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Diet and stress in pediatric eosinophilic esophagitis

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Abstract

Clinical experiences and recent studies suggest that Eosinophilic Esophagitis (EoE) has the potential to induce caregiver (CG) and child stress. The specific sources of CG EoE-related stress remain uncertain. To address this, we performed a survey of CGs and youth attending an EoE patient education symposium that measured potential stressful elements in their daily life. Our results indicated that CGs experienced most stress associated with purchasing, preparation and completion of meals. We conclude that providers should consider this in choosing therapeutic approaches for children with EoE.

Keywords

Eosinophilic oesophagitis; caregiver; children; anxiety; psychosocial stress

Introduction

Eosinophilic Esophagitis (EoE) has become one of the most common causes of feeding problems in children.¹ Management of EoE can involve dietary restrictions, and in some cases, placement of a gastrostomy tube (G-tube). Consequently, children and families can experience decreased health-related quality of life (HRQoL) that often negatively impacts the typically pleasurable activity of eating.²

EoE related stress can also be associated with a delay in diagnosis, persistent symptoms, unsuccessful trials of medications, treatment side effects, dietary restrictions, financial hardships associated with specialized diets and formulas, and the social stigma of eating differently than others.³ One recent study examined 163 CGs of children with all eosinophilic gastrointestinal diseases and found that CG stress was associated with

psychological distress, income, child behavioral problems, treatments, and disease severity.⁴ To date, stress experienced by CGs of patients with only EoE has not been examined.

To begin to address this, we administered a series of surveys to CGs to measure anxiety and stress that was encountered as a part of daily life. The aim of this study was to identify the most stressful elements experienced by CGs of children with EoE.

Methods

During the American Partnership for Eosinophilic Diseases (APFED.org) annual patient education conference, CGs of children between the ages of 2–18 years and youth with a diagnosis of EoE were recruited and compensated to complete paper-and-pencil questionnaires.

CGs responded to 3 questionnaires that asked directly about their emotional state/degree of stress and 3 questionnaires where CGs served as parent proxy by reporting on their child's emotional state. Youth were administered 3 questionnaires.

CG questionnaires included: 1) State-Trait Anxiety Inventory (STAI), STAI-Form Y.⁵ STAI assesses both state anxiety (S-Anxiety) by asking how respondents feel “right now” and trait anxiety (T-Anxiety), which evaluates stable aspects of “anxiety proneness”; 2) Food Allergy Quality of Life – Parental Burden Questionnaire (FAQoL-PB).⁶ FAQL-PB is a 17-item measure that utilizes a 7-point Likert scale ranging from 1 (not troubled) to 7 (extremely troubled). Questions assess burden of food allergies as they relate to CG's perceptions of meal preparation, social activities and food-allergy related worries and anxieties during the previous week; 3) EoE Caregiver Stress Questionnaire (EoE-CGSQ). EoE-CGSQ was developed by the authors, a gastroenterologist (GTF), allergist (DA), pediatric psychologist (JR) and a social worker (CC). EoE-CGSQ is a non-validated, 23-item questionnaire that was developed to capture child health information (e.g., length of time to diagnosis) and areas of stress as reported by CGs caring for children with EoE. It includes 15, 5-point Likert-scale items (1=not at all to 5=severe) and 8 dichotomous (yes/no) items; See Supplement 1.

Youth and CGs as proxies responded to 3 questionnaires: 1) Pediatric Quality of Life Eosinophilic Esophagitis Module Version 3.0 (PedsQL EoE, 3.0)⁷ includes 33-items developed for children ages 2 to 18 years and assesses EoE-specific HRQoL. Higher scores indicate better HRQoL; 2) Revised Child Anxiety and Depression Scale (RCADS).⁸ RCADS is a 47-item, self-report instrument and was selected because it measures specific elements of anxiety and depression that potentially correlate with disease-specific areas of functioning, and; 3) Screen for Child Anxiety Related Disorders (SCARED).⁹ SCARED asks directly about specific features of anxiety and uses a 3-point Likert scale (0 “not true or hardly ever true” to 2 “very true or often true”).

Statistical Analysis

Raw scores were entered into SAS 9.4 for analysis and when appropriate converted to standardized scores according to the measure used. Pearson's correlations were calculated to

assess the relationship between CG and youth psychological distress, EoE-HRQoL and EoE-specific stress factors.

Results

Forty-six families were recruited and 38 CGs, primarily Caucasian (92%) and mothers (84%) ranging in age from 34–44 (39.4: $\pm$ 4.9yrs, SD) years completed surveys. See Table 1. Seventeen youth (mean age 11 years $\pm$ 2.5 SD) participated. The majority of children (N=38, 63% male) experienced a diagnostic delay of over 12 months before receiving a diagnosis of EoE and 41% waited 24 months or longer. Results from the PedsQL-EoE assessment, where higher scores indicate better HRQOL, demonstrated that patients with EoE identified Food/Eating; Food/Feelings, and; Treatment as three areas most impacting HRQOL. Similarly, parent proxy reports also identified Food/Eating and Food/Feelings as most negatively impacting children's HRQOL. See Table 2. When examining stressful elements in patients and CGs lives, issues related to mealtimes and food were prominent. For instance, moderate to severe CG stress was associated with; a) buying and preparing separate foods/meals to fit children's dietary requirements, b) cost of foods to fit dietary requirements, and; c) disruption of family structure at mealtimes. See Table 3. To determine the relationship of mealtimes and food related issues with anxiety, worries and HRQoL, we performed a series of correlations.

To assess the relationship between CG anxiety and food-related factors, correlations between CG STAI-Form Y (S-Anxiety) and the EoE-CGSQ questions were conducted. We found that cost of food [$r(38) = .54$, $p = .0005$], preparation of food [$r(38) = .38$, $p = .02$] and family mealtime structure [$r(38) = .42$, $p = .01$] all correlated with CG State anxiety. Parental burden of meal preparation, social activities and food-allergy related worries as determined by the FAQoL-PB total scores correlated with CG STAI Form Y (S-Anxiety) scores [$r(38) = 0.41$, $p = .03$]. Results from the FAQL-PB questionnaire also determined that CG food-related burden (mean question score = 3.2) was similar to scores typically attributed to the stress of managing a child with three or more anaphylactic food allergies.⁶ Diminished HRQoL among youth correlated with increased anxiety and depression [PedsQL-EoE score correlated with both SCARED Total Score, $r(17)$, -0.69 , $p = < 0.004$ and RCADS $r(17)$, -0.75 , $p = < .0005$.] In fact, 50% of youth reported high frequency worry, anger and sadness related to specialized diets as measured by the PedsQL-EoE subscale of Feelings (Mean $x = 47$).

Discussion

In this study of psychosocial stressors associated with childhood EoE, we found that factors leading to CG anxiety and stress were related to cost of specialized diets, meal preparation and mealtimes. Our results suggest that providers should consider the impact that dietary treatment of EoE may bear upon the family and the unidentified burden associated with this intervention. This study did not inquire about a preexisting diagnosis of CG/youth anxiety or depression, however; our results would suggest that regardless, additional psychosocial support may be needed if diet restrictions are recommended.

Our findings add to a growing body of literature focusing on co-morbid issues related to EoE. With increasing experience, more knowledge is developing regarding not only the natural history of EoE, but also quality of life with the disease and side effects associated with treatment. While previous studies of EoE and youth HRQoL have assessed the impact of restricted diets in the treatment of EoE,⁷ results of our study underscore practical, financial and psychological burdens associated with specialized diets and the impact on CGs. Here we discovered that CG stress was linked to cost of food and preparation, lack of structure at mealtimes, social aspects of eating, and coping with large numbers of allergens. Finally half of youth were impacted by worry, anger and sadness related to specialized diets. Each of these areas of concern can readily be addressed with CGs and patients during decision-making for EoE treatments.

Our study was limited by the fact that this was a patient / CG-based survey and less than half of CGs had corresponding youth reports. Therefore, comparison of patient experience compared to CG experience proves to be tenuous. Moreover, clinical confirmation of a diagnosis was not possible, and specific diet restrictions were not assessed. It is likely that respondents were highly motivated to participate as they were already attending an out-of-town patient education conference. Therefore, results may not reflect the entire EoE related population at large but do provide critical insights into the lives of families who are faced with adhering to diets that could successfully impact clinical and histological features of their disease. Moreover, the majority of patients in our study had been under treatment (e.g., a known diagnosis for greater than 12 months) and therefore their symptom severity could have been attenuated at the time of the study due to established interventions. Future studies should assess children and families within the first 6 months of diagnosis while evaluating symptom severity and perceived stressors, something this study did not allow for as we did not inquire about symptom severity. Established care and intervention could also explain why youth did not list symptoms as one of the top three factors impacting HRQoL. Finally, we used a non-validated tool to assess EoE-specific stress. Since EoE is a relatively new disease, we felt an assessment tool to address features related to EoE was needed to begin to address this emerging issue. Future efforts and studies will be needed to develop validated tools to assess stress more completely in patients and CGs with EoE.

To enhance adherence and improve outcomes, providers should carefully consider and discuss youth and CG attitudes, resources and motivation when prescribing EoE-related diets. Such discussion will lead to improved clinical care and enhanced provider/patient communication regarding interventions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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What is known

Diet treatment is effective in resolving symptoms and inflammation related to EoE.

Adherence to diet can be difficult in some patients with EOE.

What is new

Issues related to dietary treatment of children with EoE creates CG and child stress.

Stressful factors relate, not only to food preparation and cost, but also concerns regarding mealtime structure and exposure to food allergens.

Table 1**Demographic & Clinical Variables**

Parent demographics	
Female	84.2 %
Mother of child	84.2%
Mother's Age (years; mean $\pm$ SD)	39.4 $\pm$ 4.9
Father's Age	39.8 $\pm$ 5.0
Caucasian	92.1%
Married	78.9 %
Mother's Education	
Some post high school	15.8%
Bachelor's Degree	36.8%
Master's Degree	29.0 %
Doctoral Degree	18.4%
Father's Education	
Some post high school	27.8%
Bachelor's Degree	30.6%
Master's Degree	22.2 %
Doctoral Degree	19.4%
Child demographics	
Male	63.2 %
Age	7.8 $\pm$ 3.9
Ethnicity	
Caucasian	92.1 %
African American or Black	5.3 %
Asian	2.6 %
Native Hawaiian or	5.3 %
Other Pacific Islander	
American Indian	5.3 %
Other	2.6 %
Child clinical variables	
Months from symptoms to formal diagnosis	
0–6 months	13.2 %
6–12 months	10.5 %
12–24 months	34.2 %
24–48 months	26.3 %
over 48 months	15.8 %
Months with formal diagnosis	
6–12 months	10.5 %
12–24 months	23.7 %
24–48 months	26.3 %
over 48 months	39.5 %

TABLE 2

PedsQL-EoE Health-Related QoL: Caregivers and EoE patients

Child Self-Report			
EoE Scale	n	Mean	SD
EoE Total Score	17	50.0	19.9
Symptom I	17	52.0	19.2
Symptoms II	17	61.1	25
Treatment	17	46.8	24.4
Worry	17	55.6	30.9
Communication	17	55.0	21.9
Food/Eating	17	53.3	33.2
Food/Feelings	17	45.6	34.2
Parent Proxy-Report			
EoE Scale	n	Mean	SD
EoE Total Score	26	61.1	19.8
Symptom I	26	55.3	24.5
Symptom II	26	62.5	27.9
Treatment	26	65.6	30.5
Worry	26	63.1	27.5
Communication	18	60.5	23
Food/Eating	26	40.7	18.1
Food/Feelings	26	52.6	25.5

Stress associated with EoE

TABLE 3

	Not at all	Somewhat	Moderate	Significant	Severe
<i>1. How stressful do you find the following since your child's diagnosis of EoE?</i>					
Family structure at mealtimes	13.5%	21.6%	16.2%	<u>32.4%</u>	16.2%
Buying and cooking separate foods/meals for your child	2.6%	21.1%	21.1%	<u>31.6%</u>	23.7%
Financial strain due to medical appointments	<u>26.3%</u>	15.8%	21.1%	21.1%	15.8%
Financial strain due to cost of buying food that fits diet	10.5%	21.1%	18.4%	23.7%	<u>36.3%</u>
Financial strain due to cost of medications	<u>28.9%</u>	18.4%	15.8%	23.7%	13.2%
<i>2. How stressful was it for your child to experience symptoms without a formal diagnosis of EoE?</i>					
	10.5%	7.9%	13.2%	<u>36.8%</u>	31.6%
<i>3. How much control do you feel your child's EoE has on your life?</i>					
	2.6%	7.9%	23.7%	<u>39.5%</u>	26.3%
<i>4. How much do you feel your current stress level has worsened due to your child's EoE?</i>					
	2.6%	7.9%	21.1%	<u>42.1%</u>	26.3%
<i>5. What is your current stress level in response to your child's EoE?</i>					
	2.6%	15.8%	36.8%	<u>42.1%</u>	2.6%
<i>6. Do your feel your child's EoE has affected your marital relationship?</i>					
	<u>37.8%</u>	18.9%	21.6%	10.8%	10.8%

N= 38 respondents, Underlined percentages represent the largest frequency of responses for each questions