

## Retrospective Study

# Can patients determine the level of their dysphagia?

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## Abstract

### AIM

To determine if patients can localise dysphagia level determined endoscopically or radiologically and association of gender, age, level and pathology.

### METHODS

Retrospective review of consecutive patients presenting to dysphagia hotline between March 2004 and March 2015 was carried out. Demographics, clinical history and investigation findings were recorded including patient perception of obstruction level (pharyngeal, mid sternal or low sternal) was documented and the actual level of obstruction found on endoscopic or radiological examination (if any) was noted. All patients with evidence of obstruction including oesophageal

carcinoma, peptic stricture, Schatzki ring, oesophageal pouch and cricopharyngeal hypertrophy were included in the study who had given a perceived level of dysphagia. The upper GI endoscopy reports (barium study where upper GI endoscopy was not performed) were reviewed to confirm the distance of obstructing lesion from central incisors. A previously described anatomical classification of oesophagus was used to define the level of obstruction to be upper, middle or lower oesophagus and this was compared with patient perceived level.

## RESULTS

Three thousand six hundred and sixty-eight patients were included, 42.0% of who were female, mean age  $70.7 \pm 12.8$  years old. Of those with obstructing lesions, 726 gave a perceived level of dysphagia: 37.2% had oesophageal cancer, 36.0% peptic stricture, 13.1% pharyngeal pouches, 10.3% Schatzki rings and 3.3% achalasia. Twenty-seven point five percent of patients reported pharyngeal level (upper) dysphagia, 36.9% mid sternal dysphagia and 25.9% lower sternal dysphagia (9.5% reported multiple levels). The level of obstructing lesion seen on diagnostic testing was upper (17.2%), mid (19.4%) or lower (62.9%) or combined (0.3%). When patients localised their level of dysphagia to a single level, the kappa statistic was 0.245 ( $P < 0.001$ ), indicating fair agreement. 48% of patients reporting a single level of dysphagia were accurate in localising the obstructing pathology. With respect to pathology, patients with pharyngeal pouches were most accurate localising their level of dysphagia ( $P < 0.001$ ). With respect to level of dysphagia, those with pharyngeal level lesions were best able to identify the level of dysphagia accurately ( $P < 0.001$ ). No association ( $P > 0.05$ ) was found between gender, patient age or clinical symptoms with their ability to detect the level of dysphagia.

## CONCLUSION

Patient perceived level of dysphagia is unreliable in determining actual level of obstructing pathology and should not be used to tailor investigations.

**Key words:** Deglutition disorders; Oesophageal stenosis; Oesophageal neoplasm; Gastroscopy; Fluoroscopy; Patient perception; Pharyngeal pouch

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**Core tip:** Patient perception of the level of their dysphagia is only accurate in 48% of patients. It is most accurate for those with pharyngeal pouches and for those with pharyngeal or upper oesophageal pathology which might help guide initial investigations, *e.g.*, to barium swallow. No other patient features or history helps determine patient accuracy. Endoscopists and radiologists should be aware of the importance of carefully examining the whole oesophagus to avoid missing pathology irrespective of a patient's perceived level of dysphagia.

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## INTRODUCTION

For more than 40 years, it has been established that a careful history can establish the diagnosis in up to 80% of patients presenting with dysphagia<sup>[1-3]</sup>. Indeed we and others have demonstrated that aspects of history and patient demographics can be highly predictive of specific diagnoses such as oesophageal cancer, peptic stricture, pharyngeal pouch and eosinophilic oesophagitis<sup>[4-7]</sup>.

However studies which have explored whether patients are accurately able to localise the site of the cause of their dysphagia have been inconclusive. Some have found overall poor correlation between patient localisation and actual site of pathology<sup>[2,8,9]</sup> whilst others have found it to be good<sup>[10,11]</sup>. While some studies suggest that localisation of proximal pathology is more accurate<sup>[10,11]</sup> others have shown the converse<sup>[8]</sup>. Only the study by Roeder<sup>[8]</sup> has attempted to determine if the underlying pathology was related to the patient's ability to accurately localise the level of dysphagia and that was primarily to investigate whether diffuse localisation was associated with an underlying motility disorder (which was the case in only 9%).

Whether a patient is able to accurately localise the level of their dysphagia is important. If they can accurately localise the level of dysphagia, then a focussed examination might be feasible, reducing cost, time and, for barium examinations, radiation exposure. If they are unable to accurately localise the level of dysphagia it is equally important that radiologist or endoscopist is aware of this or they may fail to focus on the whole oesophagus and miss important pathology<sup>[12]</sup>.

We reviewed the final outcome of 3668 consecutive patients presenting with dysphagia between March 2004 and March 2015. Patient localisation of the level of their dysphagia was compared to that found at endoscopy or barium swallow examination in patients with an obstructing oesophageal lesion. We explored whether the nature of the pathology, patient characteristics or clinical features were associated with the patients' ability to localise the level of dysphagia.

## MATERIALS AND METHODS

### Case ascertainment

We reviewed the final outcome of those patients presenting to our nurse led telephone triage dysphagia hotline<sup>[13]</sup> between March 2004 and March

**Table 1 Diagnoses in patients with discrete pathology investigated for dysphagia between 2004 and 2015**

Diagnosis	n (%)
Oesophageal cancer	270 (37.2)
Peptic stricture	261 (36.0)
Cricopharyngeal hypertrophy/pharyngeal pouch	95 (13.1)
Schatzki ring	75 (10.3)
Achalasia	24 (3.3)
Pharyngeal pouch and oesophageal cancer	1 (0.1)

2015. Firstly those patient with an obstructing lesion including oesophageal carcinoma, peptic stricture, Schatzki ring, oesophageal pouch and cricopharyngeal hypertrophy were identified. The patient group studied were those with an obstructing oesophageal lesion and patient-derived data regarding localisation levels. Patient data was contemporaneously recorded but reviewed retrospectively and included: patient demographics, patient perception of their level of dysphagia as upper (described as level of throat), middle (mid chest) or lower (bottom of chest); and associated symptoms.

#### Investigations and level of dysphagia

We next determined where those with an obstructing lesion who had given a defined level of obstruction had undergone upper gastrointestinal endoscopy only, barium swallow only or both. The level of dysphagia was taken as that recorded by the endoscopist (either as distance from the incisors or as upper, middle or lower oesophagus). When endoscopy was unsuccessful, refused or not performed for another reason then the level of dysphagia was taken as that recorded at barium swallow. If the radiologist had not recorded a level of dysphagia, the films were reviewed by a radiology registrar and consultant to agree a level. The final level was then recorded as per the subdivision of the oesophagus suggested by the National Cancer Institute<sup>[14]</sup>, namely. Upper: from thoracic inlet to level of tracheal bifurcation; 18-23 cm from incisors. Middle: from tracheal bifurcation to midway to gastro-oesophageal junction; 24-32 cm from incisors. Lower: from midway between tracheal bifurcation and gastro-oesophageal junction to gastro-oesophageal junction; 32-40 cm from incisors.

#### Statistical analysis

The Kappa statistic was used to define if the patient localisation and diagnostic localisation matched. Categorical variables were explored using Pearson's  $\chi^2$  test to look at the association of the clinical and patient characteristic factors, such as diagnosis, the level of pathology and history of symptoms (duration, regurgitation, reflux, odynophagia, chest pain, diet change and weight change) and gender. Following test for assumption of normality, age was explored using

Independent *t*-test to determine if there was a mean difference in age of people who could and could not determine the localisation of their obstruction. Missing data was handled using complete case analysis.

Data was analysed using IBM SPSS Statistics V22.0, and were two tailed tests where statistical significance was accepted if  $P < 0.05$ <sup>[15]</sup>.

The statistical methods of this study were reviewed by Stig B Laursen of Odense University Hospital, Odense, Denmark.

The study was reviewed by the Research, Development and Innovation sponsorship team, Royal Cornwall Hospitals NHS Trust at the Royal Cornwall Hospital who ruled that formal ethics approval was not required as it fell within the remit of audit/service evaluation.

## RESULTS

#### Patients and diagnoses

A total of 3668 consecutive patients were seen by the dysphagia hotline during the study period. Of these, 807 had an obstructing lesion of who 726 had given a perceived level of obstruction. Of these, 42.0% were female, mean age  $70.7 \pm 12.8$  years old. The final diagnoses are shown in Table 1.

Six hundred and forty-one (88.3%) had undergone upper gastrointestinal endoscopy alone, 73 (10.0%) a barium swallow only and 12 (1.6%) had undergone both. Twenty-seven point five percent of patients reported pharyngeal level (upper) dysphagia, 36.9% mid sternal dysphagia and 25.9% lower sternal dysphagia. The remaining 9.5% reported less well defined dysphagia, giving more than one level of perceived dysphagia, most commonly pharyngeal and mid sternal dysphagia (7.4%). The levels of obstructing lesions seen on diagnostic testing were upper (17.2%), mid (19.4%), lower (62.9%) or combined (0.3%).

Symptoms were described as progressive (42.5%), intermittent (56.8%), dysphagia to solids (98.9%) or dysphagia to liquids (17.4%), associated with regurgitation (63.6%) or reflux (51.5%). Odynophagia was described in 23.8%, chest pain 25.1%, diet change due to dysphagia in 48.2% and weight loss of 2 kg or more in 36.9%.

#### Association between patient localisation of disease and actual localisation

Where patients described multiple levels of dysphagia there can be no agreement between patient described levels of dysphagia and actual levels. Comparing only when patients were able to accurately pinpoint their level of dysphagia (single localisation point), gave a kappa statistic of 0.245 ( $P < 0.001$ ), indicating a fair agreement<sup>[16]</sup> between patient localisation and actual level of lesion. Of those patients indicating a single level of dysphagia, 48.0% of patient had an absolute match between perceived and actual level of dysphagia.

**Table 2 Accuracy in perceiving correct level of dysphagia correlated to final diagnosis**

Diagnosis	Perceived single level ( <i>n</i> )	Perceived diffuse level ( <i>n</i> )	Absolute match
Achalasia	23	1	34.8%
Oesophageal cancer	243	27	47.3%
Peptic stricture	235	26	38.7%
Pharyngeal pouch	88	7	84.1%
Schatzki ring	66	9	40.9%

One patient perceived the obstruction as pharyngeal and had both pharyngeal (pouch) and distal (cancer) obstruction. Their data is not included in this table.

**Table 3 Effect of level of obstructing lesion on patient ability to accurately localise the cause of their dysphagia**

Level of obstructing lesion	Total ( <i>n</i> )	Perceived as pharyngeal	Perceived as mid sternal	Perceived as lower sternal	Correct level identified
Upper	115	94	18	3	81.7%
Middle	130	39	64	27	49.2%
Lower	410	66	186	158	38.5%
Total	655	199	268	188	48.2%

Six hundred and fifty-five patients with a single obstructing oesophageal lesion with the test derived level shown in column 1 and the patient perceived level in columns 3-5. When a patient perceived their dysphagia correctly this is shown in bold. Some patients perceived more than one level of dysphagia (diffuse) but their data is not shown here for clarity (*n* = 71). Pearson  $\chi^2$  test gave *P* < 0.001.

**Table 4 Associated symptoms and their ability to improve patient localisation of dysphagia *n* (%)**

Symptom	Number reporting symptom	Number with symptom correctly localising dysphagia	<i>P</i> value
Regurgitation/choking	416/647 (67.4)	195/416 (46.9)	0.478
Reflux	339/649 (52.2)	152/339 (44.8)	0.059
Odynophagia	158/651 (24.3)	72/158 (45.6)	0.415
Chest pain	162/649 (25.0)	71/162 (43.8)	0.180
Change in diet	315/651 (48.4)	151/315 (47.9)	0.883
Weight gain	47/635 (7.9)	20/47 (42.6)	0.422
Weight loss	244/611 (39.9)	116/244 (47.5)	0.816

### **Effect of nature of obstructing lesion on localisation of dysphagia**

Patients with pharyngeal pouches were most likely to accurately localise their level of dysphagia. Regarding patients perceiving dysphagia at a single level, 84.1% accurately identified the level. The number and percentage of absolute match (single localisation level accurately identified by patient) among different diagnostic groups is shown in Table 2.  $\chi^2$  test showed this was statistically significant (*P* < 0.001), establishing a definite association between nature of the pathology and the patients' ability to localise the level of dysphagia.

### **Effect of level of obstructing lesion on localisation of dysphagia**

When the actual level of the obstructing lesion was considered, it was noted that patients with pharyngeal obstruction were most likely to accurately localise the obstruction (Table 3).

### **Effect of patient gender on localisation of dysphagia**

No association was found between gender and ability to detect the level of dysphagia. Similar figures were

seen for males (183 of 386: 47.4% absolute match) and females (132 of 270: 48.9% absolute match), *P* = 0.709.

### **Effect of patient age on localisation of dysphagia**

Three hundred and fifteen of 656 patients who correctly identified their level of obstruction had a mean age of  $71.28 \pm 13.02$  years. The mean age for patients who were incorrect in identifying the level of their dysphagia was  $70.58 \pm 13.17$  years. Independent *t* test found the mean difference not significant (*P* = 0.497) indicating that patient age does not influence ability to identify the level of dysphagia (95%CI: -2.706-1.314).

### **Effect of "associated symptoms" on patients' ability to detect level of dysphagia**

Patients with dysphagia presented with many associated symptoms. Symptoms were described as progressive (43.4%), intermittent (56.4%), dysphagia to solids (99.5%) or to liquids (17.1%). It was associated with regurgitation, reflux, odynophagia, chest pain, diet change due to dysphagia and weight loss of 2 kg or more as shown in Table 4. Duration was less than 8 wk (27.6%), 8-25 wk (35.2%) or greater than 25 wk



(37.1%) Statistical analysis indicated no association of any of these with the ability to localise the level of dysphagia.

## DISCUSSION

To our knowledge this is the largest study comparing patient localisation of dysphagia with true level of obstruction defined by endoscopy or barium swallow examination. In 48% of patients, the dysphagic symptoms accurately predicted the location of the underlying obstructive oesophageal pathology and this was most accurate (81.7%) in patients with lesions in the upper oesophagus despite only 17.6% of patients presenting with pharyngeal level lesions. No factors in patient demographics or history predicted which patients more accurately localised their pathology.

Previous studies have shown a very wide range in the ability of patients to accurately identify the level of obstructing oesophageal pathology ranging from 17% to 74%<sup>[3,8,10,11]</sup>. Possible reasons for the differences between each of these studies and our own include small patient numbers in the studies where patient localisation appeared more accurate<sup>[10,11]</sup> and differences in the populations studied. For instance, Roeder *et al.*<sup>[8]</sup> found patients with distal pathology most accurate (80%) but these comprised only a small percentage of their study (which may indicate problems with selection bias). They comprise 62.6% of a larger patient cohort in the present study population.

When comparing specific pathologies with the ability to localise, those with pharyngeal pouches were most accurate. This differs from previous studies which failed to show any difference based on underlying oesophageal pathology<sup>[8,11]</sup>. It provides some reassurance that our policy of performing barium swallow initially rather than gastroscopy for patients presenting with pharyngeal level dysphagia is correct<sup>[6]</sup>.

Again there have been differences in the pathology studied. We elected to study conditions where the pathology was well defined and could be accurately localised. Some studies have included patients with motility disorders<sup>[8]</sup> and gastro-oesophageal reflux disease<sup>[11]</sup> which are more diffuse. There are differences in investigations performed. Some studies performed barium swallow alone<sup>[10]</sup>, others manometry and gastroscopy<sup>[8]</sup>, and others barium swallow and gastroscopy<sup>[11]</sup>. Manometry was not easily accessible for our patient cohort (the nearest centre during most of the study period being 60 miles (96 km) from our centre so few patients were studied in this way). Differences in conditions studied, investigations performed, differences in the manner in which patient localisation was recorded and in the final diagnoses studied as well as the size of the patient cohort could all influence the final outcome.

The current study is retrospective and has used only 3 areas for patient localisation unlike that of Wilcox<sup>[11]</sup> who used exact patient identified levels and

determined how accurate they were in centimetres from the pathology found. But others have used 3-6 levels also<sup>[3,8]</sup>.

We also acknowledge that the pathology seen at endoscopy or on barium study is not always the underlying reason for a patient to experience dysphagia eg a patient with a Schatzki ring could have oesophageal dysmotility underlying their dysphagia, but it seems highly likely that the recorded pathology (pharyngeal pouches, achalasia, oesophageal cancer and peptic strictures) would have been responsible in the majority. Our study has included only patients with obstructing oesophageal pathology, which represents 18% of the 3668 consecutive cases presenting with dysphagia to our rapid-access dysphagia hotline clinic. Patients with dysphagia and non-obstructive oesophageal pathology were excluded from analysis. This is an important point to bear in mind, as although we have demonstrated that 48% of patients accurately predict their level of obstructing oesophageal pathology, in clinical practice when faced with a patient with dysphagic symptoms the predictive value of level of dysphagia will likely be an order of magnitude less than we observed in our selected population.

It is recognised that 11.3% of upper gastrointestinal cancers have been missed on an examination within 3 years of their diagnosis<sup>[12]</sup>. Whilst oesophageal lesions account for only 9% of this cohort it is possible that endoscopists or radiologists could be misled by patient symptoms and focus on the area of patient localisation. With this in mind, we disagree with the advice of Wright and Ellis<sup>[10]</sup> to tailor the examination to focus on the patient localised area of dysphagia.

In summary, we have shown that in 48% of patients the level of dysphagic symptoms accurately predicted the location of the underlying obstructive oesophageal pathology and this was most accurate in patients with upper oesophageal pathology. The clinical utility of the level of dysphagia in an unselected dysphagic population is likely to be low.

Patients are relatively inaccurate in localising obstructing oesophageal pathologies causing dysphagia. Those with pharyngeal pouches or pharyngeal level pathology in general are most accurate but a full examination of the oesophagus is essential in all patients presenting with dysphagia to prevent missing pathology.

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## COMMENTS

### Background

Previous studies investigating patients with dysphagia and their ability to determine the level of obstructive lesions have produced discordant results. Some have shown good correlation between actual and perceived level,

others have not. Some have shown distal pathology is better correlated, others pharyngeal level.

### Research frontiers

Dysphagia is a common symptom which can be secondary to malignancy. If patients are able to determine the level of their dysphagia, limited endoscopic or fluoroscopic examination may be feasible. It is also important to determine if patients with pharyngeal pouches in particular are able to determine the level of their dysphagia since some centres will investigate patients with pharyngeal level dysphagia initially by barium swallow to avoid endoscopy and risk of perforation.

### Innovations and breakthroughs

This study is much larger than any previous studies investigating patient perception of dysphagia level and investigates only those conditions where there is a definite level of pathology. Detailed history obtained prospectively was available and used to determine if associated features help with patient perception. Patient perceived dysphagia level with actual level correlate in 48% of patients overall but in 84.1% of those with pharyngeal pouches and 81.7% of those with pharyngeal level pathology. Ability to perceive level of obstruction was unrelated to patient age or gender or any associated symptoms.

### Applications

Patients with pharyngeal level dysphagia and pharyngeal pouches in particular are most able to accurately determine the level of their dysphagia. Patients with pharyngeal level dysphagia should therefore be considered for barium swallow as their initial investigation. Endoscopists and radiologists should be aware that they need to investigate the whole of the oesophagus for causes of dysphagia and should not be reliant on patient derived level of dysphagia.

### Peer-review

This theme of this article is unique, though more information and discussion is required. The detailed complaints of dysphagia should be discussed and the factors for the decreasing accuracy should be analyzed carefully. More information of the obstructive lesion or considering the cause in combination with the background of each subject may provide some clue.

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