Behavioral feeding problems and parenting stress in eosinophilic gastrointestinal disorders in children

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Keywords
adherence; compliance; eosinophilic esophagitis; feeding behavior; psychosocial.

Abstract

Background: Children with eosinophilic gastrointestinal disorders (EGID) and their families are asked to adhere to dietary restrictions which can present significant daily challenges. However, little is known about child and family functioning and adaptation and the impact of psychosocial functioning (e.g., behavioral feeding problems) on adherence to dietary restrictions in this pediatric population.

Methods: We conducted a gender- and age-matched case-control study wherein parents of children with EGID and healthy control children completed measures of behavioral feeding problems, parenting stress, and adherence to prescribed dietary restrictions.

Results: Children with EGID (n = 92) have significantly higher levels of behavioral feeding problems than healthy controls (n = 89; t = 5.7, p < 0.001; t = 7.9, p < 0.001). In particular, younger children demonstrated higher levels of behavioral feeding problems than older children. While behavioral feeding problems were not predictive of adherence to dietary restriction recommendations, they were positively associated with parenting stress.

Conclusions: The study results indicate that, for families caring for a child with EGID, higher levels of behavioral feeding problems are associated with parent maladjustment or dysfunction. A multidisciplinary treatment team is needed to provide comprehensive psychosocial and feeding evaluations and treatment in EGID families.

A growing literature has documented the pathology, genetics, and symptoms associated with eosinophilic gastrointestinal disorders (EGID; 1, 2). Children with EGID and their families are asked to adhere to a challenging treatment regimen, which can include medication and dietary modifications, such as tube feedings, dietary restrictions, and/or elemental diet (3). These dietary regimens may present significant challenges in children’s daily lives. Food choices at school and with friends, participation in social events (e.g., birthday parties), and ability to be in the presence of allergenic foods can all be impacted.

Despite the demanding treatment regimen, only a small literature has examined the adaptation of children with EGID and their families (4, 5). We previously reported that children with EGID have difficulty adhering to both medication and dietary regimens (6). Prior research has also demonstrated that children with EGID have worse psychosocial functioning and health-related quality of life than healthy children and children with other chronic medical conditions (4, 5). In addition, we have identified dietary restrictions as important concerns for both children with EGID and their parents (4, 5, 7). However, little is known about child and family behavioral functioning specifically related to the demanding dietary regimen to which families are expected to adhere. The literature on family adaptation to dietary restrictions for other medical conditions (e.g., diabetes, cystic fibrosis) indicates that those children display elevated levels of behavioral feeding problems which are associated with...
increased parenting stress (8, 9). Parenting stress is an important component of family functioning as it is related to poor medical and social outcomes, such as greater post-treatment disease activity among Crohn’s patients, poor expressive language development, and greater child behavioral problems (10–12).

For children with EGID, at least a subset exhibit problematic feeding behaviors (13, 14). However, prior studies relied on retrospective chart reviews of children with more severe feeding difficulties (e.g., diagnosed with a feeding disorder) and were unable to compare children with EGID to healthy control children. Thus, the potential range in behavioral feeding problems and the extent to which children with EGID demonstrate feeding problems above and beyond their peers have not been examined. Further, no studies have examined the extent to which feeding problems among children with EGID are related to dietary adherence or family behavioral factors such as parenting stress.

In an effort to address the aforementioned limitations in the current literature, the objectives of this study were the following: (i) to compare behavioral feeding problems among children with EGID as compared to healthy children, (ii) to examine whether behavioral feeding problems among children with EGID affect adherence to dietary restrictions, and (iii) to examine whether behavioral feeding problems are associated with parenting stress among families of children with EGID. We hypothesized that children with EGID would have higher levels of behavioral feeding problems than healthy control children, that increased behavioral feeding problems in children with EGID would negatively impact adherence to dietary restrictions, and that increased behavioral problems would be significantly related to higher parenting stress.

Methods

Participants and procedures

Participants were patients seen in the Cincinnati Center for Eosinophilic Disorders at Cincinnati Children’s Hospital Medical Center (CCHMC) and their caregivers, who were recruited in clinic or at an educational conference for patients with EGID and their families. Patients were eligible if they were between the ages of 2.5 and 18 yr and had a primary diagnosis of EGID, including eosinophilic esophagitis (EoE) or eosinophilic gastroenteritis (EGE). Criteria for EGID were based on previously reported histologic criteria (15). As there are many families burdened with EGID beyond the most studied subsample, EoE, we felt it necessary to also include children with EGE in order to capture an expanded range of EGID conditions. Exclusion criteria were diagnosis of severe developmental delay or a chronic health condition other than EGID (e.g., asthma). A chart review was conducted to confirm whether patients met eligibility criteria. In total, 41 children with EGID were excluded from participation based on the eligibility criteria, and 10 children (from nine families) refused to participate. Healthy comparison children were recruited from several sources: a CCHMC clinical trials database of families with healthy children who agreed to contacts about research opportunities, patients in the CCHMC Division of Pediatric Dentistry and Orthodontics seeking routine dental care, and advertisements sent to CCHMC employees. Eligibility criteria for healthy children included no history of chronic illness and no current acute illness.

After providing informed consent, children and caregivers completed study questionnaires and, if needed, were given postage-paid envelopes to return completed questionnaires. Healthy comparison children were gender- and age-matched (± 2 yr) to children with EGID. All study procedures were approved by the hospital institutional review board.

Demographic information

Parents completed a demographics form, which assessed child age, gender, and ethnicity. In addition, the form included questions about the caregiver’s relationship to the participating child, caregiver marital status, and family income.

Behavioral feeding problems

Parents completed the Behavioral Problem Feeding Assessment Schedule (BPFAS), which is a valid and reliable measure assessing frequency and number of feeding problems (16, 17). Each feeding problem is rated on its frequency (5-point Likert scale, 1 = Never to 5 = Always) and whether the behavior is problematic (0 = not a problem, 1 = is a problem). The BPFAS assesses 25 child problem behaviors (frequency range, 25–125; number of behaviors range, 0–25) and 10 parent feelings/strategies related to feeding (frequency range, 10–50; number of feelings/strategies range, 0–10). In addition, total frequency of child behaviors and parent feelings/strategies (range, 35–175) and total number of problem behaviors and feelings/strategies (range, 0–35) are calculated (16, 17). Higher scores indicate a higher frequency or number of feeding problems or maladaptive feelings/strategies. Subscale (i.e., child behavior frequency, child number of problems, parent behavior frequency, and parent number of problems) and total score reliability in the current sample was adequate to excellent (Cronbach’s alphas, 0.81–0.93).

Parenting stress

Given the wide age range of child participants, two well-established, valid, and reliable measures were used to assess parenting stress. For children under the age of 11, parents completed the Parenting Stress Index Short Form (PSI; 18), and for children aged 11 and older, parents completed the Stress Index for Parents of Adolescent (SIPA; 19), which was designed as an upward extension of the PSI (18). Both measures assess areas of stress related to the parent–child relationship (e.g., difficult child behaviors, dysfunctional parent–child interactions). Percentile total parenting stress scores were used for comparability across questionnaires. Total parenting stress scores ≥90th percentile indicate clinically significant levels of stress (18, 19). Total score reliability was excellent in the current sample (Cronbach’s alphas: PSI = 0.93; SIPA = 0.97).
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Dietary adherence

For children with EGID, parent report of adherence to dietary restrictions was assessed using the Treatment Adherence Questionnaire (6). Prior to presentation of the following question, parents were asked to list their child’s restricted foods/drinks:

“Children and adolescents often have difficulty following strict diets. They may forget they cannot have a particular food or drink, they may be accidentally exposed to a food or drink (e.g., poorly labeled products), or they may just want the food or drink very much and choose to have it even though they are not supposed to. There may be other reasons too. All of these situations are completely understandable.

Please tell us the number of times in the past 2 wk your child has had a food or drink that he or she was not supposed to have: ______.”

Because a single exposure to an allergenic food/drink could result in negative health outcomes for children with EGID, any exposure to a restricted food/drink was considered, for the purposes of this study, an indicator of ‘non-adherence’.

Statistical analysis

Analyses were conducted using SPSS 17.0 (20). For the BPFAS, mean substitution within subscales was used to replace missing values for child problem behavior and parent feeling and strategy frequency items, and a score of ‘0’ (i.e., not a problem) replaced missing items for number of problems. Differences between children with EGID and healthy children and their families on behavioral feeding problems and parenting stress were examined using independent sample t-tests. Analysis of variance (ANOVA) and post hoc Bonferroni comparisons were used to examine age differences on behavioral feeding problems. Specifically, children were divided into four age-groups consistent with age categories used in other pediatric populations (21): 2–4, 5–7, 8–12, and 13–18 yr. Differences between children with EO and EGE on behavioral feeding problems were examined using Mann-Whitney U tests because of unequal sample sizes. Linear regression analyses were used to examine the prediction of dietary adherence from behavioral feeding problems. The associations between behavioral feeding problems and parenting stress were examined using Pearson correlations. The significance level for all statistical tests was set at p < 0.05.

Results

Only families who completed measures of interest were included in the current analyses (EGID: n = 92; healthy comparison: n = 89).

Demographics

Demographic characteristics of participating children and their families are shown in Table 1. Caregivers of children with EGID reported a higher annual family income than caregivers of healthy comparison children (F(1, 175) = 14.5, p < 0.001). Consequently, group comparisons (EGID vs. healthy participants) were also run controlling for annual family income.

Behavioral feeding problems

Children with EGID had significantly higher scores on the BPFAS across all subscale and total scores than healthy comparison children, indicating greater child behavioral problems associated with feeding (M_{EGID} = 55.0, M_{Healthy} = 40.5; t = 7.9, p < 0.001), greater parent maladaptive feelings and strategies related to child feeding (M_{EGID} = 20.3, M_{Healthy} = 13.8; t = 8.1, p < 0.001), and a greater number of child problem behaviors and parent maladaptive feelings/strategies (Table 2). Results were unchanged after controlling for annual family income.

Children with EGID were divided into four age-groups: 2–4 yr (n = 26), 5–7 yr (n = 24), 8–12 yr (n = 27), and 13–18 yr (n = 15). For children with EGID, younger children had higher total frequency of behavioral feeding problems than older children (F(3, 88) = 8.2, p < 0.001). For healthy comparison children, there were no significant differences between younger and older children on total frequency of behavioral feeding problems (F(3, 85) = 1.6, p = 0.20). Post hoc Bonferroni comparisons for children with EGID indicated that toddlers had a significantly higher frequency of

Table 1 Demographics of children with eosinophilic gastrointestinal disorders (EGID), healthy children, and their families

<table>
<thead>
<tr>
<th></th>
<th>EGID</th>
<th>Healthy controls</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years (s.d.)</td>
<td>7.6 (4.2)</td>
<td>7.8 (4.2)</td>
<td>0.736</td>
</tr>
<tr>
<td>Gender (% male)</td>
<td>78%</td>
<td>78%</td>
<td>0.905</td>
</tr>
<tr>
<td>Ethnicity: n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>77 (84%)</td>
<td>69 (78%)</td>
<td>0.294*</td>
</tr>
<tr>
<td>African-American</td>
<td>2 (2%)</td>
<td>16 (18%)</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (2%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2 (2%)</td>
<td>1 (1%)</td>
<td></td>
</tr>
<tr>
<td>Biracial</td>
<td>8 (9%)</td>
<td>3 (3%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1 (1%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Caregiver relationship to child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological mother</td>
<td>100%</td>
<td>100%</td>
<td>0.327</td>
</tr>
<tr>
<td>Caregiver marital status (% married)</td>
<td>89%</td>
<td>73%</td>
<td></td>
</tr>
<tr>
<td>Median family income</td>
<td>$100,001–</td>
<td>$75,001–</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>$125,000</td>
<td>$100,000</td>
<td></td>
</tr>
<tr>
<td>EGID diagnosis: n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eosinophilic esophagitis</td>
<td>78 (85%)</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Eosinophilic gastroenteritis</td>
<td>14 (15%)</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

*Compares Caucasian participants with non-Caucasian participants. †A chi-square analysis comparing percent of caregivers for children with EGID vs. healthy children who were married, divorced, widowed, and separated could not be completed due to small cell sizes (n < 5).
behavioral problems than older children (8–12, 13–18 yr), and young children (5–7 yr) had a significantly higher frequency of behavioral problems than teenagers (Fig. 1). Toddlers had a higher total number of behavioral problems than teenagers (F(3, 88) = 3.7, p = 0.014; post hoc comparison, p = 0.009). Children with EoE vs. EGE did not differ on behavioral feeding problems (all p’s > 0.13). For children with EGID, regression results indicated that behavioral feeding problems (subscale and total scores) did not significantly predict dietary adherence (p’s > 0.40).

Parenting stress
Mothers of children with EGID reported significantly higher levels of parenting stress than mothers of healthy comparison children (M_{EGID} = 48.1, M_{Healthy} = 31.0; t = 3.7, p < 0.001). The results remained unchanged after controlling for annual family income. Mothers of children with EoE vs. EGE did not differ significantly on parenting stress (p = 0.37).

Behavioral feeding problems and parenting stress
For children with EGID, behavioral feeding problems were significantly correlated (i.e., medium effect size magnitude) with parenting stress. Specifically, higher parenting stress was associated with higher frequencies of problem parent feelings and strategies related to feeding (r = 0.28, p = 0.008). Higher parenting stress was also associated with a higher number of child feeding behavior and parent maladaptive feelings/strategies related to feeding (r = 0.25, p = 0.02; r = 0.31, p = 0.003, respectively). Finally, higher parenting stress was related to a higher total number of child and parent behavior feeding problems (r = 0.29, p = 0.007).

Discussion
The current study is the first to systematically examine a continuum of behavioral feeding problems among a large sample of children with EGID and their caregivers compared with healthy children. The study is also the first to use a well-established and valid parent-reported measure of behavioral feeding problems and to demonstrate the relationship between behavioral feeding difficulties and parenting stress in this pediatric population. Our findings add to the limited literature on the adaptation of children with EGID and their caregivers by highlighting that in addition to psychosocial difficulties and health-related quality of life impairment (4, 5), children with EGID have significantly higher number and frequency of behavioral feeding problems compared to healthy children. Their caregivers also have significantly higher number and frequency of problem feelings and strategies related to child feeding. The levels of behavioral feeding difficulties among children with EGID in the current sample are higher than those in normative samples, comparable to those in other pediatric chronic illness populations (i.e., cystic fibrosis), but are lower than those of children referred for feeding disorders (16, 17). In particular, younger children

Table 2 Descriptive statistics and group comparisons for behavioral feeding problems, parenting stress, and dietary adherence

<table>
<thead>
<tr>
<th></th>
<th>EGID participants (n = 92)</th>
<th>Healthy participants (n = 89)</th>
<th>t</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Behavioral feeding problems</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child problem behavior frequency</td>
<td>55.0 (95% CI 51.9–58.1)</td>
<td>40.5 (95% CI 38.6–42.3)</td>
<td>7.9</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Number of child behavior problems</td>
<td>6.1 (95% CI 4.9–7.2)</td>
<td>2.3 (95% CI 1.7–3.0)</td>
<td>5.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Parent feelings/strategies frequency</td>
<td>20.3 (95% CI 19.0–21.6)</td>
<td>13.8 (95% CI 13.1–14.5)</td>
<td>8.1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Number of parent feelings/strategies</td>
<td>2.7 (95% CI 2.2–3.3)</td>
<td>0.4 (95% CI 0.2–0.6)</td>
<td>8.1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Total child and parent frequency</td>
<td>75.3 (95% CI 71.1–79.5)</td>
<td>54.3 (95% CI 51.9–56.6)</td>
<td>8.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Total child and parent problems</td>
<td>8.8 (95% CI 7.2–10.4)</td>
<td>2.8 (95% CI 2.0–3.6)</td>
<td>6.8</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Total parenting stress percentile*</td>
<td>48.1 (95% CI 41.7–55.5)</td>
<td>31.0 (95% CI 24.8–37.3)</td>
<td>3.7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td><strong>Dietary adherence†</strong></td>
<td>.9 (s.d. = 1.9, range 0–10)</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

*Average percentile score across the two parenting stress measures. N = 88 for eosinophilic gastrointestinal disorders (EGID) participants due to missing data.
†Number of times in the 2 wk prior to completion of study questionnaires that children had food/drink they were not supposed to have.

Fig 1 Behavioral problems frequency by age-group for children with eosinophilic gastrointestinal disorders.

Pediatric Allergy and Immunology 23 (2012) 730–735 © 2012 John Wiley & Sons A/S. Published by Blackwell Publishing Ltd 733
with EGID (i.e., ages 2–7) had higher behavioral feeding problems, suggesting that their families may require the most support with addressing feeding behaviors.

For the entire EGID sample, problematic feeding behaviors, feelings, and strategies were not predictive of dietary treatment adherence, but they were associated with higher parenting stress. Given the association between parenting stress and poor outcomes (i.e., in disease activity, language development, behavioral problems; 10–12) and that in this sample, caregivers of children with EGID reported higher parenting stress than caregivers of healthy children, further research on the impact parenting stress has on outcomes (e.g., health outcomes, child/family functioning) in this population is warranted.

With respect to clinical implications of the current results, the continuum of problematic feeding behaviors/strategies among children with EGID and their caregivers should be assessed. Questionnaires such as the BPFAS could be administered as a screener for behavioral feeding problems to be targeted in intervention. Treatments for behavioral components to feeding problems (22) may improve families’ abilities to manage feeding challenges, even in the absence of a feeding disorder diagnosis. Also, the relationship between feeding difficulties and caregiver stress should be recognized when families are given EGID treatment recommendations. For example, the occurrence of challenging feeding behaviors and parenting stress should be normalized and difficulties addressed in a nonjudgmental manner. Caregiver stress should also be monitored, so that caregivers experiencing high levels or increasing stress are provided with support so that increased behavioral feeding problems do not impact adherence to treatment recommendations. A multidisciplinary treatment approach including psychology and speech providers or placing referrals to these providers may be useful for assessing, monitoring, and addressing family management of the treatment regimen.

The current study had several notable strengths, including use of a measure of behavioral feeding problems administered to a large sample of children with EGID regardless of whether they had been referred for feeding problems, investigation of the relationship of family factors with behavioral feeding problems (23) and dietary restriction adherence, and inclusion of a sample of healthy comparison children. In addition, several limitations of the current study should be noted. This study relied on parent report and broadly assessed dietary restriction adherence across a wide age range. Future investigations would benefit from using observational methods to assess behavioral feeding problems and assessing dietary regimen adherence in greater detail (e.g., 24-h random recall; 24, 25) or based on child self-report (i.e., for adolescents). Additionally, future studies could examine behavioral feeding problems and dietary regimen adherence within specific age-groups and in relation to time since EGID diagnosis. The current study employed a cross-sectional design and thus precluded longitudinal examination of the temporal association between behavioral feeding problems, parenting stress, and dietary adherence. Also, because of the age range of participants, two different parenting stress measures were used; however, this practice is consistent with previously published literature (26). We used the BPFAS to assess for behavioral feeding problems in children through the age of 18 yr. While the BPFAS has been used with children through age 12 in prior studies (27, 28), future research should seek to validate this measure with older children (i.e., adolescents). Finally, it should be noted that the current study included a sample of healthy comparison children with significantly lower family income than children with EGID, which may be an artifact of recruitment method (i.e., healthy sample recruitment from a clinic serving a large number of Medicaid patients). However, our results of behavioral feeding problems adversely affecting EGID children over healthy controls were unchanged after controlling for annual family income.

Future studies will need to examine whether interventions focused on behavioral feeding problems in children with EGID lead to decreased parenting stress. While the literature recommends that behavioral feeding problems are addressed as early as possible (29, 30), it will be important to investigate the impact interventions, in combination with the EGID treatment regimen, have on medical outcomes (e.g., improvements in feeding-related symptoms such as vomiting associated with EGID). In summary, the current study highlights the importance of examining behavioral feeding problems among children with EGID and their families and, more broadly, family adaptation to and management of the dietary treatment regimen.

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