Commissioner's Guide to the NCEPOD Report - 'Hard to Swallow?' A review of the quality of dysphagia care provided to patients with Parkinson's disease aged 16 years and over who were admitted to hospital when acutely unwell

Introduction

Dysphagia is a difficulty in moving food from the mouth to the stomach. Well established risk factors for dysphagia include advanced age, head and neck cancer, pulmonary disease and neurological disease, such as Parkinson's disease (PD).

Estimates of the prevalence of dysphagia in PD vary across the literature.[2] Reasons for this include patients being unaware of their dysphagia, and so not seeking medical advice, as well as dysphagia not being recognised or documented by healthcare professionals.

Lack of recognition of dysphagia can lead to serious complications. Attempting to take food or drink can result in choking or aspiration pneumonia.[3] Furthermore, patients with dysphagia may be drooling saliva, indicating their lack of ability to swallow safely. Assessment of these indicators is important, as the inability to swallow can lead to dehydration, malnutrition and weight loss.[4,5]

Patients with PD have a high rate of admission to hospital (Low et al, 2015), and screening for dysphagia at the point of admission to hospital would provide an opportunity for earlier intervention.

This study examines the process of recognition, and the provision of dysphagia care provided to patients with PD who were admitted to hospital when acutely unwell. Organisational and clinical aspects of care were reviewed, and recommendations have been made to drive quality improvement in the care provided to future patients with dysphagia and PD.

Patient population

Adult patients aged 16 and over with PD who were acutely unwell and admitted to hospital between 7th January and 3rd March 2019. Patients were identified by ICD10 codes for PD in any position:

- G20 Parkinson's disease
- G21.1 Other drug-induced secondary parkinsonism
- G21.2 Secondary parkinsonism due to other external agents
- G21.3 Postencephalitic parkinsonism
- G21.4 Vascular parkinsonism
- G21.8 Other secondary parkinsonism
- G21.9 Secondary parkinsonism, unspecified

Clinical and organisational issues

12/25 respondents to the online survey indicated that problems with eating, drinking or swallowing medication while in hospital were not taken seriously by the healthcare team.

11/25 patient/carer respondents to the online survey reported that food, drink or medication was given while the patient was lying down.

Documentation

83/277 (30%) patients had dysphagia when presenting to hospital documented in the case notes.

Screening

88/161 (54.7%) hospitals had a protocol for the screening of dysphagia, and 105/163 (64.4%) had a protocol for the assessment of dysphagia.

On arrival an assessment of whether the patient had symptoms of dysphagia was made for 179/479 (37.4%) patients.

On admission 96/449 (21.4%) patients had indicators of dysphagia. The most common indicators were difficult or slow chewing and swallowing and coughing or choking.

Clinician questionnaire data indicated 44/316 (13.9%) patients had swallow screening undertaken within 4 hours of arrival. This missed 51/75 patients who were known to have dysphagia on arrival.

During the admission 117/457 (25.6%) patients had a formal assessment of swallowing undertaken as recorded in the clinician questionnaire.

There was evidence in the notes that a formal assessment of swallowing was undertaken during the admission for 100/335 (29.9%) patients. Where such an assessment was not undertaken the case reviewers were of the opinion that one should have been undertaken for a further 51/200 (25.5%) patients.

Case reviewers indicated the presence of dysphagia was not assessed adequately during the hospital admission for 93/218 (42.7%) patients.

Case reviewers found that there was a delay in recognising dysphagia in 23/114 (20.2%) of patients while they were in hospital.

Dysphagia care was graded as good for 48/116 (41.4%) patients and adequate for 40/116 (34.5%) patients.

Referral

On arrival at hospital 51/209 (24.4%) patients were referred to speech and language therapy following swallow screening. The case reviewers were of the opinion that a further 36/132 (27.3%) patients should have been referred.

During the admission 108/317 (34.1%) patients were referred to SLT and 97/324 (29.9%) to the Parkinson's disease team. The reviewers were of the opinion that a further 46/187 (24.6%) patients should have been referred to speech and language therapy and 67/195 (34.4%) patients to the Parkinson's disease team.

Where patients were referred, case reviewers indicated there was a delay in referral to speech and language therapy in 25/96 patients and delay in referral to dietetics in 16/64 patients.

Communication

307/397 (77.3%) patients were under the care of a Parkinson's disease service prior to their admission.

180/316 (57%) sets of case notes contained no evidence that patients with Parkinson's disease had a named contact with their Parkinson's disease service.

Parkinson's disease consultants and/or specialist nurses were involved for 160/497 (32.2%) patients.

Written information at discharge

168/292 (57.5%) patients/carers were provided with information on the administration of medicines prior to discharge. The information was more likely to be provided if the patient's Parkinson's disease medication had been altered during the admission.

At discharge, the clinicians caring for the patient in hospital involved the home carers in discharge planning for 211/267 (79.0%) patients.

There was no evidence in the case notes of communication at discharge with those responsible for the care of the patient in the community in 90/275 (32.7%) cases reviewed.

There was evidence in the case notes that the patient's level of swallowing/aspiration risk in the community was considered prior to discharge for 61/210 (29.0%) patients.

There was variation in who received a copy of the discharge summary; most commonly this was the GP (422/425; 99.3%) and the patient and carers (208/425; 48.9%). The community-based team only received a copy for 28/425 (6.6%) patients, and the community pharmacist for 5/425 (1.2%) patients.

Where a summary was provided, in the opinion of the case reviewers this was adequate in 175/236 (74.2%) cases assessed.

Key features of a service

1. Document the swallow status of all patients with PD at the point of referral to hospital

Since dysphagia can occur at every stage of PD it is important to assess and communicate its presence in a referral letter. Information relating to dysphagia was not available in the referral letter of 20/79 patients who were known to have dysphagia at the point of referral.

2. Screen patients with PD for swallowing difficulties at admission

Patients admitted to hospital may have swallowing difficulties, not recorded as 'dysphagia'. Other indicators should be considered, such as the patient's ability to swallow food, fluids or medication, whether they have control of saliva or have a history of pneumonia.

3. Refer patients with PD who have swallowing difficulties (or who have problems with communication) to speech and language therapy

Early input, as needed, from speech and language therapy (SLT) is fundamental to improving swallowing difficulties and communication for many patients with dysphagia. In this study referral to SLT was made following a swallowing screen on arrival for 51/209 (24.4%) patients and case reviewers were of the opinion that a further 36/132 (27.3%) patients should have been referred.

4. Notify the specialist Parkinson's disease service (hospital and/or community) when a patient with Parkinson's disease is admitted, if there is any indication from the notes or following discussion with the patient or their relatives/carers, that there has been a deterioration or progression of their clinical state.

For any team caring for a patient with PD it is important to know if there has been any unexpected change in the patient's clinical status or care plan. While a majority of patients in this study were

under the care of a PD service prior to their admission, there was no evidence of contact with their PD service, on admission, documented in 180/316 (57%) sets of notes.

5. Provide written information at discharge on how to manage swallowing difficulties

At the point of discharge from hospital any changes in care or medication, as well as swallowing status (including the ability to take oral medication), nutrition plan or level of future risk of dysphagia should be provided to care providers as well as the patient and family members.

Supporting national guidance and reports

- National Institute for Health and Care Excellence. Parkinson's Disease. Quality Standard (QS164). 2018 https://www.nice.org.uk/guidance/qs164/resources/parkinsons-disease-pdf-75545600441029
- National Institute for Health and Care Excellence. Parkinson's disease in adults. NICE Guideline (NG71). 2017 https://www.nice.org.uk/guidance/ng71/resources/parkinsons-disease-in-adults-pdf-1837629189061
- National Institute for Health and Care Excellence. Stroke in adults. Quality Standard (QS2). 2016 https://www.nice.org.uk/guidance/qs2/resources/stroke-in-adults-pdf-58292707525
- Parkinson's UK. Consensus statement for the optimisation of Parkinson's medicines in hospital. 2017 https://www.parkinsons.org.uk/sites/default/files/2017-12/cs2877_consensus_statement_0.pdf
- Specialist Pharmacy Service. How can people who need thickened fluids take medicines? 2020 https://www.sps.nhs.uk/articles/how-can-people-who-need-thickened-fluids-take-medicines/
- National Institute for Health and Care Excellence. Nutrition support in adults. Quality Standard (QS24) https://www.nice.org.uk/guidance/qs24/resources/nutrition-support-in-adults-pdf-2098545777349
- International Dysphagia Diet Standardisation Initiative. 2019 https://iddsi.org/
- National Institute for Health and Care Excellence. Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes NICE Guideline (NG5) https://www.nice.org.uk/guidance/ng5/resources/medicines-optimisation-the-safe-and-effective-use-of-medicines-to-enable-the-best-possible-outcomes-pdf-51041805253