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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.[4]

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.[4, 14] 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 Questionnaire[16] 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 χ^2 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 ≥1 esophageal disorder: 1545 (76.1%)—1 disorder; 369 (18.2%)—2 disorders; 117 (5.8%)—≥3 disorders. The following conditions were reported: 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.[10] 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.[2, 4–9, 11–13] A US study by Camilleri et al. noted that 7.8% reported at least monthly dysphagia over the past three months.[2] An Argentina study discovered that 12.9% of respondents experienced dysphagia in the past year.[8] In contrast, lower prevalences of dysphagia have been seen in Asian countries[9, 12, 13]; Wang and colleagues noted that only 1.7% of respondents from Xi’an, China, reported difficulty swallowing in the last year.[12]

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,[17] 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.[18] 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.[17] 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[19]—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.[19] Atopic diseases such as asthma, atopic dermatitis, allergic rhinitis and food allergies also have been found to be associated with EoE[20]; a recent study showed that over three-quarters of patients with EoE have concomitant atopic disease.[21] 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.[22] 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.[23] 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.[23] 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.[23] 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.[14] 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.[24] 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.[25] However, past studies note that patients under-report their healthcare utilization[26]; 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.[27]

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:

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

References

1. Abdel Jalil AA, Katzka DA, Castell DO. Approach to the patient with dysphagia. Am J Med. 2015;128(10):1138.e17–23.
2. Camilleri M, Dubois D, Coulie B, et al. Prevalence and socioeconomic impact of upper gastrointestinal disorders in the United States: results of the US Upper Gastrointestinal Study. Clin Gastroenterol Hepatol. 2005;3(6):543–52. [PubMed: 15952096]
3. Peery AF, Crockett SD, Murphy CC, et al. Burden and cost of gastrointestinal, liver, and pancreatic diseases in the United States: update 2018. Gastroenterology 2019;156(1):254–72.e11. [PubMed: 30315778]
4. Almario CV, Ballal ML, Chey WD, et al. Burden of gastrointestinal symptoms in the United States: results of a nationally representative survey of over 71,000 Americans. Am J Gastroenterol 2018;113(11):1701–10. [PubMed: 30323268]
5. Bhattacharyya N. The prevalence of dysphagia among adults in the United States. Otolaryngol Head Neck Surg 2014;151(5):765–9. [PubMed: 25193514]
6. Cho SY, Choung RS, Saito YA, et al. Prevalence and risk factors for dysphagia: a USA community study. Neurogastroenterol Motil 2015;27(2):212–9. [PubMed: 25376877]
7. Drossman DA, Li Z, Andruzzi E, et al. U.S. householder survey of functional gastrointestinal disorders. Prevalence, sociodemography, and health impact. Dig Dis Sci 1993;38(9):1569–80. [PubMed: 8359066]
8. Chiocca JC, Olmos JA, Salis GB, et al. Prevalence, clinical spectrum and atypical symptoms of gastro-oesophageal reflux in Argentina: a nationwide population-based study. Aliment Pharmacol Ther. 2005;22(4):331–42. [PubMed: 16098000]
9. Cho YS, Choi MG, Jeong JJ, et al. Prevalence and clinical spectrum of gastroesophageal reflux: a population-based study in Asan-si, Korea. Am J Gastroenterol. 2005;100(4):747–53. [PubMed: 15784014]
10. Eslick GD, Talley NJ. Dysphagia: epidemiology, risk factors and impact on quality of life--a population-based study. Aliment Pharmacol Ther. 2008;27(10):971–9. [PubMed: 18315591]
11. Ruth M, Mansson I, Sandberg N. The prevalence of symptoms suggestive of esophageal disorders. Scand J Gastroenterol. 1991;26(1):73–81. [PubMed: 2006401]
12. Wang JH, Luo JY, Dong L, et al. Epidemiology of gastroesophageal reflux disease: a general population-based study in Xi'an of Northwest China. World J Gastroenterol. 2004;10(11):1647–51. [PubMed: 15162542]
13. Wong WM, Lai KC, Lam KF, et al. Prevalence, clinical spectrum and health care utilization of gastro-oesophageal reflux disease in a Chinese population: a population-based study. Aliment Pharmacol Ther. 2003;18(6):595–604. [PubMed: 12969086]

14. Spiegel BM, Hays RD, Bolus R, et al. Development of the NIH Patient-Reported Outcomes Measurement Information System (PROMIS) gastrointestinal symptom scales. Am J Gastroenterol. 2014;109(11):1804–14. [PubMed: 25199473]
15. Bharmal M, Payne K, Atkinson MJ, et al. Validation of an abbreviated Treatment Satisfaction Questionnaire for Medication (TSQM-9) among patients on antihypertensive medications. Health Qual Life Outcomes 2009;7:36. [PubMed: 19397800] Those seeking information regarding or permission to use the TSQM are directed to IQVIA at www.iqvia.com/TSQM or TSQM@iqvia.com.
16. Hays RD, Bjorner JB, Revicki DA, et al. Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. Qual Life Res. 2009;18(7):873–80. [PubMed: 19543809]
17. Varadarajulu S, Eloubeidi MA, Patel RS, et al. The yield and the predictors of esophageal pathology when upper endoscopy is used for the initial evaluation of dysphagia. Gastrointest Endosc. 2005;61(7):804–8. [PubMed: 15933679]
18. Pasha SF, Acosta RD, Chandrasekhara V, et al. The role of endoscopy in the evaluation and management of dysphagia. Gastrointest Endosc. 2014;79(2):191–201. [PubMed: 24332405]
19. Arias A, Perez-Martinez I, Tenias JM, et al. Systematic review with meta-analysis: the incidence and prevalence of eosinophilic oesophagitis in children and adults in population-based studies. Aliment Pharmacol Ther. 2016;43(1):3–15.
20. Gonzalez-Cervera J, Arias A, Redondo-Gonzalez O, et al. Association between atopic manifestations and eosinophilic esophagitis: a systematic review and meta-analysis. Ann Allergy Asthma Immunol 2017;118(5):582–90.e2. [PubMed: 28366582]
21. Mohammad AA, Wu SZ, Ibrahim O, et al. Prevalence of atopic comorbidities in eosinophilic esophagitis: a case-control study of 449 patients. J Am Acad Dermatol 2017;76(3):559–60. [PubMed: 28212761]
22. Dall T, West T, Chakrabarti R, et al. The complexities of physician supply and demand: projections from 2013 to 2025. Washington, DC: Association of American Medical Colleges, 2015.
23. Dellon ES, Gonsalves N, Hirano I, et al. ACG clinical guideline: Evidenced based approach to the diagnosis and management of esophageal eosinophilia and eosinophilic esophagitis (EoE). Am J Gastroenterol. 2013;108(5):679–92. [PubMed: 23567357]
24. Pew Research Center. Internet/broadband fact sheet. 2019 [cited 2019 August 5]; Available from: http://www.pewinternet.org/fact-sheet/internet-broadband/.
25. Tisnado DM, Adams JL, Liu H, et al. What is the concordance between the medical record and patient self-report as data sources for ambulatory care? Med Care 2006:132–40. [PubMed: 16434912]
26. Ritter PL, Stewart AL, Kaymaz H, et al. Self-reports of health care utilization compared to provider records. J Clin Epidemiol 2001;54(2):136–41. [PubMed: 11166528]
27. Okura Y, Urban LH, Mahoney DW, et al. Agreement between self-report questionnaires and medical record data was substantial for diabetes, hypertension, myocardial infarction and stroke but not for heart failure. J Clin Epidemiol 2004;57(10):1096–103. [PubMed: 15528061]

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[a]
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 relationship	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[b]	2458 (49.2)
Has a neurologic comorbidity[c]	698 (14.0)
Has an allergic comorbidity[d]	3124 (62.5)

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[a]

NIH PROMIS dysphagia item	All respondents, n (%) N=4998	Patients with EoE, n (%) n=399
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?		
Never	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?		
Never	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)

NIH PROMIS dysphagia item	All respondents, n (%) N=4998	Patients with EoE, n (%) n=399
Always	85 (1.7)	45 (11.3)
In the past 7 days, how often did you have difficulty swallowing pills?[b]		
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[a]

Compensatory maneuver performed in the past 7 days	All respondents, n (%) N=4998	Patients with EoE, n (%) n=399
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[b]		
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)

[a]Percentages might not add to 100% because of rounding.

[b]Among 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 dysphagia[a] n=2553	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[a] n=2553	OR (95% CI)[b]
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[c]	52.7 ± 30.4	1.012 (1.010–1.015)
Physical global health PROMIS score, t-score[d]	42.2 ± 8.3	0.991 (0.980–1.001)
Mental global health PROMIS score, t-score[d]	45.7 ± 9.4	1.017 (1.008–1.026)

[a] Data are presented as mean ± standard deviation, or n (% of row).

[b] The logistic regression model adjusted for all covariates in the table.

[c] Higher score corresponds to more severe symptoms.

[d] 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)

Variable	Has an EoE diagnosis[a] n=399	OR (95% CI)[b]
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[c]	72.7 ± 27.6	1.020 (1.014–1.025)
Physical global health PROMIS score, t-score[d]	42.5 ± 6.8	0.992 (0.970–1.015)
Mental global health PROMIS score, t-score[d]	47.6 ± 8.2	1.036 (1.018–1.055)

[a] Data are presented as mean ± standard deviation, or n (% of row).

[b] The logistic regression model adjusted for all covariates in the table.

[c] Higher score corresponds to more severe symptoms.

[d] 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[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)

[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.