status.

Keywords: food allergy, food security, food-induced anaphylaxis

Introduction

PEDIATRIC FOOD ALLERGY (FA) is a chronic condition that affects about 6 million children¹ in the United States and is increasing in prevalence.² FA reactions can result in a variety of symptoms, ranging from skin irritation to vomiting/diarrhea, and in the most severe cases, food-induced anaphylaxis (FIA; difficulty breathing, facial swelling, and changes in blood pressure), a rapid, potentially life-threatening allergic reaction.³ In the United States, FIA accounts for an estimated 2,000 hospitalizations and 200 deaths each year.⁴ Recent estimates suggest that rates of FIA hospitalization and associated healthcare costs have almost tripled since 1998.⁵

Avoiding allergenic foods can be an arduous task for all family members, impacting daily activities,⁶ meal preparation,^{7,8} and quality of life (QoL^{9–12}). Increased risk of accidental allergen ingestion¹⁰ has been associated with lower parental QoL, and the specific impact of FA within the family system may impact various family members differently. For example, Stenngaard and colleagues¹⁰ found that

reported limitations in the child's social life, including limited ability to take part in social activities such as sleepovers, parties, and playtime, were reported more frequently in mothers. Alternatively, limitations in the family's social life, restrictions in restaurants, family vacations, and social outings were reported more frequently by fathers.¹⁰ FA management can also impact psychosocial functioning. Literature has documented emotional burden in caregivers of children with FA, including increased anxiety and over-protection,¹³ increased anxiety in siblings of and children with FA,¹⁴ and impairment in daily activities. Families often report disruption in social and extended family gatherings, such as family cookouts and holiday parties.¹³

To successfully avoid allergenic foods, caregivers must examine food ingredient labels, be knowledgeable about the potential for cross-contact, and be aware of how severe their child's allergic reaction to the food may be (eg, skin, digestive, and/or respiratory symptoms; when to use an epinephrine autoinjector).³ In addition, families of children with FA may often avoid simple activities such as grocery shopping, going

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to restaurants, and attending other social events, as they can be anxiety producing, time-intensive, and expensive.^{9,11,15} Activities such as meal preparation can also place significant time and emotional burden on families.^{7,8}

Despite efforts to maintain a safe diet for children with FA, the potential for unintentional ingestions can occur. Common mistakes such as misreading food labels, eating foods that do not have labels, such as home-baked goods, or cross-contact during meal preparation can place children at risk for FIA.^{3,16} FIA can present with a variety of symptoms, which can range from topical symptoms (eg, hives) to gastrointestinal symptoms (eg, vomiting) to difficulty in breathing and hypotension. Although research has shown that adolescents and young adults are most at risk for FA-related fatalities,^{7,17–19} FA youth of all ages are susceptible to FIA.²⁰

Families of children with FA are also at risk for experiencing food insecurity (FIS). FIS is defined as the uncertainty or inability to acquire enough food to meet the nutritional requirements of all members of a household because of financial or resource constraints.²¹ Reduced access to food in the United States is associated with poor health outcomes, including poor academic performance and decreased health-care access.^{22,23} Often, higher parental/caregiver education (eg, college education) and higher incomes act as “protective” factors and increase a family’s ability to access resources such as food and healthcare. Recent findings²² highlight that families of children with FA may experience greater barriers in obtaining food and healthcare across all socioeconomic levels. Specifically, it is estimated that 20% of families with FA experience FIS, regardless of parental/caregiver education or income.²² Racial/ethnic minority populations share a significant burden of FA. Although precise estimates are not available, some data suggest that the rate of increase in FA in black children may be twice that in Caucasian children.²⁴ When compared with Caucasian children of the same age and gender, black and Hispanic youth diagnosed with FA are more likely to endorse FIS.²² Decreased access to food may result in poor nutrition, especially among minority children, and may impact the frequency and seriousness of allergic reactions.

The majority of the literature on families’ adaptation to FA has focused on examining psychosocial distress, familial and financial burden, and FIA in primarily white and upper income families (eg, more than \$100,000).²⁵ There is a specific need to include more diverse or representative populations of children with FA to broaden our understanding of the impact of FA on all families. Therefore, the primary goal of this study was to provide a preliminary investigation of food security, perceived food allergen exposure risk, and FIA in a diverse sample of children with FA. We expected that children of families who are food insecure will be more likely to have a history of FIA due to their limited control over food selection. We also expected associations between demographic characteristics (ie, ethnicity/race, income, education) and food security, such that families with more socioeconomic challenges will endorse higher rates of FIS and utilize more food assistance programs, specifically the Supplemental Nutrition Assistance Program (SNAP) and food banks than more affluent families.

Materials and Methods

Data for this study were collected online using Toluna[®], a company that provides a technological platform to conduct online and mobile survey research. Registration on the To-

luna site is free and is available to participants on both computer- and mobile-based applications. Each invitation to participate in the present study was coded with a unique identifier to prevent participants from taking the survey multiple times. Toluna has security protocols to protect personal identifiable information. At present, these protocols exceed research industry standards set forth by the Council of American Survey Research Organizations and the European Society for Opinion and Market Research. Data were collected from January to February 2017.

Participants

Eligible caregivers of children were screened before completing any additional study measures. A 3-item questionnaire was used to screen participants using the following eligibility criteria: (1) participant must be fluent in English; (2) a caregiver of a child diagnosed with an FA; and (3) participant’s child must be between the ages of 1 month–12 years. Caregivers completed a set of online questionnaires about FIS, use of food assistance programs (SNAP, food banks), and history of FIA. Participants received \$8.00 for completing the onetime survey. The study was approved by the institutional review board at a northeastern academic medical center.

Of the 492 caregivers who completed the screening items, 226 (45.9%) did not meet study criteria and thus did not participate in any additional study procedures or measures. Data from completed participants ($n=266$) were cleaned and cases were examined for survey response time (ie, completing the survey too quickly) and patterned responding (eg, straight liners). No patterned responders were detected. Because the survey was estimated and timed to take between 5 and 12 min to complete, survey responders who completed the survey in less than 4 min were removed ($n=53$; 20%). Thirty individuals (9%) were deemed eligible but terminated the survey prematurely. Our final sample included 183 caregivers. No statistical differences were observed for demographic characteristics (age, ethnicity/race, socioeconomic status) between caregivers who were removed ($n=83$) and those retained for final analyses.

Participants were recruited to be representative of racial and ethnic demographics of the United States. Given the need to better represent families from minority backgrounds, particularly in the FA literature, we requested Toluna include specific parameters in their sampling frame to oversample racial/ethnic minority families. Our estimated recruitment goal included 55%—white, 20%—black, 5%—Asian and Pacific, 20%—Hispanic. These numbers were based on the ethnic/minority estimates from the US Census Data.²⁶ Informed consent was obtained from all individual participants included in the study. Participants were 183 caregivers (50% mothers) who had a child with physician-diagnosed food allergies (57% male; $M_{Age}=7.5$ years, $SD=3.2$ years; 67% white, 22% black, 4% Asian, 3% American Indian/Alaskan Native, and 4% more than one race, and 21% Hispanic or Latino). Please see Table 1 for additional participant demographic information.

Measures

Demographics. Primary caregivers provided information on participant and family characteristics (eg, ethnicity, race, age, education, and poverty status). Poverty status was determined

TABLE 1. CAREGIVER/CHILD DEMOGRAPHICS

<i>Variables</i>	<i>Percent</i>
Child age (years; <i>M (SD)</i>)	7.5 (3.2)
Relationship to child	
Mother	50
Father	48
Grandparent/other relatives	2
Child gender	
Male	57
Female	43
Child ethnicity	
Hispanic or Latino	21
Non-Hispanic or Latino	78
Child race	
American Indian or Alaskan Native	3
Asian	4
Black/African American	22
White	67
Unspecified	4
Annual family income	
Less than \$10,000	3
\$10,000–19,999	3
\$20,000–29,999	6
\$30,000–39,999	4
\$40,000–49,999	5
\$50,000–59,999	8
\$60,000–69,999	7
\$70,000–79,999	19
\$80,000–89,999	9
\$90,000–99,999	7
\$100,000 and over	29
Poverty status	
Below poverty line	12
Caregiver education level	
Some high school	3
High school graduate	7
Vocational school or some college	10
College degree	42
Professional or graduate degree	39
Caregiver marital status	
Married/living as married	80
Separated/divorced	3
Never married	15
Widower/widowed	2
SNAP utilization	40
Food bank utilization (past year)	55

Percent of participants reported, unless otherwise noted.
SNAP, Supplemental Nutrition Assistance Program.

by dividing the family's annual income by the 2017 US federal per capita poverty threshold for a family of that size.²⁷ Please see Table 1 for additional demographic information.

History of FIA. Caregivers provided information regarding their child's FA and FA history of allergic reactions. Items on the FIA included the number of children within the household with food allergies, age of child's FA diagnosis, history of FIA, symptoms during FA reaction, and comorbid diagnoses that may result in common symptoms (ie, eosinophilic esophagitis). FIA was determined positive by using parental report [yes or no; "Has your child had an anaphylactic reaction? (Anaphylaxis is a severe allergic reaction that can happen very quickly)"]. If caregivers answered

TABLE 2. CAREGIVER REPORT OF CHILD FOOD ALLERGY: SYMPTOMS

<i>Symptoms</i>	<i>Ever experienced (percent; n)</i>	<i>Most severe experienced (percent; n)</i>
Arrhythmia (irregular or weak heartbeat)	4.5 (9)	6.6 (12)
Appearing pale or blue	4.4 (8)	5.5 (10)
Fainting	4.9 (9)	3.3 (6)
Swelling in the face (eyes, lips)	23.5 (43)	25.1 (46)
Swelling in the mouth or tongue	15.3 (28)	19.7 (36)
Throat tightening/difficulty swallowing	15.8 (29)	18 (33)
Hoarseness	9.8 (18)	11.5 (21)
Difficulty breathing	21.3 (39)	15.3 (28)
Cough	23 (42)	18.6 (34)
Wheeze	11.5 (21)	8.7 (16)
Nausea	14.2 (26)	10.4 (19)
Stomach pain	15.3 (28)	8.2 (15)
Vomiting	16.4 (30)	17.5 (32)
Itching in the mouth	44.8 (82)	41.5 (76)
Itching in the throat	39.9 (73)	32.2 (59)
Runny nose	37.7 (69)	27.3 (50)
Sneeze	37.2 (68)	26.8 (49)
Itchy/red eyes	37.7 (69)	31.1 (57)
Itching of the skin	45.4 (83)	35 (64)
Redness of the skin	41 (75)	37.2 (68)
Increased eczema	13.7 (25)	9.8 (18)
Hives	16.9 (31)	15.3 (28)
Diarrhea	9.3 (17)	7.1 (13)
Light headed or dizziness	8.2 (15)	6.6 (12)

FA, food allergy.

"yes" to this question, then that participant was categorized as positive history of FIA. We also asked parents of frequencies of epinephrine use. (ie, "Has your child ever used an Epipen®?") "If yes, how many times?") Finally, we asked parents to endorse the presence and severity of allergic reactions. Please see Table 2 for a list of these allergic reactions and parental report of frequency.

Food Allergy Independent Measure. The Food Allergy Independent Measure (FAIM)²⁸ is a self-reported 4-item questionnaire that assessed caregivers' perception of FA severity and associated risks for their child. Caregivers rated on a 7-point Likert scale (1—not at all and 7—extremely likely) their perceived risk of allergen exposure, severe allergic reactions following allergen exposure, and dying as a result of allergen exposure. (eg, "What chance do you think your child has of accidentally ingesting the food to which they are allergic to" and "what chance do you think your child has of having a severe reaction if food is accidentally ingested?") The FAIM is a well-validated measure of caregiver perceived risk when compared with other measures of caregiver FA risk ($\alpha > 0.70$).^{28–30} To examine perceived risk and the association with food security status, caregiver responses were dichotomized into low/no risk (ie, 1–3 indicated no/low risk) and moderate/high risk (ie, responses 3–7 indicated moderate/high risk).

National Health and Nutrition Examination Survey—Household Food Security Questionnaire. This 18-item

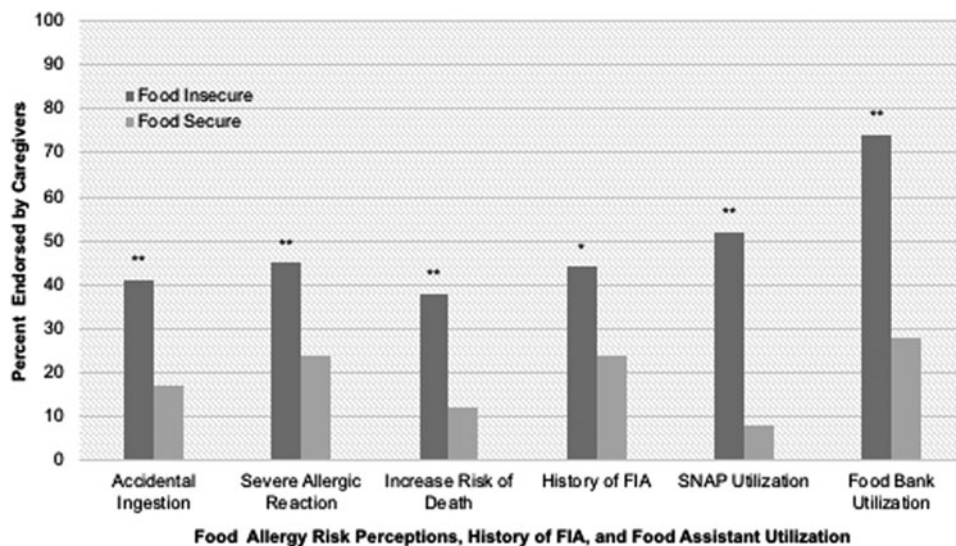
questionnaire characterizes household food security status.^{26,31,32} Items assessed food access problems, limitations, food sufficiency, or food shortage. Items also examined food quality, variety, desirability of diet, and disrupted eating patterns (eg, “we were worried whether our food would run out before we got money to buy more,” and “we couldn’t afford to eat balanced meals”). For example, balanced meals include 1 food from each food group: (1) Milk/Milk Products, (2) Vegetables, (3) Fruits, (4) Grains, and (5) Meat/Beans). Household food security, National Health and Nutrition Examination Survey (NHANES), was coded using the following guidelines: full food security: no affirmative response in any items (22%); marginal food security: 1–2 affirmative responses (19%); low food security: 3–7 affirmative responses (17%); very low food security: 8–18 affirmative responses (42%). To explore food security with our identified variables (ie, perceptions of FA-related risks, FIS), food security data were categorized into a dichotomized distribution [secure (ie, no or marginal issues in obtaining food): $n=75$, 41%; insecure (ie, moderate to high issues in obtaining food): $n=108$, 59%].

Finally, 2 questions were used to assess the frequency with which families utilized SNAP and food banks: “Do you or anyone in your household currently get SNAP, an electronic benefits transfer card, or food stamps? This includes any SNAP benefits or food stamps, even if the amount is small and even if the benefits are received on behalf of children in the household” and “in the last 12 months, did you or a family member use a food bank or other source to obtain food?”

Analysis plan

First, an independent-samples t -test was conducted to compare demographic characteristics with food security status. Next, chi-square (χ^2) analyses were utilized to assess associations between food security status (insecure versus secure), parental perception of FA-related risks, and utilization of food assistance programs. Effect sizes are expressed as Cramer’s Phi, interpreted as small (0.1), medium (0.3), or large (0.5). All analyses were conducted in SPSS version 22.

FIG. 1. Food Security States, Utilization of Food Assistance Programs, and Caregiver Perceptions of Food Allergic Reactions/Food-Induced Anaphylaxis. **Significant at $P<0.01$. *Significant at $P<0.05$. FIA = Food-induced anaphylaxis. SNAP = Supplemental Nutrition Assistance Program.



Results

Please see Tables 1–2 and Figure 1 for additional information about participant demographics and a visual representation of FA and FIS results.

Participant characteristics

Caregivers in the current sample included mothers (50%), fathers (48%), and grandparents/other relatives (2%) of male (57%) children. Caregivers were mostly white 67%, 22% black, 21% Hispanic or Latino ($M_{Age}=7.5$ years, $SD=3.2$ years) and indicated their child had been diagnosed with FA before 6 years ($M_{Age}=5.1$; $SD=3.1$). As per parent report, the majority of children had a history of FIA (68%) and multiple utilizations of self-injectable epinephrine [58% “yes”; “How many times has your child used the epinephrine auto-injector (eg, Epi-pen)?” $M=3.3$ times; $SD=1.9$ times]. Families were asked to indicate the frequency and severity of FA allergic reactions. Most common symptoms ever experienced included itching in the mouth (45%), skin (45%), and throat (40%) and redness of skin (41%). Most common severely experienced symptoms included itching in the mouth (42%), skin (37%), and redness of skin (35%). Please see Table 2 for a full list of all symptoms reported. No differences were observed in family food security status (ie, food secure versus food insecure) and poverty [ie, above or at/below poverty line; ($t(181)=-0.59$, $P=0.55$)], child ethnicity ($t(181)=-1.01$, $P=0.33$), or child age ($t(181)=0.45$, $P=0.65$).

FIS and FA-related risks (FAIM)

Caregivers classified as FIS reported increased perceived risk of accidental ingestion ($\chi^2=11.99$, $P=0.001$, $\phi=0.27$; 41% versus 17%), severe allergic reaction ($\chi^2=6.24$, $P=0.01$, $\phi=0.20$; 45% versus 24%), and death ($\chi^2=22.55$, $P<0.001$, $\phi=0.36$; 38% versus 12%).

FIS and history of FIA

FIS status was associated with child FIA ($\chi^2=5.54$, $P=0.02$, $\phi=0.19$; 44% versus 24%).

FIS and utilization of food service programs

Utilization of food assistance programs ($\chi^2=39.31$, $P<0.01$, $\phi=0.46$; 52% versus 8%) and food banks ($\chi^2=183$)=37.99, $P<0.01$, $\phi=0.46$; 74% versus 28%) was more frequent in FIS families than food-secure families.

Discussion

We sought to evaluate the association between FIS and (1) caregivers' perception of their child's FA risks, (2) history of FIA in children with FA, and (3) household use of food assistance programs (SNAP, food banks). In the present study, we observed a high proportion of FIS in families with FA. Consistent with previous research examining FA in families,²² no associations were observed for food security status and child demographic characteristics, age, or family poverty status (ie, above or at/below the federal poverty line). This is particularly interesting given the associations found between FIS and utilization of SNAP (40% of the entire sample) and food banks (55% ever-use for entire sample). A few explanations may account for this observation. Minimum gross income is typically lower to meet federal poverty status, whereas SNAP benefits can be received at income levels above the federal poverty line. According to the US Census,²⁶ the median household income is \$59,039. In the present sample, the median household income was \$70,000–79,999. Despite the higher than typical family income, the finding in the present study may be a reflection of FA-related financial burdens, regardless of gross total income, related to their child's FA needs (eg, direct and indirect medical expenses and meal preparation). Additional studies assessing FIS in families of children with FA are needed to elucidate processes driving this phenomenon.

To our knowledge, this is only the second study²² to examine the frequency of FIS in families of children with FA, and the first to examine food security and FA-related health risks. While significant differences emerged in perceptions of FA-related risks and food security status, the sample as a whole reported a high frequency of food-related worries and a history of FIA (68%). This may be a reflection of the high utilization of food assistance programs, as these programs may offer a restricted range of items for selection. These findings highlight the need to continue to assess difficulties and perceptions of food-related issues in this population and identify targeted, personalized intervention strategies to reduce FA-related burdens. Observed differences in perceptions of FA-related risks may be a consequence of the adversity these families face to meet basic nutritional needs, whereas more food secure families may not have such concerns and can dedicate more time/resources to examine food items for potential FA triggers. Further examination, using more comprehensive and intensive methodology (eg, longitudinal and qualitative), is needed to examine why FA families experience FIS despite having access to economic resources to obtain food.

While this study provides important preliminary insights of FIS in families of children with FA, we have several limitations to note. First, all data were collected online and are cross sectional in design. Utilizing longitudinal methodology to assess food security and FA-related risks or allergen exposures could provide more insight to the characteristics of these relationships. A further limitation is the use of self-report

to ascertain both household food security status and food assistance program participation. Self-report may be prone to both intentional and unintentional misreporting,³³ which could lead to bias. Due to the survey methodology, we were unable to verify physician diagnosis of FA and age at which the child was diagnosed. While there is a small chance that families participating in the present study may have not had a child diagnosed with FA, it is highly unlikely. Families recruited through Toluna were unable to participate in the present study unless inclusion criteria were met. Finally, parental report of frequency of FIA and allergic reactions related to FIA is not the most rigorous method of identifying FIA. Recent literature has highlighted the discrepancy between physician-reported FA and caregiver-reported FA, with up to 30% of caregiver-reported FA not diagnosed by a physician.³⁴ However, the primary goal for this project was to advance the literature by including more underserved and representative samples of families of children with FA. Future studies, which incorporate the use of physician-confirmed FA and electronic medical records to assess frequency and severity of allergic reactions, are needed to further assess the associations highlighted in the present study. Despite these limitations, the present study provides a snapshot into the lives of families with FAs and is one of the first to have a broader and representative population sample.

Conclusions

The extant literature indicates a variety of significant burdens for FA families, such as increased stress,¹¹ symptoms of anxiety and depression,^{6,9,11,15} and lower QoL.³⁵ Caregivers of children with FA are also at risk for experiencing significant financial burdens, with yearly direct medical costs averaging more than \$700 per child^{2,12} and out-of-pocket expenses more than \$900 per child.^{2,12} In addition to medical costs, families can be burdened by a need to allocate a significant amount of financial effort in providing special dietary and allergen-friendly foods.^{2,12} Therefore, this unique combination of variables (ie, financial costs, diligence in meal/food preparation, and psychosocial demands/stressors) may contribute to the high proportion of the FIS experienced in the present sample. Thus, the observed differences in perceptions of FA-related risks may be a consequence of the adversity these families face to meet basic nutritional needs. Families without FIS may be able to dedicate more time/resources to examine food items for potential FA triggers. Future research, including qualitative focused research, is needed to examine FA risks and the impact of FIS, given the potential risk FIS may place on families.

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Author Disclosure Statement

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