



MY LIFE WITH FOOD ALLERGY

Parent Survey Report

Spotlight on Eosinophilic Esophagitis (EoE)



Asthma and Allergy
Foundation of America

aafa.org



KIDS WITH
FOOD ALLERGIES

A Division of the Asthma and Allergy
Foundation of America

kidswithfoodallergies.org



ABOUT THE SURVEY

In 2019, the Asthma and Allergy Foundation of America (AAFA) and its food allergy division, Kids With Food Allergies (KFA) conducted a three-part food allergy study titled “My Life With Food Allergy.” These surveys aimed to understand the burden of food allergy (FA) from: parents of children with food allergies, teen/young adult patients with food allergies and adults with food allergies.

Data collected in these surveys confirmed much of the existing literature around food allergy impact on children and adults. Additionally, data from the parent survey—the subject of this report—improved our understanding of the burden of food allergy on parents and caregivers. Most notably, results pointed to a higher negative impact on the emotional and mental well-being of parents when compared to the impact on their child.

This survey sought insights on the following topics:

- Experience with FA diagnosis
- Experience with symptoms and allergic reactions
- Experience with current treatment
- Emotional, social, financial impact of FA on the caregiver (parent)
- Parent-reported emotional and social impact on the patient (child)
- Challenges in navigating school, dining and social activities
- Confidence in daily FA management
- Awareness of and thoughts about future treatment

About This Report

To explore the burden of EoE, we compared survey data from parents who indicated their child is diagnosed with EoE to data from parents whose children are diagnosed with food allergy, but not with EoE type food allergy.

This document focuses on select data from the My Life With Food Allergy: Parent Survey Report.

To see the full report, visit aafa.org/foodallergylife.

COPYRIGHT AND CITATION

©2019 Asthma and Allergy Foundation of America. All rights reserved.

If you reference this report, please cite it accordingly:

Asthma and Allergy Foundation of America. (2019). My Life With Food Allergy: Parent Survey Report (Spotlight on Eosinophilic Esophagitis)

Retrieved from aafa.org/foodallergylife

SPOTLIGHT: A LOOK AT EOSINOPHILIC ESOPHAGITIS (EOE)



EoE—a type of non-IgE mediated food allergy—can make eating difficult and painful. Diagnosis and management can be tricky due to delayed or intermittent symptoms. Removing foods that trigger EoE can help reduce symptoms, but not always. Diet modifications include eliminating multiple foods from the diet or subsisting on special medical formulas. EoE can have a costly impact on a family’s social, emotional and financial health.

To explore the burden of EoE, the Asthma and Allergy Foundation of America (AAFA) compared survey data from parents who indicated their child is diagnosed with EoE (n=106) to data from parents whose children are diagnosed with food allergy, but not with EoE type food allergy (n=1,128).

For every aspect of life that we asked about, parents of children with EoE reported more negative impact from FA. On a five-point scale (with 1 being “no impact” and 5 being “major impact”), 68% of parents of children with EoE rated the impact of their child’s food allergy on their own emotional health as a 4 or 5 (compared to 49% of parents of children with IgE-mediated FA). On the same scale, 56% of parents of children with EoE rated the impact of their child’s FA on their own relationships as a 4 or 5 (compared to 36% of parents of children with IgE-mediated FA).

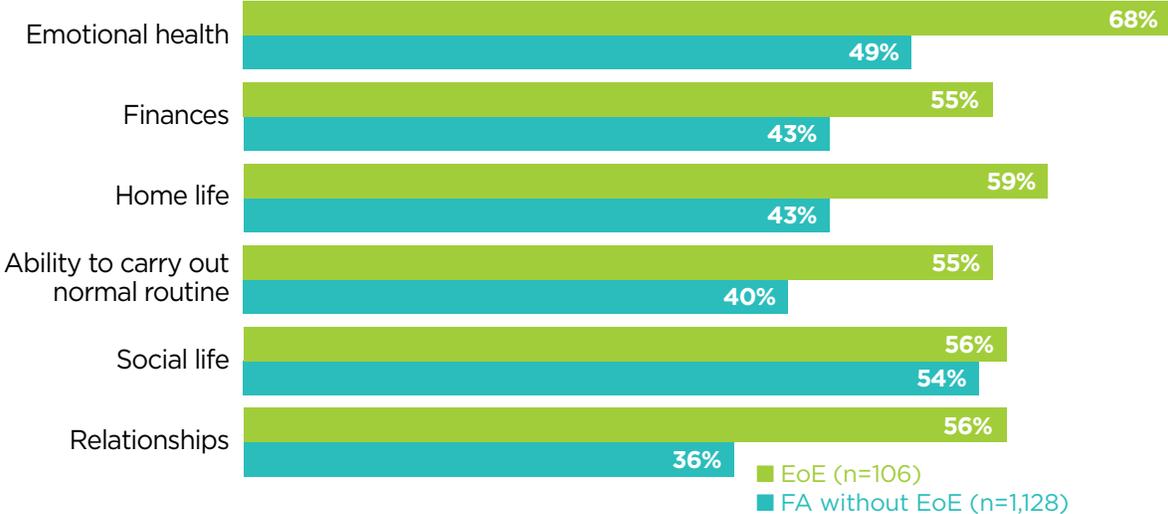
WHAT IS EOE?

Eosinophilic esophagitis (EoE) is an allergic swallowing disorder. EoE occurs when eosinophils, a type of white blood cells, collect in the esophagus (throat). The condition is often triggered by food but may be triggered by pollen as well. EoE affects people of all ages, genders and ethnic backgrounds.

Symptoms can occur days or even weeks after eating a food allergen. However, symptoms may wax and wane, meaning they are not always present. This can be confusing. Common symptoms include:

- Reflux that does not respond to usual therapy
- Difficulty swallowing
- Food impactions (food gets stuck in the throat)
- Nausea and vomiting
- Failure to thrive (poor growth or weight loss)
- Abdominal or chest pain
- Poor appetite
- Malnutrition
- Difficulty sleeping

IMPACT OF A CHILD’S FA ON VARIOUS ASPECTS OF PARENT’S LIFE (CHOOSE “4” OR “5” ON FIVE-POINT SCALE)



EoE impacted daily decision-making for all social activities we asked about: 71% of parents of children with EoE said they have changed vacation plans due to FA and 58% said they have avoided airline travel due to FA (compared to 56% and 43% of parents of children with IgE-mediated FA, respectively).

IMPACT OF FA ON ACTIVITIES (RESPONDED “YES”)

Social Impact	EoE (n=106)	FA without EoE (n=1,128)
Skipped out on an important school function	67%	51%
Cancelled or significantly changed vacation plans	71%	56%
Avoided airline travel	58%	43%
Left a restaurant in the middle of dining?	60%	52%
Changed schools?	31%	24%
Decided to home school?	27%	17%
Stopped talking to family members/friends/ others because of their lack of empathy with/ understanding of food allergies?	52%	35%

Nutrition plays a critical role in a child’s development. But EoE can threaten a child’s growth, putting heavy burden and concern on families. Because symptoms can be intermittent or delayed, managing EoE and watching for nutritional deficiencies becomes a challenging task.

“ALWAYS/OFTEN” FEEL CONCERNED ABOUT THEIR CHILD’S NUTRITION/GROWTH BECAUSE OF THEIR RESTRICTED DIET

38%
of parents whose
children have EoE

25%
of parents whose
children have FA without EoE

Additionally, more than half (54%) of parents of children with EoE reported seeing a mental health professional in the past 5 years due to their child’s FA, compared to 29% of parents whose children have FA without EoE.

HAVE SEEN A MENTAL HEALTH PROFESSIONAL (IN THE PAST 5 YEARS) RELATED TO THEIR CHILD’S FA

54%
of parents
whose children
have EoE

29%
of parents
whose children
have FA without EoE

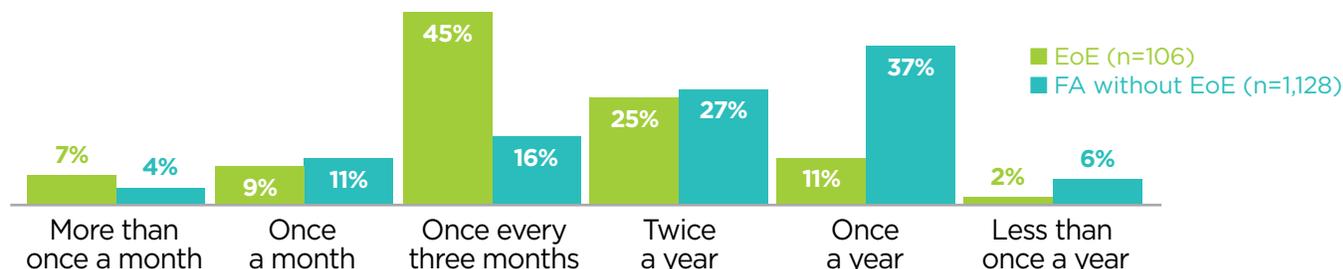
SAID THEIR CHILD HAS SEEN A MENTAL HEALTH PROFESSIONAL (IN THE PAST 5 YEARS) RELATED TO THEIR FA

47%
of parents
whose children
have EoE

27%
of parents
whose children
have FA without EoE

Due to the nature of EoE, many children with the condition may need more frequent doctor visits compared to children with IgE-mediated FA. Parents of children with EoE reported more frequent visits to the doctor, higher burden of costs of doctor visits, and higher burden of travel related to doctor visits.

FREQUENCY OF FA-RELATED CLINICAL VISITS



On a five-point scale (with 1 being “not a burden at all” and 5 being “major burden”), 46% of parents of children with EoE rated the burden of travel required to see specific health care provider as a 4 or 5 (compared to 23% of parents of children with IgE-mediated FA). On the same scale, 48% of parents of children with EoE rated the burden of the cost of copays for specialist doctor visits as a 4 or 5 (compared to 32% of parents of children with IgE-mediated FA).

FINANCIAL AND TIME BURDEN OF HEALTH CARE (CHOSE “4” OR “5” ON FIVE-POINT SCALE)



“The overwhelming problems with dealing with multiple food and environmental allergies, EoE, and asthma has led us to home school — not by choice. This has had major negative impacts on our quality of life and family relationships.” – Parent

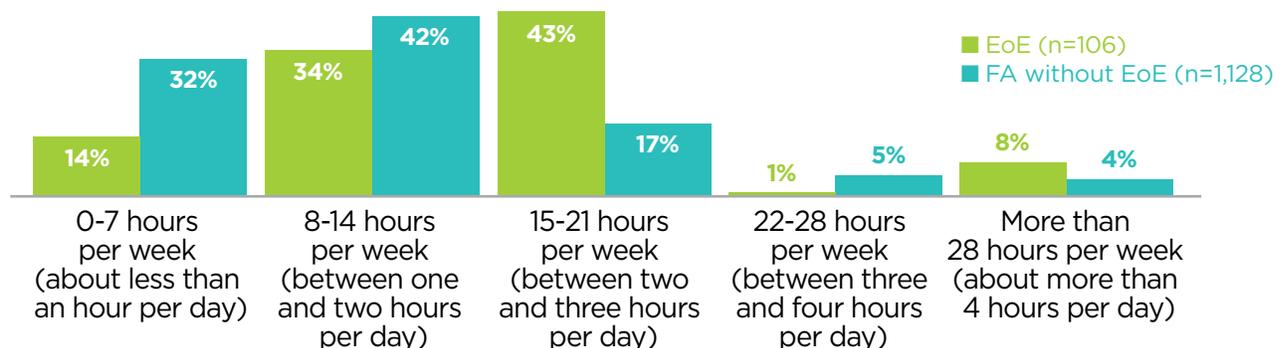
“This new diagnosis [EoE], the inability to move forward with treatment at this time, and the need to go on an elimination diet to work out triggers has impacted our emotional and financial state.” – Parent

“The cost of formula related to her EoE [is a financial burden]. An 18-day supply of amino acid-based formulas is \$260. I worry about how long she’ll need the supplement, and whether or not it will continue to keep weight on her.” – Parent

Parents of children with EoE reported a higher time burden of FA. Across the board, these parents said they spend more time shopping, researching products and preparing food than parents of children with IgE-mediated FA.

Over half (52%) of parents whose child has EoE say they spend 15 or more hours per week managing their child’s food allergy, compared to only 26% of parents whose child has FA without EoE. This includes time spent preparing foods, reading labels, visiting/traveling to doctors and volunteering at school.

TIME SPENT PER WEEK FOR FA



On a five-point scale (with 1 being “not a burden at all” and 5 being “major burden”), 54% of respondents of children with EoE rated the burden of time spent shopping for safe foods as a 4 or a 5 (compared to 38% of parents of children with IgE-mediated FA). On the same scale, 58% of parents of children with EoE rated the burden of time spent preparing/cooking safe foods as a 4 or a 5 (compared to 39% of parents of children with IgE-mediated FA).

TIME BURDEN OF HEALTH CARE (CHOOSE “4” OR “5” ON FIVE-POINT SCALE)

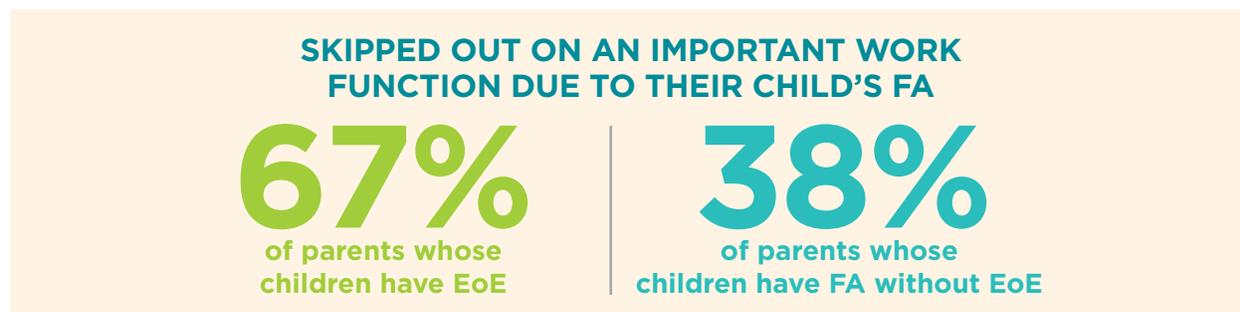


For every question related to the parent’s work, respondents whose children have EoE reported more significant burden of FA. When asked on a five-point scale the impact of their child’s FA on the parent’s work life (1 being “no impact” and 5 being “major impact”), 47% of parents of children with EoE (compared to 34% of parents of children with IgE-mediated FA) responded as a 4 or 5.

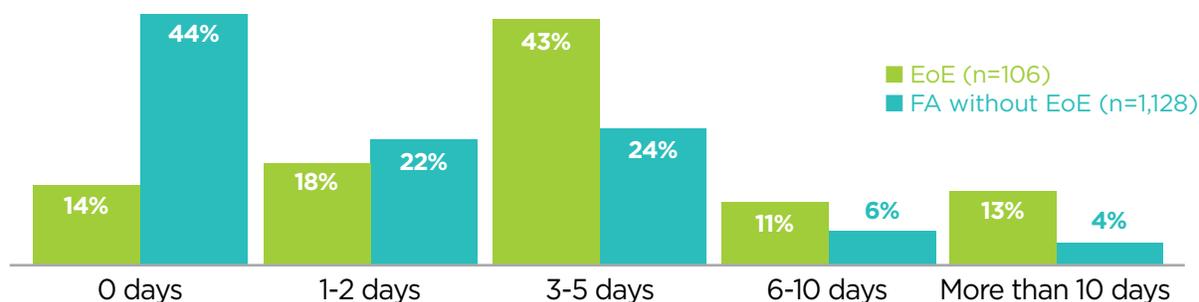
When asked whether they or their spouse had made a career choice in order to care for their child’s FA, 65% of parents of children with EoE confirmed “yes” (compared to 42% of parents of children with IgE-mediated FA).



Additionally, when asked if they have ever skipped out on an important work function due to their child’s FA, 67% of parents of children with EoE confirmed “yes” (compared to only 38% of parents of children with IgE-mediated FA).



MISSED WORK DAYS DUE TO FA (IN PAST 12-MONTH PERIOD)



Eosinophilic esophagitis is a complicated type of food allergy to manage. Parents managing their child’s EoE overwhelmingly report a higher negative impact on their quality of life than parents managing other food allergies.

Families living with eosinophilic esophagitis need emotional and social support, financial assistance/work accommodations and treatment options that are less burdensome and isolating.