

Time to diagnosis among newly diagnosed patients with eosinophilic esophagitis: a cohort study in the US-based TARGET-EGIDs consortium

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Background

- Eosinophilic esophagitis (EoE) is a chronic, progressive Type 2 inflammatory disease characterized clinically by symptoms of esophageal dysfunction and histologically by eosinophilic inflammation¹
- Without timely diagnosis, the risk of fibrosis and remodeling increases, which can lead to strictures and food impaction^{2,4}
- Patients with EoE often experience delays in diagnosis, which may be due in part to variable symptoms at presentation^{2,5,6}
- There is little real-world evidence to describe factors and symptoms associated with delays in establishing an EoE diagnosis

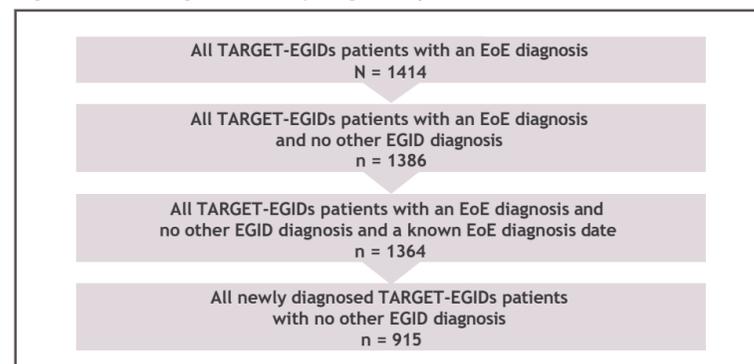
Objective

- To describe the demographic features, EoE-related symptoms or complications, and time from symptom onset when establishing a new diagnosis of EoE with a real-world dataset

Methods

- Structured data were analyzed from electronic health records (EHRs) of the US-based TARGET-EGIDs community consortium, a real-world longitudinal registry
- A cohort comprising 1414 patients with EoE from 3 sites was extracted, including a subgroup of 915 newly diagnosed patients (Figure 1)
- Newly diagnosed patients with EoE were identified by ICD-10 diagnosis code (K20.0) or physician documentation in the EHR on or after their first visit documented in the dataset between August 1, 2013, and March 27, 2024
- Patients with concomitant eosinophilic gastritis or concomitant non-EoE eosinophilic gastrointestinal diseases (EGIDs: eosinophilic gastritis, eosinophilic colitis, or gastroenteritis) were excluded
- Clinically relevant EoE-related symptoms or complications occurring prior to each patient's EoE diagnosis were identified, and time from the first occurrence to EoE diagnosis was calculated
 - Esophageal-specific symptoms included dysphagia, chest pain, and heartburn
 - Extra-esophageal nonspecific symptoms included abdominal pain and vomiting/nausea
 - EoE-related complications included food impaction, esophageal stricture, and esophageal perforation
- The baseline patient characteristics, comorbidities and related treatment use prior to EoE diagnosis, and EoE-related symptoms/complications were analyzed descriptively

Figure 1. Flow diagram of newly diagnosed patients with EoE in TARGET-EGIDs



Patients often experience a lengthy time to EoE diagnosis, with substantial variability in average time from first recorded symptom or complication to diagnosis (1.1-5.4 years); however, prompt diagnosis is critical to alleviate the burden of EoE and to expedite appropriate treatment to prevent short- and long-term complications of the disease

Results

- Of 915 patients with newly diagnosed EoE, most were male (53%) and White (83%); the mean age at EoE diagnosis was 44.8 years (SD, 16.5) (Table 1)
- Prior to diagnosis of EoE, 732 (80%) patients had ≥ 1 documented EoE-related symptom or complication (Figures 2 and 4)
 - 4% had only EoE-related complications documented
- While patients who experienced dysphagia or food impaction had the shortest times, the average time to diagnosis was still 1.6 (SD, 3.1) and 1.4 (SD, 2.3) years, respectively (Figure 3)
- Patients with more general symptoms such as abdominal pain or nausea/vomiting experienced longer time to diagnosis with an average time of 3.1 (SD, 3.3) and 2.9 (SD, 2.8) years, respectively (Figure 3)
- Patients who first presented with multiple symptoms or complications generally had shorter times to diagnosis. Among these patients, the average time to diagnosis was 1.1 (SD, 2.2) years for those with food impaction and dysphagia, and 1.9 (SD, 2.6) years for those without (Figure 3)
- Patients diagnosed with gastroesophageal reflux disease (GERD) had a lengthy time to EoE diagnosis (average of 4.7 [SD, 4.8] years) (Figure 3)

Table 1. Baseline patient characteristics

	All patients (N = 915)
Age at diagnosis, mean (SD), years	44.8 (16.5)
Age category, ^a n (%)	
< 18	24 (3)
18-29	168 (18)
30-49	359 (39)
50-64	242 (27)
≥ 65	121 (13)
Sex, ^a n (%)	
Female	426 (47)
Male	488 (53)
Race, n (%)	
Asian	41 (5)
Black	47 (5)
White	755 (83)
Other	61 (7)
Unknown	11 (1)
Ethnicity, n (%)	
Hispanic/Latino	56 (6)
Not Hispanic/Latino	842 (92)
Other/unknown	17 (2)
Insurance, n (%)	
Private	646 (71)
Medicaid	78 (9)
Medicare	133 (15)
VA/other	30 (3)
Unknown	28 (3)
Comorbidities prior to diagnosis, n (%)	
Allergic rhinitis	192 (21)
Asthma	219 (24)
Eczema/atopic dermatitis	18 (2)
Food allergy	45 (5)
Related treatments prior to diagnosis, n (%)	
PPI	512 (56)
Corticosteroids	356 (39)

^aOne patient had missing age and gender. PPI, proton pump inhibitor; VA, Veterans Administration.

Figure 2. The distribution of patients based on their first documented EoE-related symptom or complication prior to EoE diagnosis

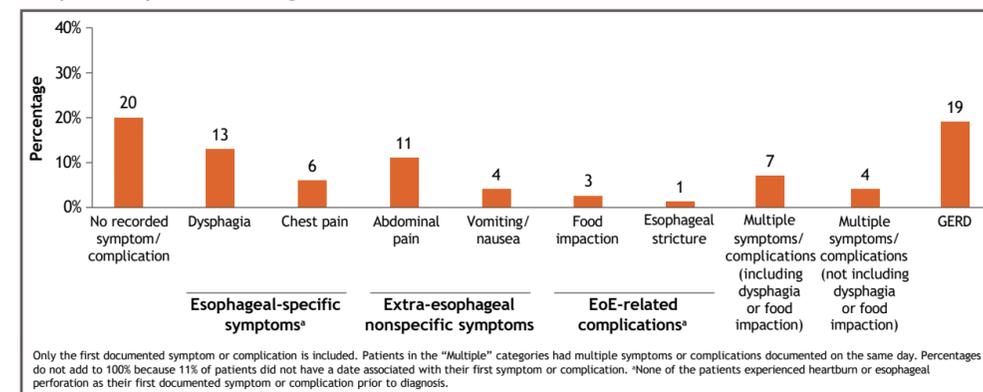
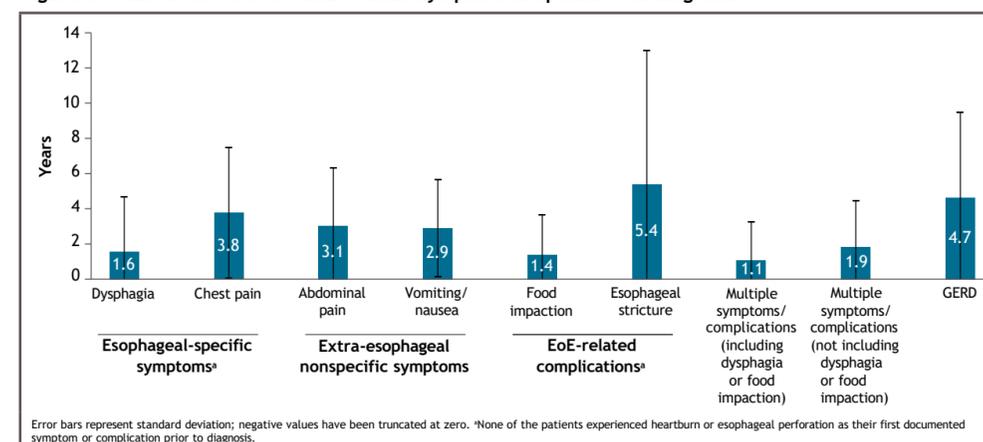
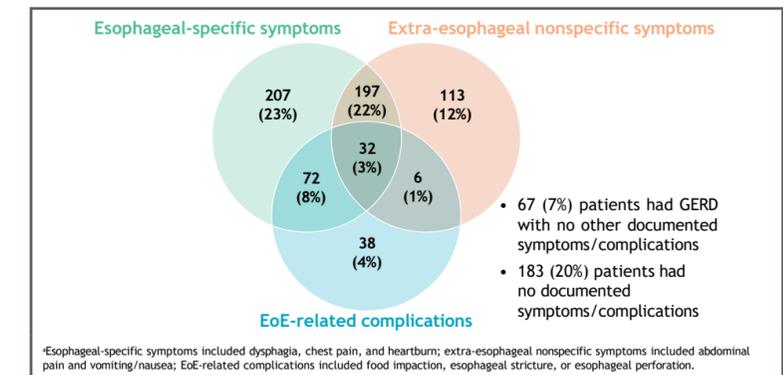


Figure 3. Mean time from first EoE-related symptom/complication to diagnosis



Error bars represent standard deviation; negative values have been truncated at zero. *None of the patients experienced heartburn or esophageal perforation as their first documented symptom or complication prior to diagnosis.

Figure 4. Venn diagram illustrating the frequency and percentage of newly diagnosed patients with EoE exhibiting EoE-related symptoms or complications at any time prior to diagnosis^a



^aEsophageal-specific symptoms included dysphagia, chest pain, and heartburn; extra-esophageal nonspecific symptoms included abdominal pain and vomiting/nausea; EoE-related complications included food impaction, esophageal stricture, or esophageal perforation.

Limitations

- Records may be incomplete for some variables; there is a chance of confounding by factors not captured in the EHR
- Participating sites in TARGET-EGIDs represent EoE expert centers; therefore, the diagnostic journey is likely an underestimate of the time to diagnosis that patients not in such highly specialized centers may experience
- Time to diagnosis is based on experience at the current center and likely does not include the portion of the diagnostic journey that occurs prior to the current center's referral, thereby underestimating the time from first occurrence of symptoms or complications for the patient to their EoE diagnosis

Conclusions

- Despite presenting with EoE-related symptoms or complications at EoE expert centers, patients faced lengthy times to EoE diagnosis, highlighting the need to expedite diagnosis to ensure appropriate treatment to prevent short- and long-term complications of the disease
- Patients with a diagnosis of GERD prior to their EoE diagnosis faced some of the longest times to diagnosis with an average of almost 5 years
- Patients with more general symptoms experienced an average of 3 years from first symptom to diagnosis
- Even patients who presented with dysphagia or food impaction experienced diagnostic journeys lasting an average of > 1 year

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Declaration of interests

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