Prevalence and Characteristics of Dysphagia Based on a Population-Based Survey

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Abstract

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BACKGROUND & AIMS: Although dysphagia is common, there is limited information about the prevalence and burden of illness of dysphagia in the United States. We performed a population-based survey of more than 31,000 adults to evaluate the epidemiology, clinical characteristics, and healthcare-seeking behavior of individuals with dysphagia.

METHODS: We performed a cross-sectional analysis of adults in the United States who completed an online, self-administered health survey from April 4 through April 19, 2018. All respondents were asked which of the following symptoms they had ever experienced (presented in random order): dysphagia, abdominal pain, bloating, bowel incontinence, constipation, diarrhea, heartburn/reflux, nausea/vomiting, or none of the above. Only respondents who selected dysphagia continued the remaining survey, which included questions about dysphagia severity, use of compensatory maneuvers, healthcare seeking, and esophageal comorbidities. We used multivariable regression methods to adjust for confounding.

RESULTS: Of 31,129 individuals who participated in the survey, 4998 respondents (16.1%) reported experiencing dysphagia; 92.3% of these had symptoms in the previous week. We found that 16.3% of respondents described their dysphagia over the previous 7 days as either “quite a bit” or “very” severe. Drinking liquids to help with dysphagia (86.0%) and taking longer to finish eating (76.5%) were the most common compensatory maneuvers. Overall, 51.1% of individuals sought care for their difficulty swallowing; older age, male sex, having a usual source of care and insurance, having comorbidities, and more severe dysphagia symptoms increased the odds for seeking care ($P < .05$). The most commonly reported esophageal comorbidities were gastroesophageal reflux disease (30.9%), eosinophilic esophagitis (8.0%), and esophageal stricture (4.5%).

CONCLUSIONS: In a large population-based survey, we found that dysphagia is common; 1 of 6 adults reported experiencing difficulty swallowing. However, half of individuals have not discussed their symptoms with a clinician and many could have treatable disorders.

Keywords
Difficulty Swallowing; Gastroesophageal Reflux Disease; Eosinophilic Esophagitis; Epidemiology

Introduction
Dysphagia is the subjective sensation of difficulty swallowing and there are many potential etiologies.$^1$ It also negatively impacts quality of life and decreases work productivity and it is the 10th leading cause of ambulatory care visits in the US among gastrointestinal (GI) symptoms with over 600,000 visits annually.$^2,^3$

Globally, the community prevalence of dysphagia ranges between 2% to 20%.$^2,^4-$13 While some of these population-based efforts were conducted in the US,$^2,^4-$7 these studies were either limited by a small number of respondents with dysphagia, had cohorts that were predominantly non-Hispanic white, were not focused solely on dysphagia or were performed ≥10 years ago. Given the evolving demographics of the US, we performed a population-based survey to determine the prevalence of dysphagia in the community. Moreover, among those with dysphagia, we assessed symptom severity as measured by National Institutes of Health (NIH) Patient-Reported Outcomes Measurement Information System (PROMIS®).
items, use of compensatory maneuvers, prevalence and predictors of healthcare seeking for dysphagia and prevalence of esophageal comorbidities.

**Methods**

**Study Design and Participant Recruitment**

We performed a cross-sectional, online, self-administered survey of community-dwelling adults in the US between April 4 and April 19, 2018. This study was approved by the Cedars-Sinai Institutional Review Board (Pro47958).

To recruit a representative, population-based sample of Americans for the study, we partnered with the survey research firm Cint. Cint uses quotas for age, sex and region of the country (Northeast, South, Midwest and West) based on the latest US Census data. They also employ a reward system based on marketplace points, which we describe elsewhere. Cint emailed participants who met Census quotas, inviting them to complete an online survey. Users who clicked the survey link were brought to our home page, which was labeled as a National Health Survey and hosted on SurveyMonkey (San Mateo, CA). The survey was described as a generic health survey and not as a dysphagia-focused study. Survey invitations were distributed until we reached our sample size goal of approximately 5000 respondents with difficulty swallowing, allowing us to create a robust dysphagia-focused dataset.

**Study Population**

To achieve our primary aim of determining the prevalence of dysphagia in the community, all respondents ≥18 years of age were asked which of the following GI symptoms they had ever experienced (presented in random order): dysphagia, abdominal pain, bloating, bowel incontinence, constipation, diarrhea, heartburn/reflux, nausea/vomiting or none of the above. Dysphagia was described as, “difficulty swallowing (food or liquids sticking in your throat or chest, discomfort with swallowing, or choking sensation when swallowing).” We employed a ‘blinded’ screener, listing eight GI symptoms in an effort to increase the likelihood that respondents had experienced dysphagia and were not just seeking compensation. Only respondents with prior dysphagia continued with the remaining survey, which examined their dysphagia characteristics and healthcare seeking as part of our secondary aims. Those with a history of esophageal or throat cancer were excluded, as they can require esophagectomy, laryngectomy and/or enteral feeding tubes, thereby confounding our assessment of their dysphagia severity and compensatory behaviors.

**Survey Instrument**

Supplementary File 1 includes the survey instrument. Respondents with dysphagia first completed questions on their symptom onset and severity as measured by NIH PROMIS. We also assessed respondents’ global self-assessment of dysphagia severity, compensatory behavioral techniques to manage dysphagia, presence of odynophagia and the extent to which respondents believed dysphagia to be a severe health problem.
Next, we assessed whether respondents sought medical care for their dysphagia. Of those individuals who reported seeking healthcare, we asked which providers they met with and which tests, if any, were performed specifically to evaluate their symptoms. Participants were then asked if they had ever undergone esophageal dilation or food disimpaction.

Respondents were additionally asked whether they have been diagnosed with eosinophilic esophagitis (EoE) by a healthcare provider. Those who responded affirmatively completed questions regarding timing of the diagnosis and providers they had seen for their condition. We also asked respondents about current EoE treatments (proton-pump inhibitor [PPI]; swallowed inhaled steroid; steroid liquid or suspension; steroid tablet; elimination diet) after which they completed the Abbreviated Treatment Satisfaction Questionnaire for Medication (TSQM-9).15

All participants also completed the PROMIS Global Health Short Form Questionnaire16 along with questions assessing comorbidities. Finally, we posed demographic and socioeconomic questions.

Outcomes

Our primary outcome was whether individuals had ever experienced dysphagia, assessed through the GI symptom screener. Among those with dysphagia, a secondary outcome was whether they sought healthcare for their difficulty swallowing. Other secondary outcomes included prevalence of EoE and use of and satisfaction with treatments for managing EoE as measured by the TSQM-9.

Statistical Analyses

All analyses were performed in Stata 13.1 (StataCorp LP, College Station, TX) and a two-tailed P-value of <.05 was considered statistically significant. We used bivariate analyses to compare individuals with dysphagia who sought healthcare for their symptoms with those who did not, and to compare those who had been diagnosed with EoE with those who had not. Specifically, we compared continuous and categorical variables between both groups using Student’s t-test and the χ² test, respectively. For multivariable analyses, we used logistic regression models to calculate odds ratios (ORs) and 95% confidence intervals (CIs). The regression models were performed on our outcomes of seeking healthcare for dysphagia and diagnosis of EoE. Both models adjusted for all dysphagia-related factors, comorbidity and sociodemographic covariates as described above, allowing us to identify independent, predictive factors of healthcare seeking and EoE diagnosis among those with dysphagia.

Results

Study Population and Dysphagia Prevalence

Overall, 84,165 individuals were invited to complete the survey. Of the 33,672 respondents who started the survey, we excluded 2061 who did not provide consent, 161 who reported a history of esophageal or throat cancer and 321 who had incomplete data. Among the 31,129 eligible participants, 4998 (16.1%) reported having experienced dysphagia and their demographics are listed in Table 1.
Dysphagia Severity and Compensatory Maneuvers

Of the 4998 respondents with dysphagia, 3362 (67.3%) reported a duration of dysphagia of <5 years, 798 (16.0%) reported a duration of 6–10 years, 782 (15.6%) reported a duration of ≥11 years; duration was unknown for 56 (1.1%) individuals. We found that 4614 (92.3%) respondents experienced dysphagia symptoms within the past week, as measured by PROMIS. Responses for each PROMIS item are listed in Table 2. The median percentile score on the scale among respondents was 40.3 (interquartile range [IQR], 17.8–70.6).

Respondents were asked to describe the severity of their dysphagia over the past 7 days: 877 (17.5%)—“not at all”; 1922 (38.5%)—“a little bit”; 1383 (27.7%)—“somewhat”; 674 (13.5%)—“quite a bit”; 142 (2.8%)—“very much”. In addition, 2114 (42.3%) participants reported odynophagia within the past week. Using a pain scale of 0 (no pain)–10 (severe pain), the median score was 6 (IQR 4–7). Finally, 4598 (92.0%) had used ≥1 compensatory technique within the past week to ameliorate their difficulty swallowing; Table 3 lists the individual maneuvers.

Dysphagia Healthcare-Seeking Behavior

Among the overall cohort, 2553 (51.1%) individuals sought care for dysphagia, and they consulted with the following clinicians: 1923 (75.3%)—primary care provider; 983 (38.5%)—gastroenterologist; 472 (18.5%)—otolaryngologist; 320 (12.5%)—urgent care or emergency room physician. In multivariable regression, we found that older age, male gender, having a usual source of care and insurance, having comorbidities and more severe dysphagia symptoms were associated with increased odds for seeking care for dysphagia (Table 4). Those who believed dysphagia to be a more severe health problem and those who had better mental health also were more likely to consult with providers. No associations were seen for the remaining variables.

Dysphagia Evaluation and Diagnoses

Among respondents with dysphagia who sought healthcare (n=2553), 1816 (71.1%) underwent procedures to assess their symptoms. Participants reported undergoing the following tests: 1342 (52.6%)—upper endoscopy; 744 (29.1%)—barium swallow video; 607 (23.8%)—barium esophagram; 344 (13.5%)—esophageal manometry; 14 (0.5%)—imaging tests; 2 (0.08%)—nasopharyngeal laryngoscopy. Supplementary Table 1 presents findings of the regression on having had diagnostic testing.

Among all respondents with dysphagia (N=4998), 2031 (40.6%) reported being diagnosed with ≥2 esophageal disorder: 1545 (30.9%)—GERD; 399 (8.0%)—EoE; 223 (4.5%)—esophageal stricture; 171 (3.4%)—diffuse esophageal spasm; 148 (3.0%)—esophageal infection; 88 (1.8%)—dermatomyositis; 72 (1.4%)—achalasia; 63 (1.3%)—jackhammer esophagus; 53 (1.1%)—PPI-responsive esophageal eosinophilia; 48 (1.0%)—scleroderma.
Esophageal Dilation and Food Disimpaction

Of the overall cohort (N=4998), 767 (15.3%) participants reported undergoing an esophageal dilation. Of these respondents, 260 (33.9%) had undergone 1 dilation, 186 (24.3%) had 2 dilations, 173 (22.6%) had 3 dilations and 148 (19.3%) had ≥4 dilations. We noted that 341 (44.5%) respondents had undergone dilation within the previous year.

In addition, 417 (8.3%) of the overall cohort reported a food impaction. Among those respondents, 94 (22.5%) had undergone 1 disimpaction, 102 (24.5%) had 2 disimpactions, 132 (31.7%) had 3 disimpactions and 89 (21.3%) had ≥4 disimpactions. Two hundred thirty (55.2%) individuals required food disimpaction during the past year.

EoE Subgroup

Of the overall cohort, 399 (8.0%) respondents reported a diagnosis of EoE (Supplementary Table 2). They were diagnosed within the following time periods: 309 (77.4%)—within the previous 5 years; 44 (11.0%)—6 to 10 years ago; 42 (10.5%)—≥11 years ago; 4 (1.0%)—“unknown”. We found that 392 (98.2%) individuals experienced dysphagia (as measured by PROMIS) during the past week. The median PROMIS percentile score was 85.0 (IQR 53.0–96.2). Responses to each PROMIS item and their dysphagia compensatory maneuvers are listed in Tables 2 and 3, respectively.

In multivariable regression (Table 5), we found that younger age, male gender, married status, higher education, higher household income, having health insurance and having a usual source of care were associated with increased odds for having a diagnosis of EoE. Non-Hispanic blacks and Latinos also had higher odds for reporting EoE than non-Hispanic whites. Those with medical comorbidities, who believed dysphagia to be a serious health problem, and had more severe symptoms of dysphagia as measured by PROMIS were also more likely to have EoE. No association was seen between allergic comorbidities and having EoE.

Those with EoE received care from the following providers: 239 (59.9%)—gastroenterologist; 207 (51.9%)—primary care provider; 100 (25.1%)—allergist; 61 (15.3%)—dietitian; 5 (1.3%)—other provider(s) (note: nine individuals were unsure which provider[s] they had seen). Among those with a known provider (n=390), they indicated that the provider most involved in management of their EoE was the following: 184 (47.2%)—gastroenterologist; 149 (38.2%)—primary care provider; 44 (11.3%)—allergist; 10 (2.6%)—dietitian; 3 (0.8%)—another provider. We also noted that 300 (75.2%) of those with EoE had undergone esophageal dilation and 265 (66.4%) reported a previous food impaction.

We found that 373 (93.5%) individuals were currently receiving treatment for their EoE. Of all respondents with EoE, 216 (54.1%) were receiving PPIs, 173 (43.4%) were taking swallowed inhaled steroids, 125 (31.3%) were following an elimination diet, 105 (26.3%) were receiving liquid or suspension steroids, 86 (21.6%) were taking steroid tablets and 4 (1.0%) were on other treatment (note: four individuals were unsure). Table 6 lists the frequencies of the various EoE treatment combinations. Supplementary Table 3 lists the TSQM-9 scores for each therapy.
Among those taking steroid liquids or suspensions (n=105), 62 (59.0%) reported that they prepared it themselves, 36 (34.3%) obtained it from a compounding pharmacy and 7 (6.7%) were unsure or reported “unknown”. Of the 62 individuals who prepared it themselves, 20 (32.3%) said that it was inconvenient, 19 (30.6%) reported that it was either somewhat convenient or convenient and 23 (37.1%) rated it as very or extremely convenient. For those following the elimination diet and who knew how much they spend at the grocery store (n=121), 59 (48.8%) stated that they were spending more money on food compared with their previous diet, 31 (25.6%) spent approximately the same, 29 (24.0%) were spending less and 2 (1.7%) were unsure.

Discussion

In this population-based survey of over 31,000 Americans we found that dysphagia is common, affecting 16.1% of adults at some point during their lives. This is comparable to findings by Eslick and Talley, as they noted that 16.4% of those in Sydney, Australia, reported ever having experienced dysphagia. However, comparisons of the prevalence seen in our study to that found in other population-based studies are challenging given the different time frames used. A US study by Camilleri et al. noted that 7.8% reported at least monthly dysphagia over the past three months. An Argentina study discovered that 12.9% of respondents experienced dysphagia in the past year. In contrast, lower prevalences of dysphagia have been seen in Asian countries; Wang and colleagues noted that only 1.7% of respondents from Xi’an, China, reported difficulty swallowing in the last year.

We also noted that 92.0% of our cohort regularly employ compensatory techniques to cope with their dysphagia. Despite this consistent need for lifestyle modifications, approximately half of those in the general population have not discussed their symptoms with a healthcare provider. These potentially represent missed opportunities where appropriate evaluation, diagnosis and treatment of the underlying condition (e.g., GERD, EoE, motility disorders) by healthcare providers would lead to improvement in dysphagia symptoms. Given the decrements to quality of life caused by dysphagia and the potential for serious underlying pathology, further research to improve understanding of individuals’ knowledge, attitudes and beliefs and the barriers to healthcare seeking is warranted. Community outreach efforts to improve awareness and education on dysphagia and when to seek medical care are also needed.

Among those who sought healthcare for their difficulty swallowing, we found that about half had an upper endoscopy. This is despite statements from the American Society for Gastrointestinal Endoscopy that endoscopy is indicated to determine the underlying etiology, to exclude malignant conditions and to assess the need for and performance of therapy. Findings by Varadarajulu and colleagues highlight the diagnostic utility of endoscopy for dysphagia, as they found that 54% and 4% of cases have major pathology and cancer, respectively. The relatively low rate of endoscopy seen in our study suggests potential suboptimal usage of this effective diagnostic and therapeutic procedure. It is important to note, though, that clinicians may have appropriately not referred some patients for
endoscopic evaluation, particularly those with infrequent dysphagia, symptoms consistent with oropharyngeal dysphagia or globus, etc.

As for specific esophageal disorders, we found that EoE—an increasingly recognized cause of dysphagia—was the second most common condition, with 8.0% of those with difficulty swallowing reporting the diagnosis. Our regression analysis supported previous findings that more men than women are diagnosed with EoE. Atopic diseases such as asthma, atopic dermatitis, allergic rhinitis and food allergies also have been found to be associated with EoE; a recent study showed that over three-quarters of patients with EoE have concomitant atopic disease. Our results are consistent with this finding: 74.4% of respondents with EoE reported an allergic comorbidity. However, multivariable regression indicated that atopic disease is not significantly associated with having a diagnosis of EoE. In other words, although atopic disease is common among those with EoE, atopy does not increase the likelihood for having EoE.

Notably, although approximately half of patients with EoE indicate that a gastroenterologist is the most involved provider in the management of their EoE, over a third reported that this role is filled by a primary care provider. This finding may reflect limited availability of gastroenterologists in various parts of the US. Although primary care providers can monitor patients for symptom improvement while they are receiving therapy, the American College of Gastroenterology also recommends that upper endoscopy with biopsies be performed to determine therapy response by assessing for decreases in esophageal eosinophilic inflammation. Thus, patients with EoE would benefit from ongoing subspecialty care with a gastroenterologist experienced in the treatment of EoE. We also noted that only 1 in 4 patients had seen an allergist for their EoE; allergists can be helpful in identifying and treating comorbid atopic conditions as well as helping to guide elimination diets. It is unknown whether this low proportion of allergist referrals reflects providers’ unfamiliarity with guidelines or limited access to specialists in certain areas, but it is worthy of further study.

We also unexpectedly found that 1 in 5 patients with EoE are currently receiving systemic steroids for treatment of their condition. National guidelines recommend prednisone only if topical steroids are ineffective or if patients require rapid improvement of symptoms. It is unclear whether the high reported use of systemic steroids seen in our study reflects providers’ unawareness of the other EoE treatment options, patients’ non-response to previous treatments including topical steroids or patients’ preference to take a tablet instead of swallowed inhaled steroids or steroid suspensions. Given the potential side effects that may result from long-term use of systemic steroids, efforts to improve understanding of this reported high use of them in EoE are warranted.

Our study has significant strengths and potential limitations. With respect to strengths, this is the largest US population-based study of participants with dysphagia. Another strength is the use of the PROMIS questionnaires, which were developed under NIH oversight and are a validated method to assess severity of dysphagia. We also assessed the impact of difficulty swallowing on respondents’ quality of life and need for compensatory techniques to manage their symptoms. Finally, we had a large subgroup of individuals with EoE, allowing us to
examine their healthcare-seeking behaviors and use of and satisfaction with the various treatments.

One limitation may be the fact that data were acquired via an Internet-based survey, so there could be concerns about generalizability, particularly among elderly individuals who may lack basic computing skills or regular access to the Internet. However, at the time of the survey in 2018, nearly two-thirds of those aged ≥65 years use the Internet. Additionally, we employed age-based quotas for respondents, ensuring an appropriate representation of elderly individuals within our sample. Response bias may have also affected the data, although we attempted to minimize this risk by labeling the survey as a generic health survey and including eight different GI symptoms in the blinded screening question. Finally, there are risks of misclassification and recall biases because the symptom, healthcare seeking, diagnosis and medication use data were self-reported. However, the recall period for the PROMIS dysphagia scale and the compensatory maneuver questions was only one week. These biases are also less of a concern for the EoE treatment-focused questions because we asked about respondents’ current therapy use. Previous investigators also found high agreement between medicines documented in the ambulatory medical record and patient survey data. However, past studies note that patients under-report their healthcare utilization; we therefore may have underestimated the prevalence of healthcare seeking for dysphagia and use of diagnostic testing. We similarly may have underestimated the prevalence of diagnoses as prior literature found that self-report of chronic diseases is highly specific but not as sensitive.

In conclusion, in this large population-based survey of over 31,000 Americans in the community, we found that dysphagia is common, affecting 1 in 6 adults. Symptoms are sufficiently bothersome that over 90% of these individuals employ compensatory maneuvers to ameliorate their difficulty swallowing. However, only half of individuals have sought healthcare for their symptoms. Efforts to better understand why these individuals do not seek care for their dysphagia are warranted as many of them may have treatable disorders.

**Supplementary Material**

Refer to Web version on PubMed Central for supplementary material.

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**ABBREVIATIONS:**

| Abbreviation | Description               |
|--------------|---------------------------|
| CI           | confidence interval       |
EoE  eosinophilic esophagitis
GERD  gastroesophageal reflux disease
GI    gastrointestinal
IQR   interquartile range
NIH   National Institutes of Health
OR    odds ratio
PPI   proton-pump inhibitor
PROMIS®  Patient-Reported Outcomes Measurement Information System
TSQM-9 Abbreviated Treatment Satisfaction Questionnaire for Medication

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**What You Need to Know**

**BACKGROUND:**
We performed a population-based survey of more than 31,000 adults to evaluate the epidemiology, clinical characteristics, and healthcare-seeking behavior of individuals with dysphagia.

**FINDINGS:**
Dysphagia is common, in that 1 of 6 adults reported experiencing difficulty swallowing. However, half of individuals have not discussed their symptoms with a clinician and many could have treatable disorders.

**IMPLICATIONS FOR PATIENT CARE:**
It is important to ask patients during examinations if they have symptoms of dysphagia.
Table 1.

Study population demographics (N=4998)

| Variable                        | Value         |
|---------------------------------|---------------|
| Age, years                      | 46.5 ± 15.7   |
| Gender                          |               |
| Male                            | 2353 (47.1)   |
| Female                          | 2645 (52.9)   |
| Race/ethnicity                  |               |
| Non-Hispanic white              | 3924 (78.5)   |
| Non-Hispanic black              | 283 (5.7)     |
| Latino                          | 433 (8.7)     |
| Asian                           | 137 (2.7)     |
| Other                           | 221 (4.4)     |
| Marital status                  |               |
| Married or in a long-term relation | 3045 (60.9)  |
| Not married                     | 1953 (39.1)   |
| Education level                 |               |
| High school graduate or less    | 1235 (24.7)   |
| Some college                    | 1521 (30.4)   |
| College graduate                | 1608 (32.2)   |
| Graduate degree                 | 634 (12.7)    |
| Employment status               |               |
| Unemployed                      | 2346 (46.9)   |
| Employed or full-time student   | 2652 (53.1)   |
| Total household income          |               |
| $0–50,000                       | 2400 (48.0)   |
| $50,001–100,000                 | 1667 (33.4)   |
| $100,001–200,000                | 659 (13.2)    |
| $200,001                        | 114 (2.3)     |
| Prefer not to say               | 158 (3.2)     |
| Has health insurance            | 4600 (92.0)   |
| Has a usual source of care      | 4092 (81.9)   |
| US region                       |               |
| Northeast                       | 944 (18.9)    |
| South                           | 1756 (35.1)   |
| Midwest                         | 1164 (23.3)   |
| West                            | 1134 (22.7)   |
| Has a medical comorbidity       | 2458 (49.2)   |
| Has a neurologic comorbidity    | 698 (14.0)    |
| Has an allergic comorbidity     | 3124 (62.5)   |
### Table 1: Variables and Values

| Variable                        | Value $^a$   |
|---------------------------------|-------------|
| Has a cancer diagnosis $^e$     | 389 (7.8)   |

$^a$ Data are presented as mean ± standard deviation or n (%).

$^b$ Includes celiac disease, chronic constipation, cirrhosis, Crohn’s disease, diabetes, fibromyalgia, gallstones, HIV/AIDS, irritable bowel syndrome, pancreatitis, peptic ulcer disease, Sjögren’s syndrome, thyroid disease or ulcerative colitis.

$^c$ Includes multiple sclerosis, myasthenia gravis, Parkinson’s disease, spinal cord injury or stroke.

$^d$ Includes asthma, chronic sinusitis, eczema or other skin allergy, food allergy or seasonal or environmental allergy.

$^e$ Includes breast, colorectal, liver, lung, lymphoma, pancreatic or stomach cancer. Those with esophageal or throat cancer were excluded from the study.
Table 2.

Dysphagia severity as measured by NIH PROMIS<sup>a</sup>

| NIH PROMIS dysphagia item                                                                 | All respondents, n (%) | Patients with EoE, n (%) |
|-------------------------------------------------------------------------------------------|------------------------|-------------------------|
| **In the past 7 days, how often did food get stuck in your chest when you were eating?** |                        |                         |
| Never                                                                                     | 1217 (24.3)            | 41 (10.3)               |
| Rarely                                                                                    | 1349 (27.0)            | 59 (14.8)               |
| Sometimes                                                                                 | 1744 (34.9)            | 121 (30.3)              |
| Often                                                                                     | 596 (11.9)             | 140 (35.1)              |
| Always                                                                                    | 92 (1.8)               | 38 (9.5)                |
| **In the past 7 days, how often did food get stuck in your throat when you were eating?** |                        |                         |
| Never                                                                                     | 1108 (22.2)            | 31 (7.8)                |
| Rarely                                                                                    | 1363 (27.3)            | 74 (18.5)               |
| Sometimes                                                                                 | 1726 (34.5)            | 119 (29.8)              |
| Often                                                                                     | 704 (14.1)             | 138 (34.6)              |
| Always                                                                                    | 97 (1.9)               | 37 (9.3)                |
| **In the past 7 days, how often did you feel pain in your chest when swallowing food?**   |                        |                         |
| Never                                                                                     | 1531 (30.6)            | 37 (9.3)                |
| Rarely                                                                                    | 1373 (27.5)            | 57 (14.3)               |
| Sometimes                                                                                 | 1419 (28.4)            | 121 (30.3)              |
| Often                                                                                     | 564 (11.3)             | 133 (33.3)              |
| Always                                                                                    | 111 (2.2)              | 51 (12.8)               |
| **In the past 7 days, how often did you have difficulty swallowing solid foods like meat, chicken or raw vegetables, even after lots of chewing?** | 1095 (21.9)           | 29 (7.3)                 |
| Rarely                                                                                    | 1317 (26.4)            | 70 (17.5)               |
| Sometimes                                                                                 | 1663 (33.3)            | 110 (27.6)              |
| Often                                                                                     | 755 (15.1)             | 135 (33.8)              |
| Always                                                                                    | 168 (3.4)              | 55 (13.8)               |
| **In the past 7 days, how often did you have difficulty swallowing soft foods like ice cream, apple sauce, or mashed potatoes?** | 2654 (53.1)           | 64 (16.0)                |
| Rarely                                                                                    | 1283 (25.7)            | 75 (18.8)               |
| Sometimes                                                                                 | 717 (14.3)             | 108 (27.1)              |
| Often                                                                                     | 269 (5.4)              | 109 (27.3)              |
| Always                                                                                    | 75 (1.5)               | 43 (10.8)               |
| **In the past 7 days, how often did you have difficulty swallowing liquids?**             |                        |                         |
| Never                                                                                     | 2390 (47.8)            | 60 (15.0)               |
| Rarely                                                                                    | 1321 (26.4)            | 93 (23.3)               |
| Sometimes                                                                                 | 905 (18.1)             | 101 (25.3)              |
| Often                                                                                     | 297 (5.9)              | 100 (25.1)              |

<sup>a</sup> NIH PROMIS: National Institutes of Health Patient Reported Outcomes Measurement Information System.
| NIH PROMIS dysphagia item | All respondents, n (%) | Patients with EoE, n (%) |
|---------------------------|------------------------|-------------------------|
|                           | N=4998                 | n=399                   |
| Always                    | 85 (1.7)               | 45 (11.3)               |
| **In the past 7 days, how often did you have difficulty swallowing pills?** |
| Never                     | 1420 (28.4)            | 40 (10.0)               |
| Rarely                    | 1180 (23.6)            | 50 (12.5)               |
| Sometimes                 | 1350 (27.0)            | 114 (28.6)              |
| Often                     | 735 (14.7)             | 122 (30.6)              |
| Always                    | 313 (6.3)              | 73 (18.3)               |

\(a\) Percentages might not add to 100% because of rounding.

\(b\) NIH PROMIS does not include a “not applicable” option for those who did not take pills in the past 7 days.

EoE, eosinophilic esophagitis; GI, gastrointestinal; NIH, National Institutes of Health; PROMIS, Patient-Reported Outcomes Measurement Information System.
Table 3.

Dysphagia compensatory maneuvers

| Compensatory maneuver performed in the past 7 days | All respondents, n (%) | Patients with EoE, n (%) |
|--------------------------------------------------|------------------------|--------------------------|
| Avoid certain foods to prevent dysphagia         |                        |                          |
| Never                                            | 2013 (40.3)            | 33 (8.3)                 |
| Rarely                                           | 927 (18.5)             | 52 (13.0)                |
| Sometimes                                        | 1172 (23.4)            | 119 (29.8)               |
| Often                                            | 694 (13.9)             | 139 (34.8)               |
| Always                                           | 192 (3.8)              | 56 (14.0)                |
| Cut food into small pieces or puree food         |                        |                          |
| Never                                            | 2155 (43.1)            | 39 (9.8)                 |
| Rarely                                           | 801 (16.0)             | 60 (15.0)                |
| Sometimes                                        | 1040 (20.8)            | 102 (25.6)               |
| Often                                            | 715 (14.3)             | 130 (32.6)               |
| Always                                           | 287 (5.7)              | 68 (17.0)                |
| Take longer to finish eating food than others    |                        |                          |
| Never                                            | 1174 (23.5)            | 21 (5.3)                 |
| Rarely                                           | 877 (17.5)             | 47 (11.8)                |
| Sometimes                                        | 1293 (25.9)            | 114 (28.6)               |
| Often                                            | 1013 (20.3)            | 125 (31.3)               |
| Always                                           | 641 (12.8)             | 92 (23.1)                |
| Drink liquid to help with dysphagia              |                        |                          |
| Never                                            | 698 (14.0)             | 15 (3.8)                 |
| Rarely                                           | 912 (18.2)             | 47 (11.8)                |
| Sometimes                                        | 1505 (30.1)            | 108 (27.1)               |
| Often                                            | 1199 (24.0)            | 141 (35.3)               |
| Always                                           | 684 (13.7)             | 88 (22.1)                |
| Crush or cut pills or take liquid forms of medicine |                    |                          |
| Never                                            | 2444 (60.9)            | 41 (11.5)                |
| Rarely                                           | 510 (12.7)             | 52 (14.6)                |
| Sometimes                                        | 537 (13.4)             | 99 (27.8)                |
| Often                                            | 350 (8.7)              | 115 (32.3)               |
| Always                                           | 175 (4.4)              | 49 (13.8)                |

aPercentages might not add to 100% because of rounding.

bAmong all respondents, 4016 individuals reported taking oral medication in the past 7 days. Of those with EoE, 356 took oral medication in the past 7 days.

EoE, eosinophilic esophagitis.
Table 4.
Predictors of having sought healthcare for dysphagia (N=4998)

| Variable                      | Sought healthcare for dysphagiaa | OR (95% CI)b |
|-------------------------------|----------------------------------|--------------|
| Age, years                    | 47.7 ± 15.4                      | 1.0052 (1.0004–1.0101) |
| Gender                        |                                  |              |
| Male                          | 1233 (52.4)                      | ref          |
| Female                        | 1320 (49.9)                      | 0.74 (0.65–0.85) |
| Race/ethnicity                |                                  |              |
| Non-Hispanic white            | 1983 (50.5)                      | ref          |
| Non-Hispanic black            | 166 (58.7)                       | 1.24 (0.92–1.66) |
| Latino                        | 237 (54.7)                       | 1.03 (0.81–1.33) |
| Asian                         | 59 (43.1)                        | 0.89 (0.60–1.33) |
| Other                         | 108 (48.9)                       | 0.80 (0.59–1.09) |
| Marital status                |                                  |              |
| Married or in a long-term relationship | 1623 (53.3)                      | ref          |
| Not married                   | 930 (47.6)                       | 0.94 (0.82–1.08) |
| Education level               |                                  |              |
| High school graduate or less  | 610 (49.4)                       | ref          |
| Some college                  | 734 (48.3)                       | 1.00 (0.84–1.18) |
| College graduate              | 852 (53.0)                       | 1.19 (0.99–1.42) |
| Graduate degree               | 357 (56.3)                       | 1.20 (0.95–1.53) |
| Employment status             |                                  |              |
| Unemployed                    | 1263 (53.8)                      | ref          |
| Employed or full-time student | 1290 (48.6)                      | 0.91 (0.78–1.06) |
| Total household income        |                                  |              |
| $0–50,000                     | 1173 (48.9)                      | ref          |
| $50,001–100,000               | 889 (53.3)                       | 1.17 (1.00–1.37) |
| $100,001–200,000              | 354 (53.7)                       | 1.07 (0.85–1.33) |
| ≥$200,001                     | 64 (56.1)                        | 1.08 (0.69–1.69) |
| Prefer not to say             | 73 (46.2)                        | 1.22 (0.85–1.76) |
| Health insurance status       |                                  |              |
| Uninsured                     | 104 (26.1)                       | ref          |
| Insured                       | 2449 (53.2)                      | 1.90 (1.45–2.48) |
| Has a usual source of care    |                                  |              |
| Yes                           | 2339 (57.2)                      | ref          |
| No                            | 190 (23.5)                       | 0.30 (0.25–0.37) |
| Unknown                       | 24 (24.5)                        | 0.26 (0.16–0.43) |
| US region                     |                                  |              |
| Northeast                     | 504 (53.4)                       | ref          |
| South                         | 893 (50.9)                       | 0.92 (0.76–1.10) |
| Variable                         | Sought healthcare for dysphagia<sup>a</sup> | OR (95% CI)<sup>b</sup> |
|---------------------------------|---------------------------------------------|-------------------------|
|                                 | n=2553                                      |                         |
| Midwest                         | 595 (51.1)                                 | 0.97 (0.80–1.18)        |
| West                            | 561 (49.5)                                 | 0.88 (0.72–1.07)        |

| Has a medical comorbidity       |                                             |                         |
|---------------------------------|---------------------------------------------|-------------------------|
| No                              | 1003 (39.5)                                | ref                     |
| Yes                             | 1550 (63.1)                                | 1.74 (1.52–2.00)        |

| Has a neurologic comorbidity    |                                             |                         |
|---------------------------------|---------------------------------------------|-------------------------|
| No                              | 2049 (47.7)                                | ref                     |
| Yes                             | 504 (72.2)                                 | 1.73 (1.41–2.12)        |

| Has an allergic comorbidity     |                                             |                         |
|---------------------------------|---------------------------------------------|-------------------------|
| No                              | 836 (44.6)                                 | ref                     |
| Yes                             | 1717 (55.0)                                | 1.16 (1.01–1.32)        |

| Has a cancer diagnosis          |                                             |                         |
|---------------------------------|---------------------------------------------|-------------------------|
| No                              | 2265 (49.1)                                | ref                     |
| Yes                             | 288 (74.0)                                 | 1.31 (1.00–1.73)        |

| Believes dysphagia is a serious health problem |                                             |                         |
|-----------------------------------------------|---------------------------------------------|-------------------------|
| 1 (not at all)                                | 203 (26.4)                                 | ref                     |
| 2                                             | 479 (40.3)                                 | 1.53 (1.24–1.90)        |
| 3                                             | 785 (52.9)                                 | 2.14 (1.73–2.65)        |
| 4                                             | 652 (67.5)                                 | 3.26 (2.56–4.16)        |
| 5 (very much)                                | 434 (73.4)                                 | 4.30 (3.26–5.67)        |

| Dysphagia PROMIS score, percentile, 0–100<sup>c</sup> | 52.7 ± 30.4 | 1.012 (1.010–1.015) |
|-------------------------------------------------------|-------------|-------------------|
| Physical global health PROMIS score, t-score<sup>d</sup> | 42.2 ± 8.3  | 0.991 (0.980–1.001) |
| Mental global health PROMIS score, t-score<sup>d</sup>  | 45.7 ± 9.4  | 1.017 (1.008–1.026) |

<sup>a</sup>Data are presented as mean ± standard deviation, or n (% of row).

<sup>b</sup>The logistic regression model adjusted for all covariates in the table.

<sup>c</sup>Higher score corresponds to more severe symptoms.

<sup>d</sup>Higher score corresponds to better health.

CI, confidence interval; OR, odds ratio; PROMIS, Patient-Reported Outcomes Measurement Information System; ref, reference.
Table 5.
Predictors of having an EoE diagnosis (N=4998)

| Variable                     | Has an EoE diagnosis \(^a\) (n=399) | OR (95% CI) \(^b\) |
|------------------------------|-------------------------------------|-------------------|
| Age, years                   | 36.1 ± 11.4                         | 0.947 (0.937–0.958) |
| Gender                       |                                     |                   |
| Male                         | 251 (10.7)                          | ref               |
| Female                       | 148 (5.6)                           | 0.52 (0.40–0.67)  |
| Race/ethnicity               |                                     |                   |
| Non-Hispanic white           | 226 (5.8)                           | ref               |
| Non-Hispanic black           | 46 (16.3)                           | 1.82 (1.18–2.82)  |
| Latino                       | 95 (21.9)                           | 1.88 (1.33–2.66)  |
| Asian                        | 14 (10.2)                           | 1.14 (0.56–2.29)  |
| Other                        | 18 (8.1)                            | 1.18 (0.67–2.10)  |
| Marital status               |                                     |                   |
| Married or in a long-term relationship | 298 (9.8)                      | ref               |
| Not married                  | 101 (5.2)                           | 0.66 (0.50–0.88)  |
| Education level              |                                     |                   |
| High school graduate or less | 92 (7.5)                            | ref               |
| Some college                 | 57 (3.8)                            | 0.63 (0.43–0.93)  |
| College graduate             | 156 (9.7)                           | 1.20 (0.85–1.68)  |
| Graduate degree              | 94 (14.8)                           | 1.64 (1.07–2.52)  |
| Employment status            |                                     |                   |
| Unemployed                   | 113 (4.8)                           | ref               |
| Employed or full-time student| 286 (10.8)                          | 1.15 (0.85–1.57)  |
| Total household income       |                                     |                   |
| $0–50,000                    | 133 (5.5)                           | ref               |
| $50,001–$100,000             | 146 (8.8)                           | 1.07 (0.78–1.46)  |
| $100,001–$200,000            | 92 (14.0)                           | 1.30 (0.87–1.93)  |
| ≥$200,001                    | 25 (21.9)                           | 2.21 (1.19–4.10)  |
| Prefer not to say            | 3 (1.9)                             | 0.53 (0.16–1.79)  |
| Health insurance status      |                                     |                   |
| Uninsured                    | 8 (2.0)                             | ref               |
| Insured                      | 391 (8.5)                           | 2.52 (1.17–5.46)  |
| Has a usual source of care   |                                     |                   |
| Yes                          | 362 (8.9)                           | ref               |
| No                           | 32 (4.0)                            | 0.65 (0.43–0.99)  |
| Unknown                      | 5 (5.1)                             | 0.51 (0.17–1.49)  |
| US region                    |                                     |                   |
| Northeast                    | 83 (8.8)                            | ref               |
| South                        | 134 (7.6)                           | 0.97 (0.68–1.37)  |

* \(^a\) \(p<0.05\)*
| Variable                        | Has an EoE diagnosis<sup>a</sup> | OR (95% CI)<sup>b</sup> |
|--------------------------------|---------------------------------|-------------------------|
|                                | n=399                           |                         |
| Midwest                        | 72 (6.2)                        | 1.02 (0.69–1.51)        |
| West                           | 110 (9.7)                       | 1.38 (0.95–2.01)        |
| Has a medical comorbidity      |                                 |                         |
| No                             | 89 (3.5)                        | ref                     |
| Yes                            | 310 (12.6)                      | 4.10 (3.06–5.50)        |
| Has an allergic comorbidity    |                                 |                         |
| No                             | 102 (5.4)                       | ref                     |
| Yes                            | 297 (9.5)                       | 1.28 (0.97–1.70)        |
| Believes dysphagia is a serious health problem | | |
| 1 (not at all)                 | 10 (1.3)                        | ref                     |
| 2                              | 29 (2.4)                        | 1.42 (0.67–3.01)        |
| 3                              | 97 (6.5)                        | 2.48 (1.24–4.99)        |
| 4                              | 142 (14.7)                      | 3.36 (1.64–6.88)        |
| 5 (very much)                  | 121 (20.5)                      | 5.80 (2.81–12.00)       |
| Dysphagia PROMIS score, percentile, 0–100<sup>c</sup> | 72.7 ± 27.6 | 1.020 (1.014–1.025) |
| Physical global health PROMIS score, t-score<sup>d</sup> | 42.5 ± 6.8 | 0.992 (0.970–1.015) |
| Mental global health PROMIS score, t-score<sup>d</sup> | 47.6 ± 8.2 | 1.036 (1.018–1.055) |

<sup>a</sup>Data are presented as mean ± standard deviation, or n (% of row).

<sup>b</sup>The logistic regression model adjusted for all covariates in the table.

<sup>c</sup>Higher score corresponds to more severe symptoms.

<sup>d</sup>Higher score corresponds to better health.

CI, confidence interval; EoE, eosinophilic esophagitis; OR, odds ratio; PROMIS, Patient-Reported Outcomes Measurement Information System; ref, reference.
Table 6.

EoE treatment combinations (n=395\textsuperscript{a})

| EoE treatment(s)                                      | n (%)   |
|------------------------------------------------------|---------|
| One steroid-based medicine only                       | 77 (19.5) |
| PPI and steroid-based medicine(s)                     | 72 (18.2) |
| PPI only                                             | 69 (17.5) |
| PPI, steroid-based medicine(s) and elimination diet   | 56 (14.2) |
| Steroid-based medicine(s) and elimination diet        | 39 (9.9)  |
| Two or more steroid-based medicines                   | 22 (5.6)  |
| PPI and elimination diet                              | 17 (4.3)  |
| Elimination diet only                                 | 13 (3.3)  |
| Other medicine only                                   | 2 (0.5)   |
| PPI and other medicine                                | 1 (0.3)   |
| Steroid-based medicine(s) and other medicine         | 1 (0.3)   |
| No EoE treatment                                      | 26 (6.6)  |

\textsuperscript{a}Four of the 399 individuals with EoE reported that they did not know which treatments they were receiving.

EoE, eosinophilic esophagitis; PPI, proton-pump inhibitor.