Preliminary Evaluation of Maternal Caregiver Stress in Pediatric Eosinophilic Gastrointestinal Disorders

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Objective   To characterize caregiver stress (CS) in parents of children with Eosinophilic Gastrointestinal Disorders (EGIDs) and understand relationships with psychological functioning and child behavior.
Methods   Caregivers with a child (0–17 years) with EGID completed questionnaires for demographics, EGID severity, treatments, CS, psychological distress, self-efficacy, and child behaviors.   **Results**   A total of 163 caregivers (98% mother, 94% Caucasian) participated. CS correlated with psychological distress, income, child behavioral problems, treatments, and disease severity. Children were rated higher than age-specific norms for emotional difficulties. Behavioral difficulties associated with gender, age, EGID severity, and duration. Parent psychological distress was most strongly associated with CS. Parental self-efficacy, dietary treatments, and child emotional difficulties were also related to stress.   **Conclusions**   Mothers reported stress and psychological distress from caring for a child with EGID. The relationship between these variables suggests these parents may benefit from supportive psychotherapy interventions. Evaluation of parental self-efficacy and child behavior is also warranted.

Key words   child behavior; eosinophilic gastrointestinal disorders; parental caregiver stress; psychological functioning.

Introduction

Eosinophilic Gastrointestinal Disorders (EGIDs) are chronic diseases of the digestive system, characterized by inflammation due to an increase in the number of *eosinophils* (white blood cells) in the mucosal lining of the gastrointestinal tract. When there is a disruption to the gastrointestinal environment, eosinophils engulf and kill harmful bacteria. In EGID patients, eosinophils fail to die off after they complete this process and instead permeate the mucosal lining of the gut, leading to gastrointestinal symptoms, tissue damage and chronic inflammation. Variations of eosinophilic disorders depend on the location of eosinophil infiltration and include: Esophagitis (esophagus), Gastritis (stomach/intestinal tract), Enteritis (small intestine), Gastroenteritis (diffuse throughout GI tract), and Colitis (large intestine) (Oh & Chetty, 2008; Verheijden

& Ennecker-Jans, 2010). Some common EGID symptoms are abdominal pain, diarrhea, acid reflux, dysphagia (difficulty swallowing), nausea, and vomiting (Kelly & Hewson, 2000). Symptoms vary depending on the location of the disease as well as the age of the patient (Eroglu et al., 2009; Liacouras, 2003; Spergel et al., 2009).

Over the past decade, EGIDs have gained increasing attention due to steadily rising global prevalence (Franciosi, 2009; Noel, Putnam, & Rothenberg, 2004). The majority of these data are for Eosinophilic Esophagitis (EoE), with considerably less information available for the other EGID subtypes. Pediatric EoE occurs in approximately four out of every 10,000 children (Noel et al., 2004). The age of initial diagnosis varies widely (0–18 years, mean 6.2 years), with higher rates in Caucasians (84%) and males (75%). (Assa'ad et al., 2007;

Eroglu et al., 2009; Franciosi, Tam, Liacouras, & Spergel, 2009; Spergel et al., 2009). Accurate EGID diagnosis can be challenging, often requiring patients to undergo several invasive procedures including food allergy testing, colonoscopy, or upper endoscopy.

Current EGID treatments are intensive, require significant parental monitoring, and are not always satisfactorily effective (Liacouras, 2003; Liacouras et al., 2011). These aim to reduce exposure to antigens that would disrupt the gastrointestinal environment and cause eosinophils to proliferate. Given the high incidence of food sensitivities in EGID patients, many treatments target inflammatory reactions to food antigens. Corticosteroid treatment or steroid-sparing agents directly target the inflammation in the gut (Liacouras, 2003; Oh & Chetty, 2008). Dietary treatments include food elimination, formula-based diets, and gastric tube feedings (Assa'ad, 2009; Pratt, Demain, & Rathkopf, 2008). Food introduction trials involve elimination of the top eight allergy-producing foods (dairy, soy, eggs, wheat/gluten, peanuts, tree nuts, fish, and shellfish) for a period of several weeks followed by a systematic reintroduction of one food at a time to the child's diet. In some children, additional foods are involved in invoking inflammatory responses, creating a longer and more complicated reintroduction trial.

The behavioral and psychological consequences associated with pediatric chronic illness are widespread (Farnik et al., 2010; Klinnert, 2009; Wiedebusch et al., 2010). Chronically, ill children often display increased behavioral and psychological problems as a result of their condition (Hysing, Sivertsen, Stormark, Elgen, & Lundervold, 2009; Louis-Jacques & Samples, 2011; Reynolds & Helgeson, 2011). Caregivers of these children report lower quality of life, greater personal health concerns (Brehaut et al., 2009; Farnik et al., 2010; Murphy, Christian, Caplin, & Young, 2007), limit their activities, and have increased depression, marital issues, and family problems (Brehaut et al., 2009; Murphy et al., 2007).

Based on the intensity of EGID symptoms and treatments, we expect similar challenges to be present in this population. Adult EGID patients report challenges in managing their illness that adversely impact health-related quality of life (Taft, Kern, Keefer, Burstein, & Hirano, 2011; Taft, Kern, Kwiatek, et al., 2011). A recent pediatric study found that both parents and children have multiple disease-specific concerns about managing an EGID (Franciosi et al., 2011). These concerns differed from general measures of quality of life, highlighting the need to investigate the unique experiences of children with EGIDs and their parents.

To date, no study has evaluated the role of caregiver stress (CS) in children with EGIDs. Understanding this phenomenon in these patients is important since poor caregiver health and distress has a direct impact on the child, including more hospitalizations (Kelly & Hewson, 2000), more functional disability (Streisand, Swift, Wickmark, Chen, & Holmes, 2005), and possibly more behavioral problems (Hilliard, Monaghan, Cogen, & Streisand, 2011). As CS is often associated with increased psychological distress (Hauenstein, 1990; Yee & Schulz, 2000) and may be mediated by levels of perceived self-efficacy (Keefe et al., 2003; Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999), it is important to assess these factors when understanding CS in this population. The main goals of this study are to: (a) characterize CS, psychological distress and self-efficacy in parents of children with EGIDs; (b) characterize behavioral difficulties in children with EGIDs; and (c) evaluate the relationships between CS, psychological distress, self-efficacy, and child behavior.

Patients and Methods
Participant Recruitment
Caregivers aged 18–70 years with a child between the ages of 0 and 17 years diagnosed with an EGID were recruited via two patient advocacy groups: (a) the American Partnership for Eosinophilic Disorders website (http://www.apfed.org) parent support group listing and (b) The Campaign Urging Research for Eosinophilic Disease Foundation. Support group administrators were emailed with study information to disseminate to group members. Parents of either gender who were responsible for caring for the child with EGID met inclusion criteria outlined in the recruitment email. Nineteen support groups located across the United States received the initial inquiry. Of these, twelve (63%) responded and agreed to share the study information with group members, two email addresses were invalid, and 5 did not respond to the initial contact. This study was approved by the institutional review board of Northwestern University.

Demographic and Clinical Backgrounds
A total of 192 caregivers consented and 163 completed study measures (Completion rate = 85%). Demographic and clinical data (Table I) were normally distributed with the exception of parental education. Thirty-one children (19%) were under the age of 3 years. Most children in this sample used EGID medications, with 54% using a proton pump inhibitor (e.g. omeprazole), 45% oral or inhaled steroids, 27% Montelukast, and 25% an acid reducer. Dietary therapies were common, with more than half

Table I. *Sample Demographic & Clinical Variables*

Variable	$N = 163$
Parent demographics	
Female	98%
Mother to child	98%
Age (years; mean ± SD)	38.5 ± 7.0
No. of children with EGID	
1	83%
2	15%
3 or more	2%
Caucasian	94%
Non-Hispanic	98%
Married/cohabitating	90%
Education (years)[a]	16.0
Family Income	
$10 K–$40 K	23%
$41 K–$85 K	36%
>$85 K	41%
Urban/suburban dweller	83%
Child demographics	
Male	72%
Age	7.7 ± 5.1
Grade in School	
PreK or Earlier	45%
1–6	31%
7–12	24%
>9 Missed School Days	37%
Child clinical variables	
EGID Dx (years)	6.1 ± 4.0
>12 months to Dx	50%
Have EGID Symptoms Every Day	45%
Recent Flare Severity (out of 10)	6.0 ± 2.6
No. of food sensitivities	12.1 ± 8.0
Current remission	28%
No. of medications	
1–3	64%
4–9	20%
>4 Procedures (past year)	27%
>4 MD appointments (past year)	85%
Dietary treatments (last 30 days)	
Elimination diet	58%
Elemental diet	22%
Elemental formula diet	51%
Food reintroduction trial	35%
Feeding tube use (last 30 days)	23%

[a]Nonnormal distribution presented as median.

using one in the past 30 days, and 23% utilizing a feeding tube within this timeframe.

Measures

All participants completed online questionnaires. Caregivers self-reported all information about themselves

and one child with EGID. Cookies were used to prevent participants from completing the survey more than once, with Internet protocol address logging and review to identify duplicate entries for removal.

Caregiver Demographic Information
Gender, relationship to child, ethnicity, race, age, marital status, education, family income, and town population.

Child Information
Gender, age, school grade, number of years with EGID, months from symptom presentation to receive diagnosis, number of food sensitivities, all EGID symptom frequency in a given week, remission status, most recent flare severity (scale of 1 ''most mild'' to 10 ''most severe''), current medications, and dietary therapies including a general question about the child being on a restricted diet for EGID in the last 30 days. Number of missed school days, doctor visits, procedures, and emergency room visits in the past year were collected.

CS
Caregivers completed the Pediatric Inventory for Parents (PIP), a 42-item self-report measure of frequency of and difficulty with various caregiver-specific stressors over the last 7 days. These are categorized by Communication, Emotional Functioning, Medical Care, and Role Function (Streisand, Braniecki, Tercyak, & Kazak, 2001). The PIP yields four subscale scores, a total frequency score, and total difficulty score with higher scores indicating greater CS. The PIP demonstrates excellent reliability (α from .80 to .96) and validity across several illness groups and is considered a ''well-established'' measure by evidence-based assessment standards (Alderfer et al., 2008). The PIP demonstrated excellent internal consistency in this sample (Cronbach's α: Frequency = 0.95, Difficulty = 0.95).

Caregiver Psychological Distress
The Brief Symptom Inventory-18 (BSI-18) measured caregivers' psychological distress, yielding a global severity index and three symptom scales: depression, anxiety, and somatization (Derogatis & Melisaratos, 1983). Higher scores indicate more distress. The BSI-18 demonstrates good reliability (Cronbach's α for global severity = 0.89; somatization = 0.74; depression = 0.84; anxiety = 0.89) and validity. For the current sample, Cronbach's α values for the global scale (0.92) and each subscale ($S = 0.82$, $D = 0.86$, $A = 0.86$) were good. Established clinical cutoff scores for significant pathology are ≥ 13 for women and ≥ 10 for men on all subscales (Derogatis, 2000).

Caregiver Self-Efficacy

The General Self-Efficacy Scale (GSES) measured caregivers' belief in their ability to cope with a variety of difficult life demands (i.e. perceived self-efficacy). Ten items are answered via a 4-point Likert scale. The GSES is available in 30 languages and is a widely used unidimensional measure of general perceived self-efficacy. The GSES consistently demonstrates excellent reliability (α from .76 to .90) and validity (Schwarzer, 1995) across multiple cultures (Scholz, Dona, Sud, & Schwarzer, 2002). Reliability statistics for the current sample were consistent with previously reported data (Cronbach's $\alpha = 0.89$). Normative data are available for a US sample of 1,594 adults.

Child Behavioral Difficulties

The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) measured behavioral attributes of the child with EGID as perceived by the participant caregiver. The SDQ is a 25-item measure with five subscales: Emotional Symptoms, Conduct Problems, Hyperactivity/Inattention, Peer Relationship Problems, and Prosocial Behavior. There are three age-specific versions to the SDQ (3–4, 5–10, and 11–17 years). Normative data for the SDQ are available by age and country. The SDQ demonstrates acceptable reliability (subscale α from .51 to .76) and validity. In the current sample, Cronbach α scores for each subscale were adequate (Emotional = 0.69, Conduct = 0.60, Hyperactive = 0.84, Peer = 0.60, Prosocial = 0.68).

Data Analysis

Raw scores were exported from the online system and entered into the Statistical Package for the Social Sciences v19 (IBM-SPSS, Chicago IL, USA) for analysis. Data were sufficiently powered ($\geq$.80) for all analyses). Preliminary tests for normal distribution, outliers, and missing data were conducted. Independent measures t-tests and one-way ANOVA with Tukey's HSD post hoc testing evaluated differences between demographic groups on dependent variables. To ensure that parents of children under 3 years had sufficient experience with caring for a child with EGID, we divided the sample (0–2 years vs. 3 or more years of age) and compared the mean results for the PIP, BSI-18, and GSES via independent samples t-tests. No significant differences for outcome measures were found between the two age categories; thus all parents were included in analyses using these scales. We removed those children under the age of 3 years from analyses using the SDQ, since it is only validated for children aged 3 years and older. Pearson's correlations and stepwise multiple

regressions evaluated the relationships between CS and psychological distress, self-efficacy, and child behavior.

Results

Parental CS, Psychological Distress, and Self-Efficacy

Mothers reported CS related to caring for a child with an EGID. Unmarried parents reported greater frequency of, $t(154) = -3.10$, $p = .002$), and difficulty with, $t(148) = -2.98$, $p = .003$, 95% CIs (-47.9 to -10.5) and (-44.4 to -9.0] CS. Those from households with lower income reported greater difficulty with CS, $F(8,148) = 2.43$, $p = .02$. Significant differences for CS were not found for parent age and education level. Increased CS was associated with higher psychological distress and lower self-efficacy (Table II). Several caregivers reported psychological distress above BSI-18 clinical cutoff scores, including approximately 25% reporting significant depression and somatization and 50% reporting significant anxiety. Caregivers had similar levels of perceived self-efficacy as U.S. normative controls.

Child Behavior

Children with an EGID were rated as having greater emotional difficulties (borderline or abnormal range) than US normative controls (Table III). Females demonstrated more emotional difficulties than males (Mean $\pm$ SD; 5.4 ± 2.6 vs. 4.4 ± 2.5), $t(136) = -2.02$, $p = .046$, 95% CI (-2.0 to -0.02), as did children not in remission (5.1 ± 2.4 vs. 3.7 ± 2.7), $t(136) = 3.02$, $p = .003$, 95% CI (0.48 to 2.3). Children aged 11 years and older rated poorer for peer problems while children under the age of 8 years exhibited more and hyperactivity/inattention. All age groups fell within the "Normal" range for conduct problems and prosocial behavior, although significantly lower than peers. Behavior ratings correlated with several child demographic and clinical variables (Table IV) including the number of procedures the child has had, time since the EGID diagnosis, and symptom severity.

Predictors of CS

Next, we analyzed the relationships between parent and child variables and CS frequency and difficulty via Pearson's correlations. Those with statistical significance at or below .05 were entered into a series of stepwise hierarchical regression models. Model 1 evaluated the relative contributions of parent and child variables to the frequency of CS; Model 2 repeated this regression with difficulty with CS as the criterion (Table V). For each model, Step 1 included the significantly correlated parent demographic

Table II. *Means, Standard Deviations and Intercorrelations for CS, Psychological Distress, and Self-Efficacy Scores*

Variable	M (SD)	Norm†	1	2	3	4
1. CS (PIP) Frequency—Total[e]	133.0 (32.2)	N/A	–	.69**	.57**	−.27**
Communication[a]	18.6 (4.8)					
Emotional function[b]	54.8 (12.5)					
Medical care[c]	26.1 (9.1)					
Role function[d]	34.6 (8.8)					
2. CS (PIP) Difficulty—Total[e]	135.4 (31.0)	N/A		–	.61**	−.26**
Communication[a]	17.1 (5.1)					
Emotional function[b]	55.3 (12.3)					
Medical care[c]	28.2 (8.0)					
Role function[d]	34.8 (8.9)					
3. Psychological distress (BSI-18)—Total[h]	34.0 (13.0)	≥ 13.0			–	−.24**
Depression[f]	11.1 (5.1)	28%				
Anxiety[g]	13.2 (5.6)	46%				
Somatization [g]	9.8 (4.3)	20%				
4. Perceived Self-Efficacy (GSES) [i]	31.1 (4.8)	29.5 ± 5.1				–

Note. Maximum possible score: [a]30, [b]80, [c]45, [d]55, [e]210, [f]25, [g]30, [h]85, [i]40.

†BSI-18: 1,122 (517 female) US adults. Established clinical cutoff score of 13.0 for female respondents on each subscale. GSES: 1,594 (49.1% female) US adults.

PIP: normative data not currently available.

*P ≤ .05, **P ≤ .01.

variable (marital status), psychological distress, and self-efficacy; Step 2 included significantly correlated child demographic and clinical variables (recent flare severity, feeding tube use, number of medications, elemental formula use, elemental diet use); Step 3 included significantly correlated child behavior variables.

Parental psychological distress, child EGID flare severity, and child emotional difficulties remained significant predictors of both frequency and difficulty with CS. Psychological distress demonstrated the greatest predictive weight, accounting for 38% of the variance in frequency, and 44% of the variance in difficulty. Using a feeding tube as treatment for the EGID predicted frequency but not difficulty with CS, and parental self-efficacy showed a negative predictive relationship with frequency of CS.

Discussion

The EGIDs are emerging chronic conditions with an increasing prevalence in the past decade, garnering much needed attention to optimize their diagnosis and medical management. Only within the last year has focus shifted to include the psychosocial impact EGIDs may have. Our findings demonstrate a multifaceted relationship between the clinical presentation of the EGID, its treatment, CS, and child behavior. Mothers in the current sample appear to be experiencing significant CS and burden associated with these illnesses, warranting further inquiry in this area.

Certain demographic traits make caregivers more susceptible to CS, such as the child's gender (Holden, Chmielewski, Nelson, Kager, & Foltz, 1997), parent's age (Canning, Harris, & Kelleher, 1996), and socioeconomic status (Canning et al., 1996; Holden et al., 1997). We found lower family income and not being married were associated with increased CS. This may be due to costs often associated with EGID treatments, such as purchasing allergen-free foods or shopping at specialty stores (Taft, Kern, Keefer, et al., 2011), or increased costs from formulas, medications, or insurance copayments for multiple contacts with the medical system. Since our sample was mothers of children with EGIDs, CS may be associated with balancing work, home, and childcare responsibilities.

A modest percentage of caregivers had significant levels of psychological distress and decreased perceived self-efficacy, both associated with greater CS. These findings are similar to those identified among parents of children with Type 1 diabetes (Streisand et al., 2005). Parents of children with an EGID may benefit from interventions targeting comorbid depression or anxiety which may be impacting their ability to cope effectively with CS. Treatments should also seek to improve parental self-efficacy, especially as it relates to managing their child's EGID.

We also sought to evaluate parent-rated behavior in children with EGIDs. The greatest difference found when compared to same-age peers was for emotional difficulties across all age groups. Younger children were rated higher

Table III. *SDQ Scores of Children With EGID Versus 9,878 Normative Controls[a] (United States) by Age Group*

SDQ Scale	Age group	U.S. norms[b]	EGID children[c]	P	95% CI	EGID class
Emotional difficulties	4–7	1.5 ± 1.7	4.1 ± 2.5	All	−2.9 to −2.3	Borderline
	8–10	1.5 ± 1.9	4.9 ± 2.8	<.00001	−1.2 to 0.4	Abnormal
	11–14	1.7 ± 2.0	5.3 ± 1.9		−3.9 to −3.3	Abnormal
	15–17	1.5 ± 1.8	5.4 ± 2.6		−4.2 to −3.6	Abnormal
Conduct problems	4–7	1.4 ± 1.6	2.3 ± 1.9	<.00001	−1.2 to −0.6	Normal
	8–10	1.3 ± 1.7	2.2 ± 1.3	<.01	−1.2 to −0.6	Normal
	11–14	1.4 ± 1.8	2.6 ± 2.0	<.001	−1.5 to −0.9	Normal
	15–17	1.2 ± 1.5	1.9 ± 1.4	<.03	−0.9 to −0.5	Normal
Hyperactivity inattention	4–7	3.2 ± 2.5	6.0 ± 3.0	All	−3.2 to −2.4	Borderline
	8–10	2.9 ± 2.6	5.4 ± 2.9	<.00001	−2.9 to −2.1	Normal
	11–14	2.7 ± 2.6	4.8 ± 3.0		−2.5 to −1.7	Normal
	15–17	2.3 ± 2.2	4.0 ± 3.2		−2.1 to −1.3	Normal
Peer problems	4–7	1.3 ± 1.5	2.2 ± 1.9	<.00001	−1.1 to −0.7	Normal
	8–10	1.5 ± 1.6	2.2 ± 1.5	<.03	−1.0 to −0.5	Normal
	11–14	1.4 ± 1.6	2.7 ± 2.1	<.00001	−1.6 to −1.0	Borderline
	15–17	1.4 ± 1.5	2.9 ± 2.0	<.0001	−1.7 to −1.3	Borderline
Prosocial behavior	4–7	8.4 ± 1.9	7.4 ± 1.8	<.0002	5.4 to 7.6	Normal
	8–10	8.8 ± 1.7	7.7 ± 1.6	<.001	0.8 to 1.4	Normal
	11–14	8.7 ± 1.8	7.7 ± 1.6	<.0004	0.7 to 1.3	Normal
	15–17	8.7 ± 1.6	7.5 ± 1.8	<.0003	0.9 to 1.5	Normal

[a]U.S. normative controls. Data obtained from the National Health Interview Survey (NHIS) conducted by the Centers for Disease Control in 2001. A total of 91% of reporters were parents.
[b]Sample size for normative age groups: 4–7, n = 2779; 8–10, n = 2064; 11–14, n = 2770; 15–17, n = 2265.
[c]Sample size for experimental age groups: 4–7, n = 58; 8–10, n = 27; 11–14, n = 28; 15–17, n = 25.

Table IV. *Correlations between Child Demographic and Clinical Characteristics and Behavioral Ratings*

Child variable	ED	HI	PP	CP	PB
Age	.26**	−.27**	.08	−.11	.19*
Years with EGID	.16*	−.09	−.06	−.07	.22**
No. of food allergies	−.02	.22**	.04	.08	−.15
Recent Flare Severity	.19*	.11	.18*	.14	−.02
No. of procedures past year	.02	.09	−.10	.19*	−.19*
No. of MD visits past year	.26**	.06	.09	.10	−.23**

Note. ED = emotional difficulties; HI = hyperactivity inattention; PP = peer problems; CD = conduct problems; PS = prosocial behavior.
*P ≤ .05, **P ≤ .01.

for hyperactivity-inattention, while older children demonstrated greater peer problems. While within the normal range, children with EGID demonstrated lower prosocial behavior and greater peer rejection than their peers. Parents may perceive their child is different from peers and thus attempt to protect their child by limiting social interactions. Alternatively, parents may see their child as being left out or avoidant of social events due to food restrictions that may make socializing challenging (Franciosi et al., 2011). Children with EGIDs may be susceptible to peer rejection due to being judged based on their illness status (Alderfer, Wiebe, & Hartmann, 2001),

with children with more severe EGID symptoms or intrusive treatments experiencing greater peer rejection (Alderfer, Wiebe, & Hartmann, 2002). Cumulatively, these factors could lead to decreased social behavior in these children. Psychosocial interventions with these children should consider age-specific issues, whereas addressing overall emotional difficulties that are likely to be present.

Congruent with other pediatric illnesses such as cerebral palsy (Sipal, Schuengel, Voorman, Van Eck, & Becher, 2010), asthma, abdominal pain, and headaches (Feldman, Ortega, Koinis-Mitchell, Kuo, & Canino,

Table V. *Stepwise Multivariate Analyses of Parental and Child Predictors of CS*

Predictor variables	CS–frequency				CS–difficulty			
	r	R^2 *Adj*	$\triangle R^2$	β	*r*	R^2 *Adj*	$\triangle R^2$	β
Parent variables (Step 1)								
Global BSI-18	.58**	.36	.37	.60	.61**	.43	.43	.66
Self-efficacy	−.29**	.38	.02	−.15	−.26**			
Unmarried	.24**	.39	.02	.14	.24**			
Disease variables (Step 2)								
Recent Flare Severity	.26**	.45	.03	.15	.26**	.44	.01	.11
Feeding tube use	.21*	.43	.04	.19	.15			
No. of medications	.18*				.10			
Elemental formula	.18*				.15			
Elemental diet	.17*				.15			
Child behavior (Step 3)								
Emotional difficulty	.26**	.46	.01	.12	.25*	.46	.01	.10
Conduct problems	.16				.18*			
Hyperactivity	.09				.07			
Peer problems	.14				.14			
Prosocial behavior	−.16				−.13			

Betas reported are from the step at which the variable was entered into the equation.

*$P < .05$, **$P < .01$.

2010), CS is related to child behavior in this population. Children with EGIDs exhibiting greater emotional difficulties and conduct problems have parents who report greater CS. Conversely, children rated higher in prosocial behavior have parents with lower CS levels. Based solely on parent ratings, we cannot conclude children with EGID actually have greater behavioral problems or if parent CS and psychological distress influence perceptions of their child's behavior (Hilliard et al., 2011). Further inquiry into this relationship is warranted.

There are some limitations to this study to consider when interpreting its results. This study utilized a cross-sectional, nonexperimental design, and relied on self-report data from a single informant. Future studies utilizing prospective or longitudinal designs with input from multiple people in contact with the child would provide more in depth explanations of the preliminary relationships we have identified. We recruited caregivers from regional support group members with 100% online participation. It is possible these caregivers are more distressed or utilize coping strategies that differ from parents who do not use support groups. Parents seek support groups when their child exhibits more severe behavioral problems (Mandell & Salzer, 2007) or to gain information about their child's condition and available services (Koroloff & Friesen, 1991). Since EGIDs are emerging conditions, parents who join support groups may have less access to information about their child's condition, which could exacerbate CS levels. To improve generalizability of study findings, participants should be recruited via other sources such as outpatient pediatric general practice and pediatric gastroenterology clinics.

The study sample is essentially Caucasian mothers of children with an EGID, with the majority having a college education and all having Internet access thereby reflecting a sample likely from a higher socioeconomic status. Caution should be taken in applying these results to fathers and caregivers of other racial or ethnic backgrounds or those with less educational attainment. We did not differentiate between EGID diagnoses so we are unable to evaluate any potential differences by disease location. Current epidemiological data on EGIDs are evolving and vary by diagnosis, with eosinophilic esophagitis (EoE) being more prevalent in Caucasian males but eosinophilic gastroenteritis (a much rarer condition than EoE) being evenly distributed by gender and ethnicity; our sample paralleled EoE epidemiology data.

As the medical management of EGIDs evolves, it is important to acknowledge the role CS, psychological distress, or child behavior problems may have in outcomes, especially in refractory cases. Future research should seek to replicate these findings in more diverse samples and investigate interventions that may mitigate CS in EGIDs. Interventions should aim to alleviate parent CS and psychological distress via empirically supported methods (e.g., CBT, family systems therapy). Psychological treatment should also take into account the child's EGID symptom severity and treatment regimens. Specifically, parents of

children using a feeding tube, on a greater number of medications, or being treated with an elemental diet may be at the highest risk for CS. Health care providers should be mindful of the effects of EGID treatments on both caregivers and the child and take care to engage the primary caregiver in the diagnostic and treatment processes.

Funding

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