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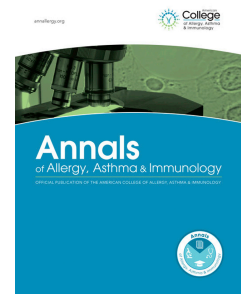
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Title:

Food-allergic teenagers report worse quality of life: Results from 174 Quality of Life Patient Questionnaires.

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Abbreviations:

EI score: emotional impact score

FA score: Food Anxiety score

FAIM score: Food Allergy Independent Measure score

FAQLQ-PF: Food Allergy Quality of Life Questionnaire - Parent Form

FAQLQ-TF: Food Allergy Quality of Life Questionnaire – Teenager Form

IQR: Interquartile range

QoL: Quality of Life

SDL score: Social and Dietary Limitations score

Key words: food allergy, children, teenagers, quality of life

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1 Introduction:

2 Food allergies are common, affecting 1 in 13 children in the US ^{1 2}. They pose a significant
3 burden on the allergic child and their family with reported physical and emotional impact.
4 Food-allergic children are required to avoid their food triggers; unfortunately, this can be
5 difficult when eating outside the home or travelling ^{3 4}. Additionally, food labels can often be
6 misleading and accidental exposures may result in severe allergic reactions ⁵. The risk of a
7 severe reaction creates a lot of anxiety in the daily life of food-allergic children and is often
8 associated with significant limitations in their social interactions. Multiple disease-specific
9 instruments have been developed to measure quality of life (QoL) in patients with food allergy
10 and their families ^{6 7 8}.

11
12 Previous published research has shown that food-allergic children have worse QoL compared to
13 children with type 1 diabetes as a result of their fear of accidental exposure and life-threatening
14 reactions ⁹. Additionally, parents of peanut-allergic children, compared to the parents of
15 children with a rheumatological disease, reported that their children had significantly more
16 disruption in their daily activities and more impairment in the familial-social dimension of their
17 life ¹⁰.

18
19 The aims of our research were: a) to investigate the impact of food allergy on our patients' QoL
20 b) to identify any demographic factors or baseline characteristics (as reported on the Food
21 Allergy QoL Questionnaire - FAQLQ) associated with worse QoL and c) to compare the impact of
22 food allergies on the QoL of teenagers versus younger children.

23

24 **Methods:**

25 Subjects between 0-17 years old with a physician-confirmed diagnosis of food allergy were
26 recruited from the Allergy Clinics at Texas Children's Hospital over a period of 2 years (June
27 2017-June 2019). Patients and/or their parents were invited to participate in this study by
28 completing the Food Allergy QoL Questionnaire - Parent Form (FAQLQ-PF) ⁶ for children 0-12
29 years of age or the Food Allergy QoL Questionnaire – Teenager Form (FAQLQ-TF) ¹¹ for
30 adolescents between 13-17 years of age. The Parent Form was completed by the parent (proxy
31 report) whereas the Teenager Form was completed by the teenager (self-report). Verbal
32 consent was obtained from parents and older children. IRB approval was obtained for this
33 study. All data were collected from the anonymized QoL instruments, as reported by the
34 participants.

35

36 The Food Allergy QoL Questionnaires include various subscales such as emotional impact (EI) ,
37 food anxiety (FA), and social and dietary limitations (SDL). These subscales can be combined to
38 average an overall Food Allergy QoL score (FAQLQ). The Food Allergy Independent Measure
39 (FAIM) score can also be assessed from the questionnaire. The FAIM score reflects concerns
40 about accidental exposure and disease severity. Higher scores reflect worse QoL.

41

42 **Statistical analysis:**

43 Patient characteristics and survey scores were summarized using median with minimum and
44 maximum, or frequency with percentage. Summary scores were then stratified by survey type

(child or teen), and compared using the Wilcoxon rank sum test, Fisher's exact test or the Chi-square test. Independent median regressions were used to test the association between potential risk factors and QoL outcomes (total FAQLQ score, EI score, FA score, SDL score and FAIM score). Factors found to be significant at the $p < 0.05$ level were considered for inclusion in a multiple median regression. Backwards elimination, followed by forward re-entering of variables, was used to create a more parsimonious model.

Results

A total of 174 pediatric food-allergic patients participated in this study, including 150 children (0-12 years) and 24 teenagers (13-17 years). Response rates were 80% in children and 72% in the teenage/adolescent group. We excluded patients who had outgrown their food allergy.

Overall, in our cohort, the median EI score was significantly higher in teens compared to children (3.8 vs. 3.1, $p = 0.019$). The median SDL score (5.2 vs. 4, $p = 0.002$), and the median overall FAQLQ score (4.7 vs. 3.5, $p = 0.007$) were also higher in teens compared to children. (See Table 1)

Detailed summary statistics for all patients are shown in Table 2. Briefly, the majority of our cohort were allergic to peanut and just over half had experienced anaphylaxis previously. Most common symptoms experienced during allergic reactions included cutaneous and gastrointestinal.

Table 2, 3 and 4 stratify summary statistics by survey type (child/teen) in terms of demographics (Table 2), previous anaphylaxis and epinephrine use (Table 3) and allergic reaction symptoms (Table 4) respectively. Compared to children, a larger percentage of teens have had previous anaphylaxis (79.2% vs. 47.3%, $p=0.004$), reported anxiety caused by epinephrine auto-injectors (50% vs. 22%, $p=0.006$), experienced mouth itching (58.3% vs. 35.3%, $p=0.042$), throat itching (75% vs. 38.7%, $p=0.001$), lip itching (54.2% vs. 30.0%, $p=0.034$), tight throat (58.3% vs. 22.7%, $p=0.001$), dyspnea (54.2% vs. 19.3%, $p=0.001$), shortness of breath (41.7% vs. 14%, $p=0.003$), wheezing (50% vs. 19.3%, $p=0.003$), urticaria (79.2% vs. 56.0%, $p=0.043$), abdominal cramps (41.7% vs. 15.3%, $p=0.005$), and light-headedness (20.8% vs. 6.0%, $p=0.028$) as part of their allergic reaction.

FAQLQ total score: After adjusting for variables that remained significant in multiple regression, the median FAQLQ total score is shown to increase (=worsen) by 0.12 points (95% CI: 0.07, 0.17) per year increase in child age (Figure 1a). Compared to patients whose food allergy does not cause any stress to their family, the median FAQLQ total score is 1.73 points higher (95% CI: 0.80, 2.67) among those whose food allergy causes a lot of stress to their family. Compared to patients whose food allergy does not limit family activities, the median FAQLQ total score is 1.65 points higher (95% CI: 0.67, 2.63) among those whose food allergy limits family activities a lot. (See Figure 1)

Emotional impact score: After adjusting for variables that remained significant in multiple regression, the median EI score increases by 0.09 points (95% CI: 0.05, 0.13) per year increase in

child age (Figure 1b). The median EI score is 0.42 points higher (95% CI: 0.05, 0.79) among children or teens who have anxiety regarding epinephrine auto-injectors. Compared to parent's whose child's emotional well-being does not cause any worry, the median EI score is 1.34 points higher (95% CI: 0.58, 2.10) among parents whose child's emotional well-being causes a lot of worry. Compared to those whose family activities are not limited due to food allergy, the median EI score is 1.83 points higher (95% CI: 1.04, 2.62) among those whose family activities are limited a lot.

Food allergy independent measure score: After adjusting for variables that remained significant in multiple regression, the median FAIM is 1.06 points higher (95% CI: 0.46, 1.66) among patients who are allergic to peanuts compared to those who are not. Number of food allergies was independently associated with the FAIM, but when used in multiple regression, was no longer significant

Food anxiety score (child only): After adjusting for variables that remained significant in multiple regression, the median FA score increases 0.18 points (95% CI: 0.12, 0.26) per year increase in child age (Figure 1c). The median FA score is 0.56 points higher (95% CI: 0.05, 1.08) among those with diarrhea. Compared to those whose food allergy causes family a lot of stress, the median FA score is 1.77 points lower (95% CI: -3.14, -0.40) among families with a little stress. Compared to those whose family activities are limited a lot due to food allergy, the median FA score is 1.91 points lower (95% CI: -2.94, -0.88) among those whose family activities are not limited.

Social and dietary limitations score: After adjusting for variables that remained significant in multiple regression, the median SDL score is 0.09 points higher (95% CI: 0.03, 0.14) per year increase in child's age (Figure 1d). The median SDL score is 0.42 points higher (95% CI: 0.08, 0.76) among those who had anaphylaxis > 2 years ago, and 0.48 points higher (95% CI: 0.05, 0.91) among those with hoarseness. Compared to those with no worries due to child's emotional well-being, the median SDL score is 1.18 points higher (95% CI: 0.05, 2.30) among those with a lot of worries due to child's emotional well-being. Compared to those whose family activities are not limited due to food allergy, the median SDL score is 3.06 points higher (95% CI: 2.56, 3.55) among those whose family activities are limited a lot.

Discussion:

A significant finding of our study is that QoL worsens with increasing age, with teenagers reporting significantly more impact from their food allergy compared with younger children (based on parental report). When directly comparing these two groups, significant differences emerge in the overall FAQLQ score ($p=0.007$), and these are reflected in both the EI ($p=0.019$) and SDL ($p=0.002$) scores. Specifically, the median FAQLQ total score was shown to increase by 0.12 points (95% CI: 0.07, 0.17) per year increase in the child's age. Our findings support those of others who have reported worse QoL in older children^{12 13}, but to our knowledge, we are the first group to directly compare teenagers to younger children with a physician-confirmed diagnosis of food allergy. Teenagers often have better awareness of the unique challenges

posed by their food allergy, and are required to take on more responsibilities in managing their condition outside a protected home environment and parental supervision. Additionally, they may face multiple emotional challenges, including peer pressure and food-allergy related bullying, with studies showing that a third of food-allergic children reported having being bullied due to their food allergy at least once^{14 15}.

In families with increased levels of stress surrounding the diagnosis of their child's food allergy, total FAQLQ scores were higher (reflecting worse QoL), suggesting that parental attitudes influence their child's QoL. Caregivers of food-allergic children experience high levels of stress and fear¹⁶. Similarly, the total FAQLQ score worsened with increasing limitations in family activities imposed by the diagnosis of food allergy. Limitations in family activities was a finding significantly affecting specific QoL subscales in our study including EI, FA and SDL subscales. When considering the effort required to create a safe environment for a food-allergic child, it is not surprising that daily family activities are impacted. A previous study showed that more than 60% of caregivers reported that food allergy affected meal preparation, whereas 10% of caregivers chose to home school their child, 16% avoided going to restaurants, 11% did not allow their child to play at friends' homes and 26% avoided camp and sleep-overs because of the child's food allergy¹⁷. In contrast, a small qualitative study from Finland reported that the majority of families with food-allergic children were able to balance new demands and arrange their daily activities in a meaningful way, suggesting that there may be ways to address food-allergy related challenges effectively in selected cases¹⁸.

Factors associated with a worse EI score in our patient cohort included increasing child age, parents whose child's emotional well-being caused worry due to the child's food allergy, limited family activities and child anxiety regarding epinephrine use. Half (51.7%) of our patients had experienced a previous episode of anaphylaxis, and almost all (94.3%) had an epinephrine prescription available. More teens were noted to have previous episodes of anaphylaxis (79.2% vs 47.3%, $p = 0.004$). This could be due to having a food allergy for a longer period of time, or the fact that teenagers tend to be higher risk-takers and may be at higher risk of accidental exposure to the allergenic food resulting in anaphylaxis.

Interestingly, carrying an epinephrine autoinjector device was mostly reassuring for parents, less so for children and adolescents, with 26% of the latter reporting that having epinephrine available caused them some anxiety. It is possible that parents feel empowered when medication that can save their child's life is available to them, as suggested by a previous study¹⁹. With regards to epinephrine use, teenagers were more likely to have anxiety around the use of an epinephrine auto-injector ($p = 0.006$). A previous study from Australia reported worse QoL in food-allergic patients who had been issued an epinephrine auto-injector reinforcing our findings from another geographical area²⁰. Epinephrine is a life-saving medication for severe allergic reactions, but teenagers are often reluctant to comply with both carriage and use of epinephrine. A recent study reported that adherence to epinephrine auto-injector carriage is poor, with 49% of 10-14 year-old students never carrying their epinephrine auto-injector in 1 or more locations, 32% never carrying it when they were by themselves, 28% never carrying it while out with friends, and 36% never carrying their epinephrine auto-injector to sporting

activities²¹. Various reasons for non-compliance have been reported including failure to recognize anaphylaxis, uncertainty about auto-injector technique and when to administer it and fear of using the auto-injector²².

The SDL score was worse in patients who were older and those with limitations in family activities. A worse FA score was noted in children with diarrhea. This may be due to the inconvenience of managing this symptom in a public area. Older children, children whose food allergy caused their family a lot of stress, and those whose family activities were limited due to food allergy also reported worse FA scores.

Most of our patients reported a peanut (89.1%) or nut (56.9%) allergy, followed by egg (21.8%), milk (17.2%) and shellfish (12.6%) allergies. When assessing food allergy symptoms that patients experienced, teens were more likely to have reported itching of the mouth, lip and throat as well as tight throat. This is not surprising since younger children are often unable to verbalize subjective symptoms or possibly experience these less often. Additionally, urticaria, abdominal cramps, lightheadedness, and respiratory symptoms including dyspnea, shortness of breath, and wheezing were more common in teenagers. It has been reported previously that adolescents are more at risk of severe allergic reactions compared to younger children²³. The FAIM score was noted to be higher in patients with peanut allergy, suggesting that fear of accidental exposure is likely higher. This can be explained by the fact that peanuts are used in a multitude of food and non-food products and precautionary labelling is confusing and

burdensome to patients and their families, resulting in difficulty to find 'safe' products and longer shopping times^{24 25 26}.

Strengths of our study include a well-characterized population with a physician-confirmed diagnosis of food allergy and a direct comparison between teenagers and younger children. Limitations of our study include a smaller number of teenage patients compared to children (likely a reflection of our clinic population), parental proxy report for QoL in the younger children and results from a tertiary allergy center that may not be directly applicable to the wider community setting. Additionally, questionnaires were completed entirely by parents and teenage patients and the data are therefore subject to recall bias.

In summary, our research from a tertiary center population of food-allergic children highlights the fact that teenagers are affected more than younger children in terms of QoL due to their food allergies, with a direct reflection to all areas of their daily life (emotional, dietary and social). Additionally, when educating families about managing food allergies, it is important to strongly encourage participation in family activities, as it is clearly demonstrated in our study that limitation in these due to the child's food allergy, significantly affects the QoL and well-being of all family members.

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Table 1: Quality of Life Scores Comparison between Children and Teenagers

Emotional impact score, food anxiety score, social and dietary limitations score, total FAQLQ score and FAIM score are shown for children and teens. p-values were calculated using the Wilcoxon rank-sum test

NA: not applicable

Quality of Life Scores	Child (N=150)		Teen (N=24)		p-value
	N	Median (Min, Max)	N	Median (Min, Max)	
Emotional impact score	145	3.1 [1.0,6.8]	24	3.8 [1.8,6.3]	0.019*
Food anxiety score (child only)	145	3.8 [1.0, 7.5]	NA	NA	NA
Social and dietary limitations score	147	4 [1.0,7.0]	24	5.2 [2.3,7.0]	0.002**
Total FAQLQ score	147	3.5 [1.1,6.9]	24	4.7 [1.9,6.8]	0.007**
FAIM	149	3 [0.4,5.0]	22	2.7 [0.6,4.7]	0.775

Table 2: Demographics and characteristics comparison of Children (0-12) and Teenagers (13-17)

Age, gender (parent and child), reported food allergies and healthcare professional who made the diagnosis of food allergy are shown for both children and teenagers with comparison between the two age groups. P-values were calculated using Fisher's exact test or Chi-square test

Demographics & characteristics	Child (N=150)	Teen (N=24)	P-value
	N, (%)	N, (%)	
Parent gender			0.205
Female	123, (84.8)	23, (95.8)	
Male	22, (15.2)	1, (4.2)	
Child gender			1.000
Female	66, (44.6)	11, (45.8)	
Male	82, (55.4)	13 (54.2)	
Food allergic to:			
Peanuts	132, (88.0)	23, (95.8)	0.478
Nuts	83, (55.3)	16, (66.7)	0.377
Milk	27, (18.0)	3, (12.5)	0.771
Egg	32, (21.3)	6, (25)	0.790
Wheat	3, (2.0)	2, (8.3)	0.141
Soya	7, (4.7)	4, (16.7)	0.048*
Sesame	16, (10.7)	3, (12.5)	0.730
Fish	10, (6.7)	1, (4.2)	1.000
Shellfish	20, (13.3)	2, (8.3)	0.743
Fruit	7, (4.7)	0, (0.0)	0.595
Vegetables	3, (2.0)	0, (0.0)	1.000
Other foods	15, (10.0)	3, (12.5)	0.718
Diagnosis made by			
GP	29, (19.3)	2, (8.3)	0.257
Allergist	107, (71.3)	22, (91.7)	0.043*
Pediatrician	41, (27.3)	7, (29.2)	0.811

Dermatologist	4, (2.7)	1, (4.2)	0.528
Dietician	0	0	-
Other	2, (1.3)	0, (0.0)	1.000

Table 3: Previous anaphylaxis and epinephrine use comparison of Children (0-12) and Teenagers (13-17)

This table includes information on previous anaphylaxis and issues surrounding epinephrine use. Specifically, previous anaphylaxis and timing of episode, epinephrine prescription, effect of having epinephrine available on parent and child (reassurance or anxiety) are shown for both children and teenagers with comparison between the two age groups. P-values were calculated using Fisher's exact test or Chi-square test

	Child (N=150)	Teen (N=24)	P-value
	N, (%)	N, (%)	
Previous anaphylaxis	71, (47.3)	19, (79.2)	0.004**
Anaphylaxis very recently	7, (4.7)	1, (4.2)	1.000
Anaphylaxis 6-12 months ago	6, (4.0)	3, (12.5)	0.111
Anaphylaxis ~1 year ago	13, (8.7)	1, (4.2)	0.696
Anaphylaxis ~2 years ago	9, (6.0)	5, (20.8)	0.028*
Anaphylaxis >2 years ago	46, (30.7)	9, (37.5)	0.489
Epi prescription	140, (93.3)	24, (100.0)	0.361
Epi causes parent reassurance	136, (90.7)	22, (91.7)	1.000
Epi causes child reassurance	94, (62.7)	19, (79.2)	0.166
Epi causes parent anxiety	55, (36.7)	8, (33.3)	0.822
Epi causes child anxiety	33, (22.0)	12, (50.0)	0.006**

Table 4: Allergic reaction symptoms comparison of Children (0-12) and Teenagers (13-17)

Reported symptoms of allergic reactions are shown for both children and teenagers with comparison between the two age groups. P-values were calculated using Fisher's exact test or Chi-square test

Allergic symptoms	Child (N=150)	Teen (N=24)	P-value
	N, (%)	N, (%)	
Mouth itching	53, (35.3)	14, (58.3)	0.042*
Throat itching	58, (38.7)	18, (75.0)	0.001**
Ear itching	18, (12.0)	7, (29.2)	0.053*
Lip itching	45, (30.0)	13, (54.2)	0.034*
Runny nose	47, (31.3)	7, (29.2)	1.000
Stuffy nose	29, (19.3)	8, (33.3)	0.176
Sneeze	35, (23.3)	6, (25.0)	0.801
Itchy eyes	59, (39.3)	10, (41.7)	0.826
Tears	26, (17.3)	3, (12.5)	0.770
Red eyes	33, (22.0)	6, (25.0)	0.793
Tight throat	34, (22.7)	14, (58.3)	0.001**
Dysphagia	19, (12.7)	4, (16.7)	0.530
Hoarseness	14, (9.3)	3, (12.5)	0.709
Dyspnea	29, (19.3)	13, (54.2)	0.001**
Shortness of breath	21, (14.0)	10, (41.7)	0.003**
Wheeze	29, (19.3)	12, (50.0)	0.003**
Cough	45, (30.0)	11, (45.8)	0.158
Itching skin	63, (42.0)	14, (58.3)	0.184
Redness of skin	63, (42.0)	11, (45.8)	0.825
Eczema	41, (27.3)	5, (20.8)	0.622
Urticaria/hives	84, (56.0)	19, (79.2)	0.043*
Skin swelling	47, (31.3)	10, (41.7)	0.352
Nausea	37, (24.7)	8, (33.3)	0.451

Abdominal cramps	23, (15.3)	10, (41.7)	0.005**
Vomiting	61, (40.7)	9, (37.5)	0.826
Diarrhea	12, (8.0)	4, (16.7)	0.243
Light-headedness	9, (6.0)	5, (20.8)	0.028*
Palpitations	3, (2.0)	2, (8.3)	0.141
Inability to stand	3, (2.0)	1, (4.2)	0.451
Syncope	0	0	-

Figure 1 : Median regressions for FAQLQ Total Score and Subscales

FAQLQ total score, emotional impact score, food anxiety score and social and dietary limitations score with increasing age (in years).

		Unadjusted			Adjusted			
		Coefficient	95% Confidence Interval	p-value	Adjusted for	Coefficient	95% Confidence Interval	p-value
FAQLQ Total Score (Figure 1a)	Child age (years)	0.14	0.07 – 0.21	<0.001	Diarrhea, level of stress FA causes family, whether FA limits family activities, and whether FA limits activities child can participate in	0.12	0.07 - 0.17	<0.001
Emotional Impact Score (Figure 1b)	Child age (years)	0.11	0.03 – 0.19	0.006	Whether Epi causes child anxiety, amount of worry caused by child's emotional health, and whether FA limits family activities	0.09	0.05 - 0.13	<0.001
Food Anxiety Score (child survey only) (Figure 1c)	Child age (years)	0.27	0.14 – 0.40	<0.001	Diarrhea, level of stress FA causes family, and whether FA limits family activities	0.18	0.12 - 0.26	<0.001
Social and Dietary Limitations Score (Figure 1d)	Child age (years)	0.13	0.03 – 0.23	0.010	Anaphylaxis > 2 years ago, hoarseness, amount of worry caused by child's emotional health, and whether FA limits family activities	0.09	0.03 - 0.14	<0.001

Figure 1a

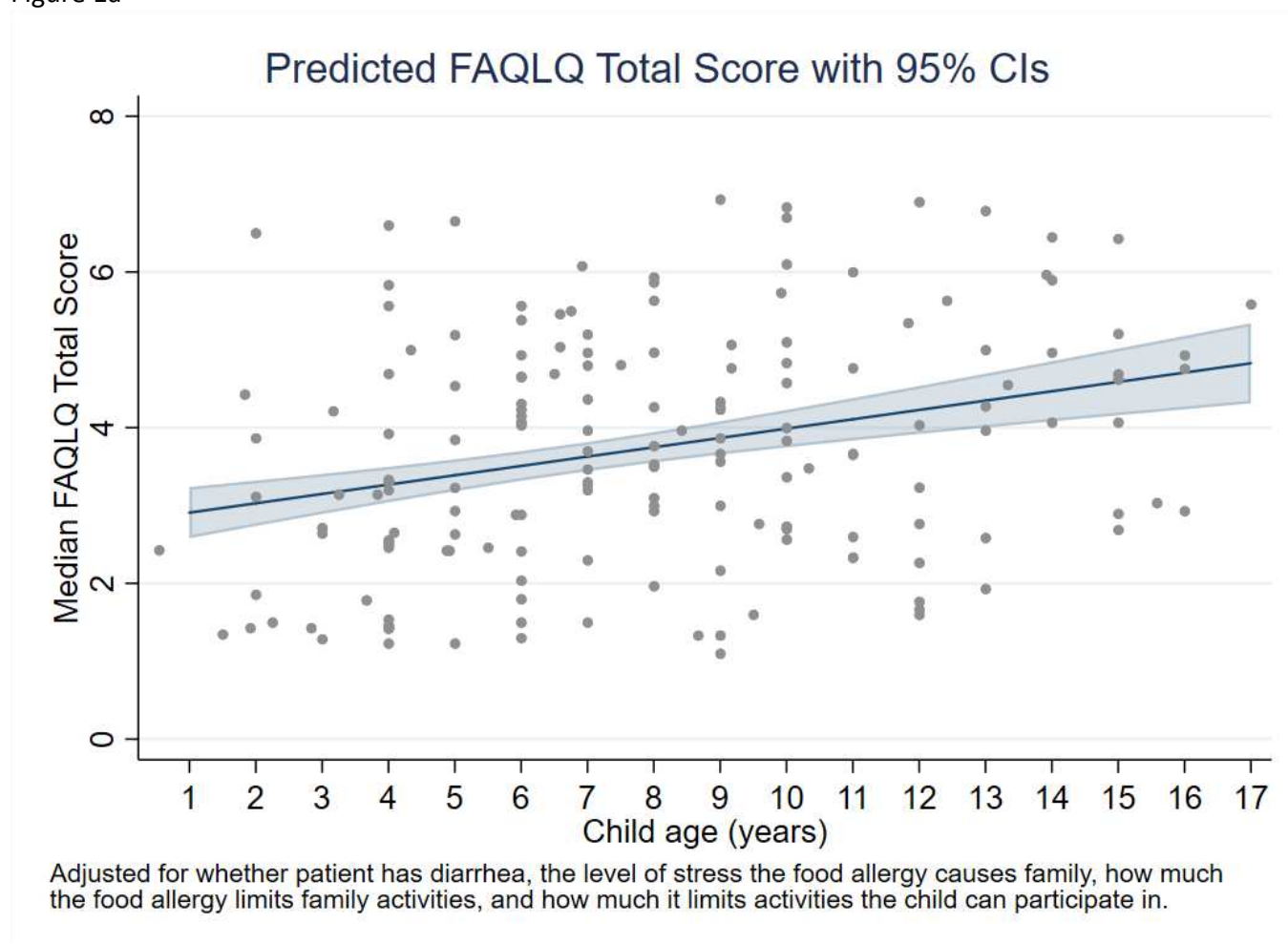


Figure 1b

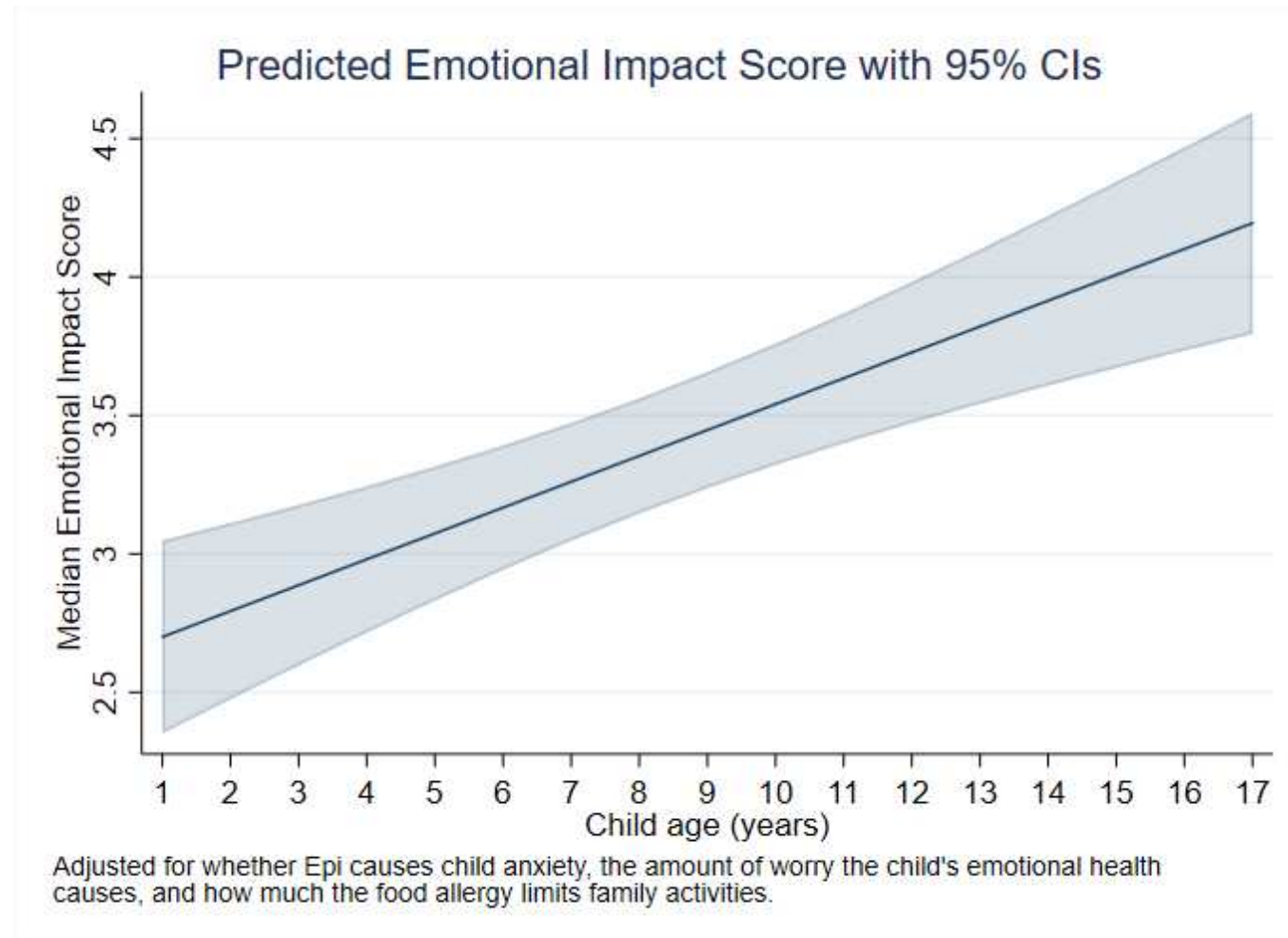


Figure 1c

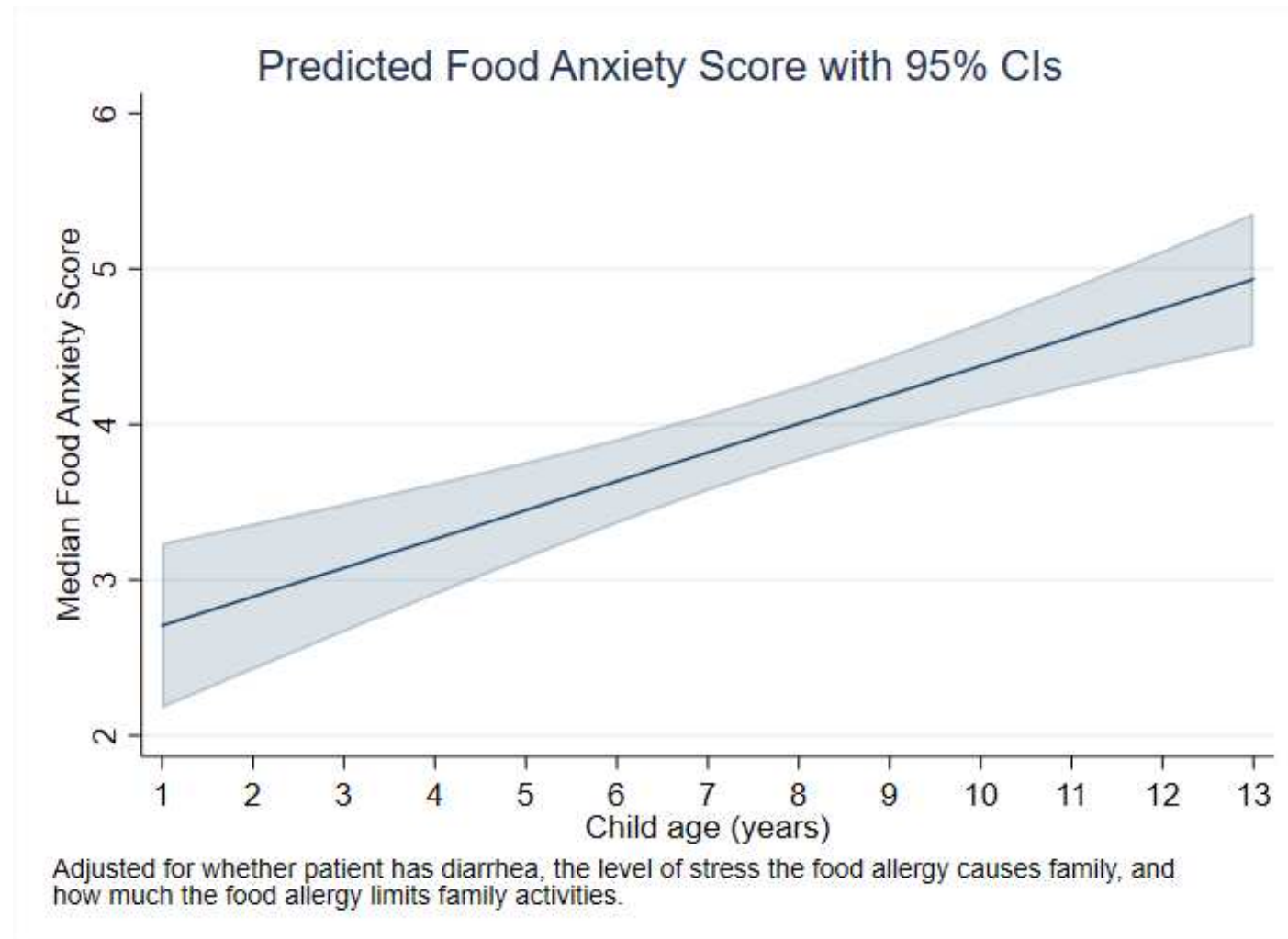


Figure 1d

