

# The Prevalence of Dysphagia in Primary Care Patients: A HamesNet Research Network Study

Thad Wilkins, MD, Ralph A. Gillies, PhD, Andria M. Thomas, PhD, and Peggy J. Wagner, PhD

**Purpose:** A number of disorders cause dysphagia, which is the perception of an obstruction during swallowing. The purpose of this study was to determine the prevalence of dysphagia in primary care patients.

**Methods:** Adults 18 years old and older were the subjects of an anonymous survey that was collected in the clinic waiting room before patients were seen by a physician. Twelve family medicine offices in HamesNet, a research network in Georgia, participated.

**Results:** Of the 947 study participants, 214 (22.6%) reported dysphagia occurring several times per month or more frequently. Those reporting dysphagia were more likely to be women (80.8% women vs 19.2% men,  $P = .002$ ) and older (mean age of 48.1 in patients with dysphagia vs mean age of 45.7 in patients without dysphagia,  $P = .001$ ). Sixty-four percent of patients with dysphagia indicated that they were concerned about their symptoms, but 46.3% had not spoken with their doctor about their symptoms. Logistic regression analyses showed that increased frequency [odds ratio (OR) = 2.15, 95% CI 1.41–3.30], duration (OR = 1.91, CI 1.24–2.94), and concern (OR = 2.64, CI 1.36–5.12) of swallowing problems as well as increased problems eating out (OR = 1.72, CI 1.19–2.49) were associated with increased odds of having talked to a physician.

**Conclusions:** This is the first report of the prevalence of dysphagia in an unselected adult primary care population. Dysphagia occurs commonly in primary care patients but often is not discussed with a physician. (J Am Board Fam Med 2007;20:144–150.)

Swallowing is a complex motor reflex requiring coordination among the neurologic system, the oropharynx, and the esophagus. A number of disorders, both benign and malignant, interfere with the swallowing process and cause dysphagia.<sup>1</sup> Patients with dysphagia suffer significant social and psychological burdens associated with their symptoms of difficulty with swallowing, including anxiety with meals or avoidance of eating with others.<sup>2</sup>

The diagnosis of dysphagia is important because of the associated morbidity and mortality. Un-

treated dysphagia can lead to dehydration, malnutrition, respiratory infections, and death.<sup>2</sup> The elderly with symptoms of dysphagia are at increased risk of the complications of dysphagia, including aspiration pneumonia.<sup>3</sup> Several studies have identified the elderly as being at risk for the development of dysphagia.<sup>4,5</sup> The prevalence of solid-food dysphagia was found to be 7% in elderly patients (62 years old and older) in a family medicine clinic in a medical university.<sup>6</sup>

The prevalence of dysphagia varies depending on the concomitant medical disorders, the population studied, and the diagnostic instrument used. For example, dysphagia is estimated to occur in 29% to 64% of stroke patients.<sup>7–9</sup> The prevalence of dysphagia varies in other neurologic disorders: from 24% to 34% in people with multiple sclerosis<sup>10,11</sup> to 81% in people with Parkinson's disease.<sup>12</sup> Dysphagia is associated with gastroesophageal reflux disease (GERD).<sup>1</sup> A population-based study found the overall prevalence of dysphagia to be 13.5%; however, dysphagia was significantly more common in subjects with GERD (30%) versus subjects without GERD (4%).<sup>13</sup>

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From the Department of Family Medicine, Medical College of Georgia, Augusta, GA.

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Corresponding author: Thad Wilkins, MD, Department of Family Medicine, Medical College of Georgia, HB-4031, Augusta, GA 30912 (E-mail: [twilkins@mail.mcg.edu](mailto:twilkins@mail.mcg.edu)).

Research to date on dysphagia has been in general populations or in elderly primary care patients. The primary purpose of this study was to determine the prevalence of dysphagia in all adult primary care patients. In this publication and in the survey, we use the term “dysphagia” to mean ever having 1 or more episodes of the feeling that food was stuck in their chest or throat or choking or coughing with swallowing. We define clinically important dysphagia as having these symptoms a minimum of several times per month. We were also interested in the behavioral and psychological impact of dysphagia, the frequency of dysphagia symptoms, and whether patients had discussed their symptoms with their physician.

## Methods

### *Instrument*

A survey instrument was developed (Flesch-Kincaid reading level 6.6) to assess patients’ concerns related to swallowing problems (Appendix). The survey included 4 demographic items (ie, age, sex, ethnicity, and race) and 9 content items addressing swallowing difficulties (ie, frequency, duration, foods, patient concern, impact on daily functioning, discussion with physician, medicine, additional treatment efforts, prior diagnostic testing). Patients with a self-reported history of a swallowing problem were prompted to complete the entire survey; patients with no swallowing problems stopped after the history and demographic items. The survey and research protocol for this study were approved by our institutional review board.

### *Subjects*

Nonacute, English-speaking, adult patients presenting to primary care practice sites participating in the HimesNet Research Network during 2 specified periods (ie, 2 weeks in spring 2004 and 2 weeks in fall 2004) were eligible to participate in the survey. The data collection sites included 1 large (40 physicians) urban family medicine center located at a southeastern medical school and 4 medium (3 or 4 physicians) and 7 small (1 or 2 physicians) rural family medicine clinics located throughout Georgia. Based on data obtained from clinics initially joining HimesNet, the demographics of the patient population were expected to be approximately 32.5% African American, 0.4%

American Indian, 1.2% Asian, 9.6% Hispanic, 0.2% Hawaiian, and 56% white.

### *Design*

A clinic staff member or research assistant approached potentially eligible patients in each clinic’s waiting room and asked whether they were willing to complete the survey before their office visit. Staff members were encouraged to present the questionnaire to all sequential patients. Willing patients were given the survey, an information sheet providing instructions for completing the survey, and a printed explanation that participation was completely voluntary and independent of the health care received. Assistance with completing the survey was provided if requested by the patient. The surveys were returned to the clinic staff member or dropped in a secured collection box located in the waiting room. Finally, all completed surveys were forwarded to the study investigators for data entry and analysis.

### *Data Analysis*

For statistical comparison of demographic variables between patients with and without dysphagia, we used Pearson  $\chi^2$  analysis. Exploratory multiple regression analysis and log linear regression analyses were conducted, examining demographics, speaking to a physician, and concern about dysphagia. SPSS software, version 13.0, was used for all analyses. In our analysis, only patients who reported swallowing problems several times per month or more were categorized as having clinically significant dysphagia.

Logistic regression analyses were conducted to determine how likely patients were to have talked to their physicians about dysphagia symptoms, have taken medications for symptoms, or have been tested for symptoms. A bivariate correlational matrix was generated for all independent factors (eg, age, race, gender, frequency, duration, interference with eating out, concern) and the outcome factors. Any independent factor that correlated with an outcome factor at  $P < .05$  was included in the logistic regression model. All logistic regression analyses were examined for multicollinearity, and none was detected.

### *Results*

Of the 947 study participants, 214 (22.6%) reported dysphagia a minimum of several times per

**Table 1. Descriptors of Patients with Clinically Significant Dysphagia (a Minimum of Several Times Per Month) and without Dysphagia (n = 947)\***

	Total n (%)	No. Patients with Dysphagia (%)†	No. Patients without Dysphagia (%)†
Patients with dysphagia	214 (22.6)		
Patients without dysphagia	733 (77.4)		
Age (mean ± SD)		48.1 (14.4)‡	45.7 (16.6)
Gender			
Male		41 (19.2)§	213 (29.1)
Female		173 (80.8)§	519 (70.1)
Ethnicity			
Hispanic		4 (2.1)	23 (3.6)
Non-Hispanic		183 (97.9)	624 (96.4)
Race			
African American		90 (43.1)	281 (39.2)
White		115 (55.0)	426 (59.3)
Other		4 (1.9)	11 (1.5)
Frequency of dysphagia			
Several times per month	106 (49.5)		
Several times per week	68 (31.8)		
Several times per day	40 (18.7)		
Duration			
<1 year	56 (26.8)		
1 to 5 years	99 (47.4)		
5 or more years	54 (25.8)		
Consistency of food associated with dysphagia			
Solids only	101 (49.0)		
Liquids only	13 (6.3)		
Both solids and liquids	92 (44.7)		
Patients with dysphagia who do not take medication for their symptoms	126 (60.6)		
Patients with dysphagia who have not had a diagnostic test for their symptoms	136 (65.1)		
Concerned about dysphagia	136 (63.6)		

\* Numbers do not include missing data.

† Percentages are within demographic group. For example, 19.2% of male patients reported dysphagia.

‡ Patients with dysphagia were significantly older than patients without dysphagia ( $P = .001$ ).

§ Gender difference in dysphagia is significant ( $P = .002$ ).

month. Those reporting dysphagia were more likely to be women (80.8% women vs 19.2% men,  $P = .002$ ) and older (mean age of 48.1 in patients with dysphagia vs mean age of 45.7 in patients without dysphagia,  $P = .001$ ). There were no racial differences in the prevalence of dysphagia.

Of those with dysphagia, 19% of patients reported experiencing the symptoms several times per day. Thirty-two percent and 49.5% reported the symptoms several times per week and month, respectively. Of the patients who reported dysphagia, 49.0% reported problems swallowing with solids only, 6.3% with liquids only, and 44.7% with both solids and liquids. More than one quarter

(26.8%) of patients with dysphagia reported having problems swallowing for less than 1 year, 47.4% for 1 to 5 years, and 25.8% for more than 5 years. (See Table 1 for a summary of descriptors of patients with dysphagia.)

A relatively high response rate (71.6%) among approached subjects was observed at the largest practice site; however, the smaller sites were not able to track response rates because of insufficient clinic staff and time limitations. Rates of reported dysphagia ranged from 5% to 40%, with 10 of the 12 sites reporting percentages between 14% and 27%, including the largest site where response rate was tracked. Excluding the 2 outlying sites did not

**Table 2. Behavioral and Psychological Impact of Dysphagia\***

Impact	No. Who Have Talked with Physician about Dysphagia (%)†	No. Who Have Not Talked with Physician about Dysphagia (%)	P
Concerned about dysphagia	86 (63.2)	50 (36.8)	<.0005
Dysphagia affects eating out or eating with other people	74 (67.9)	35 (32.1)	<.0005
Avoids certain foods	38 (71.7)	15 (28.3)	.001
Takes smaller bites	51 (60.0)	34 (40.0)	.058
Washes down food with liquids	51 (56.7)	39 (43.3)	.207
No medications for dysphagia symptoms	45 (35.7)	81 (64.3)	<.0005
No diagnostic tests for dysphagia symptoms	65 (89.0)	8 (11.0)	<.0005

\* Data presented on  $\chi^2$  analysis of patients with dysphagia only (n = 214), missing data not included.

† Percentages are within group. For example, 63.2% patients who were concerned about their dysphagia spoke with their doctor about their symptoms.

change the mean frequency of self-reported dysphagia. The number of surveys obtained at each site varied from 21 to 572 (largest practice site). The average number of surveys obtained at the 11 community sites was 35.6.  $\chi^2$  analysis revealed that there were some demographic differences between the sites in terms of gender ( $P = .029$ ) and percentage of African Americans ( $P < .0005$ ). However, there were no statistically significant differences in dysphagia prevalence or any other survey items by site.

### Reporting Dysphagia to the Physician

Nearly one half of the patients with dysphagia (46.3%) had not spoken with their doctor about their symptoms. As expected, patients who were concerned about their swallowing problem were more likely to speak with a doctor about their symptoms than unconcerned patients ( $P < .0005$ ). See Table 2 for a complete summary of the behavioral and psychological impact of dysphagia.

### Regression Analyses

Increased frequency (OR = 2.15, 95% CI 1.41–3.30), duration (OR = 1.91, CI 1.24–2.94), and concern (OR = 2.64, CI 1.36–5.12) about swallowing problems as well as increased problems eating out (OR = 1.72, CI 1.19–2.49) were associated with increased odds of having talked to a physician. These independent factors accounted for 26.2% (Nagelkerke  $R^2$ )<sup>14,15</sup> of the variance in the model of who talks to physicians about symptoms. As described earlier, only independent factors that correlated significantly with an outcome factor were included in the logistic regression model. However,

although medication and testing correlated with talking to a physician about swallowing problems, we excluded these variables from the regression because medication and testing were highly likely to have occurred after discussing the problem with a physician, violating the temporal progression of the regression model.

For patients who had talked with their physicians about dysphagia symptoms, being female (OR = 4.27, CI 1.23–14.83) and testing related to swallowing problems (OR = 4.60, CI 1.82–11.61) were associated with increased odds of having taken medication for dysphagia symptoms. The independent factors accounted for 29% (Nagelkerke  $R^2$ ) of the variance of who receives medication for symptoms. Both frequency of swallowing problems and duration of symptoms were in the model, but neither added significantly to the model.

In addition, for patients who have talked with their physicians, use of medication for dysphagia symptoms (OR = 5.16, CI 2.1–12.66) and duration of symptoms (OR = 2.33, CI 1.18–4.61) was associated with increased odds of having been tested for dysphagia symptoms. These independent factors accounted for 28.5% (Nagelkerke  $R^2$ ) of the variance of patients who received testing for symptoms. No other factors were included in this model.

### Discussion

This practice-based study revealed a high rate of self-reported dysphagia (approximately one fifth of patients). This prevalence is higher than in previous studies and indicates that when the question is simple (do you have trouble swallowing?) as well as



when data are gathered in a distributed practice-based study, a different picture of patient-perceived prevalence of dysphagia arises. The value of self-report data are frequently called into question, yet self-reporting of symptoms is the hallmark of patient care and medical interviewing.<sup>16</sup> We recognize the limitations of self-report data as it corresponds to occurrence of disease<sup>17</sup> but see little reason why reporting of trouble swallowing would be influenced by a patient's desire to "look good" or to distort recall of the frequency of this particular symptom in a positive or negative way.

In addition, the high prevalence rate may in part be explained by the greater sampling of women in the study population and the corresponding fact that women were more likely to report trouble swallowing than men. In the absence of any biological explanation for this gender difference, it may be explained by the similar greater likelihood of women than men to report gastrointestinal symptoms.<sup>18</sup> It is interesting that one predictor of receiving medications for this symptom is gender. Perhaps women are more assertive in requesting treatment, are more likely to receive a recommendation for testing from their physician, and are more likely to adhere to medication recommendations. Further research is needed to clarify that finding.

As expected, dysphagia was more likely in older adults. One study found that people over the age of 65 may account for two thirds of all people with dysphagia.<sup>19</sup> Medical conditions predisposing patients to dysphagia include stroke, Alzheimer disease, amyotrophic lateral sclerosis, and Parkinson's disease.<sup>3</sup> The prevalence of all these conditions increases with increasing age. However, there is no significant difference in the prevalence of dysphagia in elderly patients with gastroesophageal reflux disease.<sup>6</sup>

The data also revealed that 35% of patients with self-reported trouble swallowing are not concerned about the symptom and 46% have not discussed this symptom with their physician. These data reflect the continuous process of problem definition that occurs as patients translate symptoms to problems and identify problems as needing medical care. Previous research suggests that, at any given time, between 70% and 90% of people have a treatable medical condition but of those who feel "ill," only approximately 40% seek care.<sup>20</sup> Pennebaker's classic work on the experience of symptoms suggests the presence and psychological nature of the interpretation of symptoms, with such interpretation and health

care seeking behavior varying by gender, culture, mood, prior experience, perceived seriousness, and use of the lay referral network recommendations.<sup>21</sup>

The regression analyses suggest that ultimately talking with one's physician is determined by the symptom duration and frequency, how much the symptoms interfere with eating in public, and how concerned the patients are about the symptoms. Given that 46% of patients with dysphagia do not talk to their physician regarding their swallowing problems, patients in high-risk groups (patients with a history of stroke, multiple sclerosis, or chronic GERD associated with weight loss or bleeding) may be at significant clinical risk for cancer or aspiration pneumonia. Future research needs to include comorbidities to examine the differences in reporting levels between those in high-risk groups and those who are not. Perhaps a 2-tier identification process in which high-risk patients are more aggressively treated could prove important in preventing significant morbidity and mortality.

Trouble swallowing is an intermittent symptom, with almost 80% of patients reporting trouble swallowing but not at a clinically significant level. Surely it is less likely for these patients to interpret this symptom as one that needs physician care because of this low and intermittent frequency. As clinicians, it may be important to pay close attention when a patient does choose to report dysphagia because it seems that some level of frequency is needed to prompt reporting to physicians.

### **Limitations**

Several limitations of this study exist. Surveys were distributed by front desk personnel who may have inconsistently approached potentially eligible subjects. Smaller community sites inconsistently tracked the number of subjects approached, a common challenge in conducting research in practice-based research networks. Second, we did not assess concomitant GERD symptoms and other medical problems that would have been useful to determine prevalence rates in conjunction with these symptoms and diseases. Third, the cross-sectional nature of data collection makes it difficult to determine the temporal direction of regression findings, and they should be taken as suggestive only. Furthermore, some patients may have misinterpreted our survey item which asked, "How often do you have a problem with swallowing?" We are uncertain what impact, if any, this misinterpretation may have had on

our prevalence rate. Finally, it should be clear that this is a patient perception of dysphagia study, and there was not follow-up of symptoms to verify patient self-report. An interesting subsequent study would be to compare patient experience with actual test results and/or chart audit.

## Conclusion

Patients report high rates of dysphagia but do not necessarily disclose this symptom to their physician. Thus, care should be taken by the health care provider when obtaining the medical history as to what is asked of the patient. Relying on patients to self-report may result in underrecognition of some symptoms and overestimation of other symptoms. For some patients with dysphagia, additional testing is critical. However, for other patients, trouble swallowing does not seem to be a worry. In that case, a watchful approach may be the best. Our results suggest the need for a more detailed schematic for the actual diagnosis of dysphagia to assist in diagnostic and treatment decisions. Patient concern and experience of frequency, duration, and life interference are critical variables in determining the treatment decisions, testing, and use of medications. With up to one fifth of the population experiencing frequent difficulty swallowing, primary care physicians should remain alert to the presence of dysphagia in their patients but may need to consider multiple approaches because of corollary risk factors.

## Appendix

### *Difficulty Swallowing Study*

The following survey asks questions related to swallowing problems in patients who visit the doctor in Georgia. This survey takes approximately 5 minutes to complete.

1. What is your age? (Write-in) \_
2. What is your gender? (Check one)  
\_ Female \_ Male
3. What is your ethnicity? (Check one)  
\_ Hispanic \_ Non-Hispanic
4. What is your race? (You may select more than one)  
African American or Black  
American Indian or Alaska  
Native Asian  
Native Hawaiian

or other Pacific Islander  
White Other

5. Approximately, how often do you have a problem swallowing, that is, having the feeling that food gets stuck in your throat or chest or coughing or choking with swallowing? (Circle best answer)
  - a. Never
  - b. Several times per day
  - c. Several times per week
  - d. Several times per month
  - e. Several times per year

If your answer to question 5 above is "never," then STOP here.

For questions 6 through 10, circle the best answer.

6. How long have you had a problem swallowing? (Circle best answer)
  - a. Never
  - b. Less than 1 year
  - c. 1 to 5 years
  - d. More than 5 years
7. What kinds of foods do you have problems swallowing? (Circle best answer)
  - a. Solid foods only (for example meats, breads, or rice)
  - b. Liquids only (for example water, coffee, or tea)
  - c. Both solids and liquids
8. How concerned are you about your swallowing problem? (Circle best answer)
  - a. Very unconcerned
  - b. Unconcerned
  - c. Concerned
  - d. Very concerned
9. How often does your swallowing problem keep you from eating with other people or eating out? (Circle best answer)
  - a. Never
  - b. Rarely
  - c. Sometimes
  - d. Always
10. How often have you talked to your doctor about your swallowing problem? (Circle best answer)
  - a. Never
  - b. Rarely
  - c. Occasionally
  - d. Every visit

For questions 11 through 13, circle *all* answers that apply.

11. What medicines are you now taking for your swallowing problem? (Circle all that apply)
  - a. Nothing
  - b. Over-the-counter medicines
  - c. H2 blockers like Zantac, Tagamet, Pepcid, or Acid
  - d. hProton-pump inhibitors like Prilosec, Prevacid, Protonix, Nexium, or Aciphex
  - e. Not sure
12. What else have you tried to help with your swallowing problem? (Circle all that apply)
  - a. Nothing
  - b. Avoiding certain foods
  - c. Taking smaller bites
  - d. Washing food down with liquids
13. Which test(s) have you had to check out your swallowing problem? (Circle all that apply)
  - a. Nothing
  - b. Radiograph (an upper GI or barium swallow)
  - c. EGD (a tube inserted in your mouth to examine your GI tract)
  - d. Other test(s)
  - e. Not sure

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