The Tortuous Path to Diagnosis of Eosinophilic Gastritis and Eosinophilic Gastroenteritis (EG/EGE) in the United States: A Real-World, Population-Based Study

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**BACKGROUND**
- Eosinophilic gastritis and eosinophilic gastroenteritis (EG/EGE) are rare diseases characterized by elevated eosinophils in gastrointestinal (GI) tract biopsies based on standard H&E histopathology, though no standard diagnostic guidelines exist.
- Patients with EG/EGE suffer from a decreased quality of life due to debilitating GI symptoms, compounded by a lengthy path to diagnosis.
- Here we present a robust analysis of the medical history of patients with EG/EGE prior to diagnosis, utilizing a large, highly representative claims database of >205 million US individuals.

**METHODS**
- **Symphony Health’s database of >295 million US individuals.** Billing records were identified for patients between 2016 to 2018.
- **Year of presentation, n (%):** 2016 (9.3%), 2017 (28.3%), 2018 (62.4%).
- **Comorbidities, n (%):** Unknown (2139, 66%), All Patients (3250) (141, 4%), Eosinophilic Esophagitis (EoE) (111, 3%), Adult (18 y) (24, 3%).

**RESULTS**
- **Patients with a variety of gastrointestinal symptoms** (n=3250) where defined as 0 to 10 years (children), 11 to 17 y (adolescents), and ≥18 y (adults).
- **Abdominal pain, vomiting and diarrhea** were the most frequent GI symptoms experienced prior to EG/EGE diagnosis (Figure 1).
- **Overall, 15% of patients** with EG/EGE newly presented prior to diagnosis; there were no significant differences in age groups.
- **Time to diagnosis** was significantly shorter for children and adolescents vs adults (Figure 4).

**CONCLUSIONS**
- **This study characterizes the lengthy journey to diagnosis** for patients with EG/EGE, and highlights the urgent need for improved diagnostic practices and disease education.
- **Time to GI referral, failure to diagnose on first endoscopy,** and lack of disease education may contribute to the shorter mean time to diagnosis.
- **Shorter time to endoscopy** and increased likelihood of biopsy/histopathology may contribute to the shorter mean time to diagnosis observed in children and adolescents.
- **Heightened disease awareness,** tools to increase suspicion of EG/EGE (e.g., presence of atopic conditions, peripheral eosinophilia) and standardized criteria for endoscopy, biopsy, and histopathology may improve the time to diagnosis.

**Table 1.** Patient baseline characteristics

<table>
<thead>
<tr>
<th>Age group (y)</th>
<th>All Patients (n=3250)</th>
<th>Children (0-10 y) (n=2326)</th>
<th>Adolescents (11-17 y) (n=318)</th>
<th>Adults (≥18 y) (n=606)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± SD</td>
<td>38 ± 24</td>
<td>14 ± 2</td>
<td>10 ± 2</td>
<td>10 ± 2</td>
</tr>
<tr>
<td>Age range (%)</td>
<td>10 to 18 (79%)</td>
<td>10 to 18 (79%)</td>
<td>10 to 18 (79%)</td>
<td>10 to 18 (79%)</td>
</tr>
<tr>
<td>Gender (%)</td>
<td>Male (51%)</td>
<td>Female (49%)</td>
<td>Male (52%)</td>
<td>Female (48%)</td>
</tr>
<tr>
<td>Race (%)</td>
<td>Black (22%)</td>
<td>White (78%)</td>
<td>Black (21%)</td>
<td>White (79%)</td>
</tr>
<tr>
<td>Ethnicity (%)</td>
<td>Hispanic (21%)</td>
<td>Non-Hispanic (79%)</td>
<td>Hispanic (22%)</td>
<td>Non-Hispanic (78%)</td>
</tr>
<tr>
<td>Education (%)</td>
<td>≤ High School (46%)</td>
<td>High School or above (54%)</td>
<td>≤ High School (48%)</td>
<td>High School or above (52%)</td>
</tr>
<tr>
<td>Diagnosis (%)</td>
<td>Eosinophilic gastrectasis (EG) (66%)</td>
<td>Eosinophilic gastroenteritis (EGE) (34%)</td>
<td>EG (67%)</td>
<td>EGE (33%)</td>
</tr>
<tr>
<td>Referral (%)</td>
<td>GI referral (25%)</td>
<td>GI referral (22%)</td>
<td>GI referral (27%)</td>
<td>GI referral (23%)</td>
</tr>
<tr>
<td>Other (%)</td>
<td>Primary care (30%)</td>
<td>Primary care (35%)</td>
<td>Primary care (25%)</td>
<td>Primary care (30%)</td>
</tr>
<tr>
<td>Endoscopy (%)</td>
<td>≥2 endoscopies (20%)</td>
<td>≥2 endoscopies (25%)</td>
<td>≥2 endoscopies (15%)</td>
<td>≥2 endoscopies (25%)</td>
</tr>
</tbody>
</table>

**Figure 5.** Frequency of biopsy and histopathology associated with endoscopy

- **Biopsy/histopathology not performed routinely for all endoscopies.**
- **Biopsy and histopathology were performed** in 74% of all endoscopies.

**Table 2.** Frequency of atopic comorbidities

- **Atopic comorbidities** were present in 80% of patients and significantly more common in children and adolescents vs adults (Table 2).

**Figure 6.** Proportion of patients presenting with atopic comorbidities

- **Time to GI referral and/or endoscopy contributes to delayed diagnosis.** Patients were more likely to present to emergency medicine vs primary care if they experienced vomiting (p<0.001).

**Figure 4.** Mean time from presentation to event, months

- **Mean time from presentation to diagnosis** was 40.6 (3.4 years), and was significantly shorter for children and adolescents vs adults (Figure 3).

**Figure 3.** Mean time from presentation to diagnosis

- **EG/EGE diagnosis takes an average of 3.4 years** to thrive.

**Figure 2.** Frequency of other GI diagnoses prior to EG/EGE diagnosis

- **Overall, 66% of patients** received an alternate diagnosis of one or more non-eosinophilic GI conditions prior to their EG/EGE diagnosis (Figure 2).

**Figure 1.** Frequency of GI symptoms prior to EG/EGE diagnosis (n=3250)