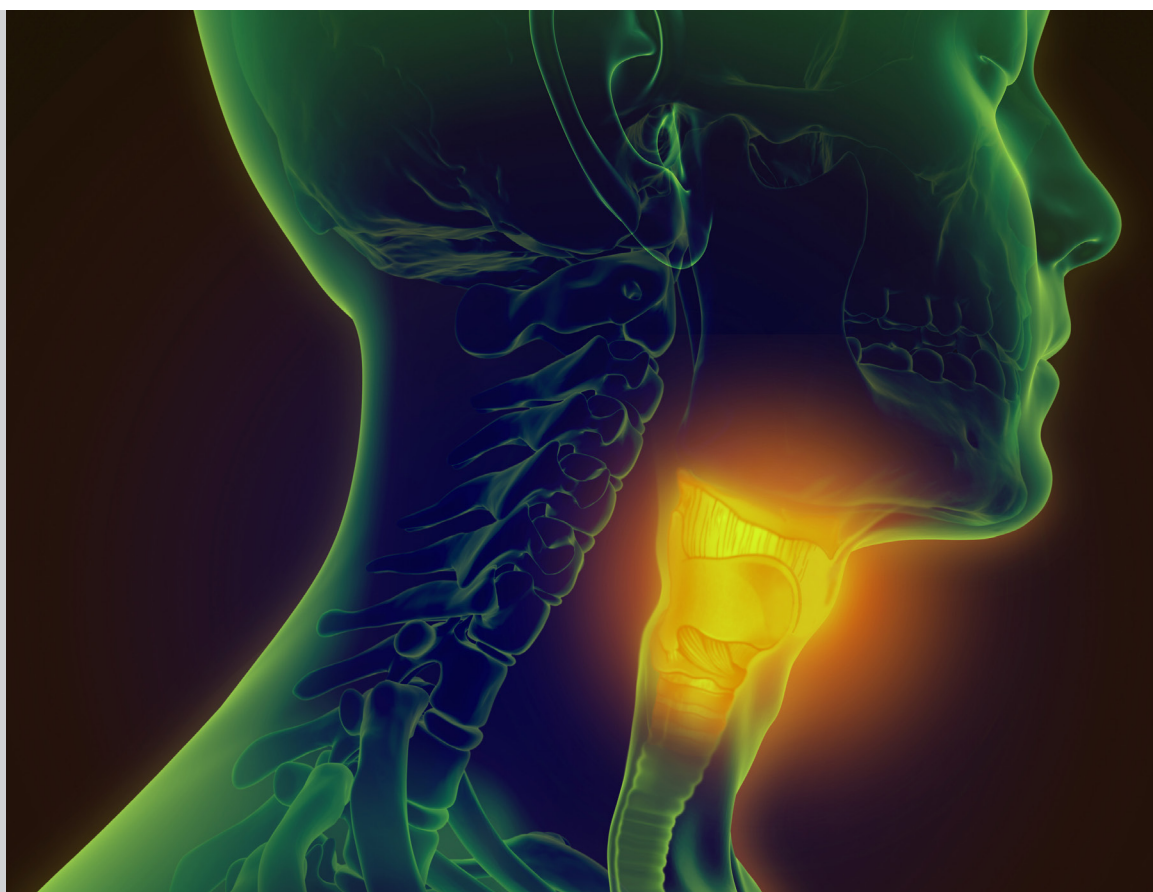


Hard to Swallow?

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

SUMMARY



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

A report published by the National Confidential Enquiry into Patient Outcome and Death (2021)

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Study Proposers: Royal College of Speech and Language Therapists

The Medical and Surgical Clinical Outcome Review Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes. The Clinical Outcome Review Programmes, which encompass confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers, and policy makers to learn

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Contents

INTRODUCTION	4
EXECUTIVE SUMMARY	5
INFOGRAPHIC	6
RECOMMENDATIONS	7
METHOD AND DATA RETURNS	13

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). PD is a neurodegenerative disease which is increasingly prevalent, and also more common with increasing age.¹

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,⁶ and the most common reason for this is pneumonia. As dysphagia is an independent predictor of poor outcome in acute care,⁷ is common in PD and can occur at any stage of PD, screening for it at the point of admission to hospital would provide an opportunity for earlier intervention.

In addition to eating and drinking, difficulty swallowing can also lead to problems taking oral medication. Timely administration of medications for PD helps with symptom control, as outlined in the Parkinson's disease UK Medicines Optimisation Consensus Statement.⁸ The NICE Quality Standard for Parkinson's disease (QS 164) also highlights that missed doses of levodopa can lead to worsening symptoms and serious complications, leading to a negative impact on quality of life and prolonged hospital stay.⁹

There are a number of national guidelines written for the care of patients with PD, in addition to NICE QS 164. NICE Guideline 71¹⁰ states that patients with PD should have a PD nurse specialist as a point of contact with specialist services to facilitate continuity of care, information sharing, advice and support. NICE Guideline 71¹⁰ and NICE QS 164⁹ state that patients with PD should be referred to speech and language therapy if problems are identified with communication, swallowing or saliva control. Speech and language therapists can provide effective assessment, care and advice for patients with dysphagia.¹¹

The NICE Quality Standard on nutrition support in adults (QS24) also recommends that all patients should be screened for the presence (or risk) of malnutrition on admission.¹² Screening should be repeated weekly for inpatients. A validated screening tool, such as the Malnutrition Universal Screening Tool (MUST) can aid with this.¹³

Discharge planning should start as early as possible during an admission. For people with PD, plans for discharge should be co-ordinated across the different groups of professionals who are involved in their care during the hospital admission and their ongoing care in the community. As well as speech and language therapists and the specialist PD team, this also includes dietitians, pharmacists, physiotherapists, occupational therapists, and the patient's family where appropriate. Any change in PD medication and/or specific dietary modifications while in hospital should be communicated to the patient's GP or specialist PD team.⁹

This study was developed and designed with multidisciplinary clinical input as well as patient and lay input, to examine the process of recognition and 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.

Executive summary

Aim

To examine the pathway of care for patients with Parkinson's disease (PD) who were admitted to hospital when unwell, and to explore multidisciplinary care and organisational factors in the process of identifying, screening, assessing, treating and monitoring of their ability to swallow.

Method

Adult patients aged 16 and over with PD who were acutely unwell and admitted to hospital for at least one day, between 7th January and 3rd March 2019. From the whole group a maximum of four patients per hospital were randomly selected for inclusion. The treating clinician was asked to complete a questionnaire and case notes were requested for peer review.

Key messages

Five key messages listed here, have been agreed as the primary focus for action, based on the report findings and recommendations (see pages 9-11 and Appendix 1).

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 PD service (hospital and/or community) when a patient with PD 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.

Key messages aimed at improving the care of people with Parkinson's disease and swallowing difficulties whilst in hospital

MESSAGE 1. DOCUMENT THE SWALLOW STATUS OF ALL PATIENTS WITH PARKINSON'S DISEASE AT THE POINT OF REFERRAL TO HOSPITAL



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

83/277 (30%) patients had **dysphagia when presenting to hospital**

20/79 sets of notes of patients who were **known to have dysphagia did not contain information relating to dysphagia**

MESSAGE 2. SCREEN PATIENTS WITH PARKINSON'S DISEASE FOR SWALLOWING DIFFICULTIES AT ADMISSION



30/409 (7.3%) patients had a **history of aspiration pneumonia** prior to their admission

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

287/479 (59.9%) patients had their ability to continue with normal diet and fluid intake, which is an **indicator of dysphagia**, assessed at admission.

MESSAGE 3. REFER PATIENTS WITH PARKINSON'S DISEASE WHO HAVE SWALLOWING DIFFICULTIES (OR WHO HAVE PROBLEMS WITH COMMUNICATION) TO SPEECH AND LANGUAGE THERAPY



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

96/377 (25.5%) patients were **referred to speech and language therapy on admission**, and in 87 patients this was for dysphagia

Case reviewers indicated there was **a delay in referral to speech and language therapy in 25/96 patients**

MESSAGE 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 THAT THERE HAS BEEN A DETERIORATION OR PROGRESSION OF THEIR CLINICAL STATE



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**

MESSAGE 5. PROVIDE WRITTEN INFORMATION AT DISCHARGE ON HOW TO MANAGE SWALLOWING DIFFICULTIES



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

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**

Recommendations

Line of sight between the recommendations, key findings and existing supporting evidence

<p>Suggested groups to action the recommendation are shown in italics after each one, this is a guide only, not exhaustive.</p> <p><i>The term 'healthcare professionals' includes all specialties and grades who would be involved in the care of this group of patients</i></p>	<p># represents the number of the supporting key finding</p>	<p>Associated guidelines and other related evidence</p>
<p>1 Document the swallow status of all patients with Parkinson's disease at the point of referral to hospital.</p> <p><i>Document the swallow status of all patients with Parkinson's disease at the point of referral to hospital.</i></p>	<p>CHAPTER 2: PAGE 17 #3. 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 CHAPTER 3: PAGE 20 #6. 83/277 (30%) patients had dysphagia when presenting to hospital documented in the case notes CHAPTER 4: PAGE 25 #10. 20/79 sets of notes of patients who were known to have dysphagia at the time of arrival did not contain information relating to dysphagia</p>	<p>NICE QS 164</p>
<p>2 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.</p> <p><i>Target audiences: Healthcare professionals who see patients at admission, clinical and medical directors</i></p>	<p>CHAPTER 3: PAGE 22 #7. 307/397 (77.3%) patients were under the care of a Parkinson's disease service prior to their admission #8. 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 CHAPTER 6: PAGE 36 #32. Parkinson's disease consultants and/or specialist nurses were involved for 160/497 (32.2%) patients</p>	<p>NICE QS 164 NICE GUIDELINE 71</p>
<p>3 Screen patients with Parkinson's disease for swallowing difficulties at admission, irrespective of the reason for admission. This should include:</p> <ul style="list-style-type: none"> • Ability to swallow food, fluids and medication • Control of saliva • A history of pneumonia <p><i>Target audiences: Healthcare professionals who see patients at admission and clinical directors</i></p>	<p>CHAPTER 3: PAGE 24 #9. 30/409 (7.3%) patients had a history of aspiration pneumonia prior to their index admission. Of these 30 patients, 18/24 patients had dysphagia. Of those without aspiration pneumonia, 48/320 (15%) had dysphagia</p> <p><i>continued over</i></p>	<p>NICE QS 2</p>

RECOMMENDATIONS

	<p>CHAPTER 4: PAGE 26</p> <p>#11. An assessment of whether the patient had symptoms of dysphagia was made for 179/479 (37.4%) patients</p> <p>#12. 287/479 (59.9%) patients had their ability to continue with normal diet and fluid intake, which is an indicator of dysphagia, assessed at admission. Similarly, assessment of dehydration and difficulty in controlling saliva, were assessed in 222/479 (46.3%) and 62/479 (12.9%) patients respectively</p> <p>#13. 123/312 (39.4%) patients had documented assessments of dysphagia at the initial assessment, while a similar number of patients (133/335; 39.7%) reported difficulty with speech</p> <p>CHAPTER 4: PAGE 27</p> <p>#14. 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</p> <p>CHAPTER 4: PAGE 28</p> <p>#16. 96/449 (21.4%) patients had indicators of dysphagia on admission. The most common indicators were difficult or slow chewing and swallowing and coughing or choking</p> <p>CHAPTER 5: PAGE 34</p> <p>#22. 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</p> <p>#23. 117/457 (25.6%) patients had a formal assessment of swallowing undertaken during the admission as recorded in the clinician questionnaire</p> <p>#24. 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</p> <p>#26. Case reviewers indicated the presence of dysphagia was not assessed adequately during the hospital admission for 93/218 (42.7%) patients</p> <p>CHAPTER 5: PAGE 35</p> <p>#27. Case reviewers found that there was a delay in recognising dysphagia in 23/114 (20.2%) of patients while they were in hospital</p> <p>#28. Where there was a delay in recognising dysphagia, case reviewers were of the opinion that this affected the outcome for 6/18 patients</p> <p>CHAPTER 12: PAGE 62</p> <p>#66. Dysphagia care was graded as good for 48/116 (41.4%) patients and adequate for 40/116 (34.5%) patients</p>	
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RECOMMENDATIONS

<p>4</p>	<p>Refer patients with Parkinson’s disease who have swallowing difficulties* (or who have problems with communication) to speech and language therapy.</p> <p>Target audiences: Healthcare professionals who see patients throughout their admission and clinical directors</p> <p><i>*See Figure 4.3 in the report for a list of indicators of swallowing difficulties</i></p>	<p>CHAPTER 4: PAGE 26 #11. An assessment of whether the patient had symptoms of dysphagia was made for 179/479 (37.4%) patients CHAPTER 4: PAGE 28 #15. 51/209 (24.4%) patients were referred to speech and language therapy following swallow screening on arrival at hospital. The case reviewers were of the opinion that a further 36/132 (27.3%) patients should have been referred #16. 96/449 (21.4%) patients had indicators of dysphagia on admission. The most common indicators were difficult or slow chewing and swallowing and coughing or choking CHAPTER 4: PAGE 30 #17. 96/377 (25.5%) patients were referred to speech and language therapy on admission, and in 87 patients this was for dysphagia CHAPTER 6: PAGE 39 #34. 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 CHAPTER 6: PAGE 41 #36. 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</p>	<p>NICE QS 164</p> <p>NICE GUIDELINE 71</p>
<p>5</p>	<p>Ensure patients are able to take the medication they have been prescribed at, and throughout, their admission. If there are concerns about whether or not the patient can swallow safely consider other formulations of medication (e.g. liquid rather than a tablet) or ways of administering them.</p> <p>Target audiences: Healthcare professionals who see patients at, and throughout, their admission, pharmacists, and clinical directors</p> <p><i>NB: Levodopa should be administered within 30 minutes of the prescribed administration time. This is in line with NICE Quality Standard 164. See also the Parkinson’s UK medication optimisation consensus statement</i></p>	<p>CHAPTER 4: PAGE 31 #18. 81/283 (28.6%) patients admitted via the emergency department missed one or more doses of medication. For a further 158/505 (31.3%) patients it was unclear whether they had missed a dose. Of the 114 responses recorded as to why medication was not given, 21/114 (18.4%) were due to a clinical suspicion of dysphagia and 20/114 (17.5%) were due to a decision to keep the patient ‘nil by mouth’ CHAPTER 8: PAGE 50 #48. 121/416 (29.1%) patients missed medication during their hospital stay. The principal reasons for this were the patient being ‘nil by mouth’ (33/110; 30.0%) and being unable to take the medication (32/110; 29.1%) CHAPTER 8: PAGE 51 #49. 113/156 (72.4%) hospitals reported a policy for the administration of medication to patients who have dysphagia or who develop it in hospital in place. Where this policy was in place, it complied with the Parkinson’s UK Medicines Optimisation Consensus Statement in 75/81 hospitals #50. On admission, there was no check for 96/257 (37.4%) patients that their last scheduled dose of PD medication had been taken</p>	<p>NICE QS 164</p> <p>https://www.parkinsons.org.uk/professionals/resources/medicines-optimisation-consensus-statement</p> <p>https://www.sps.nhs.uk/articles/how-can-people-who-need-thickened-fluids-take-medicines/</p>

RECOMMENDATIONS

6	<p>Ensure there is a hospital policy for the different ways of administering medication and the review of medications at the point of patient discharge. This includes the use of rotigotine patches.</p> <p>Target audiences: Clinical directors, medical directors, hospital pharmacists, specialist Parkinson's disease teams and quality improvement leads</p>	<p>CHAPTER 8: PAGE 53 #54. 127/158 (80.4%) hospitals had a policy for the use of rotigotine patches in patients with Parkinson's disease #55. 88/468 (18.8%) patients were prescribed a rotigotine patch while in hospital #56. Where a rotigotine patch was prescribed, alternative forms of medication had been considered for 42/68 patients; the Parkinson's UK Medicines Optimisation Consensus Statement consulted for 21/50 patients, and there was a clear plan in place to review the patch before discharge for 44/75 patients</p>	<p>https://www.parkinsons.org.uk/professionals/resources/medicines-optimisation-consensus-statement</p>
7	<p>Screen the nutritional status of patients admitted to hospital with Parkinson's disease and act on the findings.</p> <p>Target audiences: Clinical directors, dietitians, nutrition team members and healthcare professionals who see patients at, and throughout, their admission</p> <p><i>NB: All patients admitted to hospital should undergo a nutritional screen using a validated screening tool such as the BAPEN Malnutrition Universal Screening Tool (MUST) this in line with NICE Quality Standard 24</i></p>	<p>CHAPTER 4: PAGE 32 #19. 69/152 (45.4%) hospitals did not have a policy for the nutritional assessment of patients admitted with Parkinson's disease #20. 295/434 (68.0%) patients had a nutrition screen undertaken on admission as recorded in the clinician questionnaire. This was documented in the case notes of 162/336 (48.2%) patients #21. There was evidence in the case notes that a Malnutrition Universal Screening Tool (MUST) score was calculated on arrival for 119/316 (37.7%) patients</p>	<p><i>Malnutrition Universal Screening Tool (MUST)</i></p> <p><i>NICE QS 24</i></p>
8	<p>Involve speech and language therapists, pharmacists, dietitians and nutrition team members in any multidisciplinary (MDT) discussion of patients with Parkinson's disease and swallowing difficulties.</p> <p>Target audiences: Clinical directors, speech and language therapists, pharmacists, dietitians and nutrition team members</p>	<p>CHAPTER 6: PAGE 39 #34. 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 CHAPTER 6: PAGE 41 #36. 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 CHAPTER 6: PAGE 44 #39. Specialist multidisciplinary team (MDT) reviews took place for patients admitted with Parkinson's disease in 75/168 (44.6%) hospitals, with 32/73 reporting the presence of speech and language therapy, 28/73 dietetics and 19/73 nutrition team members #40. 221/426 (51.9%) patients had their care reviewed at an MDT meeting during their admission CHAPTER 6: PAGE 45 #41. 158/246 (64.2%) patients had an appropriate MDT discussion undertaken during their admission in the opinion of the case reviewers</p>	<p><i>NICE QS 164</i></p> <p><i>NICE GUIDELINE 71</i></p>

RECOMMENDATIONS

<p>9</p>	<p>Formalise pathways for the provision of modified texture diet and fluids to include input from:</p> <ul style="list-style-type: none"> • Speech and language therapists • Pharmacists • Dietitians or other nutrition team members • Hospital housekeeping and catering services • Community care <p><i>This is in line with the International Dysphagia Diet Standardisation Initiative (IDDSI)</i></p> <p>Target audiences: Medical directors, clinical directors, clinical teams caring for patients with dysphagia. This includes speech and language therapists, pharmacists, dietitians, hospital housekeeping and catering services, community Parkinson’s disease teams and quality improvement leads</p>	<p>CHAPTER 4: PAGE 32 #19. 69/152 (45.4%) hospitals did not have a policy for the nutritional assessment of patients admitted with Parkinson’s disease</p> <p>CHAPTER 7: PAGE 47 #42. 101/314 (32.2%) patients required a modified texture diet whilst they were an inpatient in the opinion of the case reviewers</p> <p>#43. Where was evidence in the case notes that a modified texture diet was advised for 95/278 (34.2%) patients; in 80/95 patients this was advised by speech and language therapy</p> <p>CHAPTER 7: PAGE 48 #45. 100/138 (72.5%) hospitals had a multidisciplinary approach to meal planning</p> <p>#46. Where a thickener was advised, there was evidence in the notes that catering/housekeeping were notified in only 17/44 instances, and this was communicated to pharmacy in 17/45 instances</p> <p>#47. A hospital policy for the prescribing and use of thickeners was in place in 99/148 (66.9%) hospitals</p>	<p><i>International Dysphagia Diet Standardisation Initiative (IDDSI)</i></p>
<p>10</p>	<p>Ensure there is a hospital policy for ‘risk feeding’ which includes the assessment or re-assessment (if already undertaken at admission) of mental capacity regarding this decision. The policy should state that discussion should involve:</p> <ul style="list-style-type: none"> • Patients • Family members and/or carers • Speech and language therapists • Dietitians/nutrition team members • Pharmacists <p>Target audiences: Clinical directors, medical directors, speech and language therapists, pharmacists, dietitians and nutrition team members and quality improvement leads</p>	<p>CHAPTER 9: PAGE 56 #58. 104/160 (65.0%) hospitals were reported as having a policy for ‘risk feeding’</p> <p>#59. The assessment of mental capacity undertaken in 17/22 patients who were being assessed for ‘risk feeding’</p> <p>#60. Speech and language therapists were involved in the discussions related to ‘risk feeding’ for 41/110 (37.3%) patients. ‘Risk feeding’ was subsequently undertaken in 36/46 patients</p>	

RECOMMENDATIONS

<p>11</p>	<p>Provide written information at discharge on how to manage swallowing difficulties, including:</p> <ul style="list-style-type: none"> • Swallow status • Ability to take oral medication • Changes to medication including any new ways of administering them • Nutrition screening tool score and care plan including any texture modifications to food and/or fluids • Positioning • Level of dysphagia risk in the community <p>To:</p> <ul style="list-style-type: none"> • The patient • Family members and/or carers • Community healthcare professionals (e.g. GP, community Parkinson’s disease team, community pharmacist, care home staff) <p>A proforma could be used for this discharge summary.</p> <p>Target audiences: Clinical directors, healthcare professionals who see patients throughout their admission, quality improvement leads</p>	<p>CHAPTER 2: PAGE 17</p> <p>#2. 11 patient/carer respondents to the online survey reported that food, drink or medication was given while the patient was lying down</p> <p>CHAPTER 8: PAGE 54</p> <p>#57. 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</p> <p>CHAPTER 11: PAGE 59</p> <p>#61. At discharge, the clinicians caring for the patient in hospital involved the home carers in discharge planning for 211/267 (79.0%) patients</p> <p>#62. 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</p> <p>#63. 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</p> <p>CHAPTER 11: PAGE 61</p> <p>#64. 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</p> <p>#65. Where a summary was provided, in the opinion of the case reviewers this was adequate in 175/236 (74.2%) cases assessed</p>	<p><i>NICE Guideline 5</i></p>
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Method and data returns

Study Advisory Group

A multidisciplinary group of clinicians was convened to identify the objectives of the study and advise on the key questions to be asked of their peers. The Study Advisory Group (SAG) comprised physicians in acute medicine, neurology, palliative and geriatric medicine, speech and language therapists, physiotherapists, dietitians, pharmacists, specialist nurses, otolaryngology and gastrointestinal surgeons, rehabilitation specialists and lay and patient representatives.

Study aim

To examine the pathway of care for patients with Parkinson's disease (PD) who were admitted to hospital when unwell, and to explore multidisciplinary care and organisational factors in the process of identifying, screening, assessing, treating and monitoring of their ability to swallow.

Objectives

The SAG identified specific objectives that would address the aim of the study.

These included:

- Initial assessment and recognition of dysphagia, including risk assessment and any delays in diagnosis
- Assessment of swallowing
- Ongoing management of dysphagia with regard to food, drink and medications
- Decision-making, including multidisciplinary input and clinician seniority
- Treatment planning, including continuity of care and communication
- Dietary modifications, including modified textures and diets, nutritional screening and 'risk feeding'

- Medication management, including pharmacological and non-pharmacological care of patients, and the availability of PD medications
- End of life care, where appropriate
- Discharge/follow-up arrangements, including communication with relevant healthcare professionals
- Organisational factors that impacted on patient outcomes

Study population and sampling criteria

Inclusion criteria

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

Exclusions

- Patients admitted as a day case, as not enough data would be available for a review
- Patients who were admitted to Level 3 (ICU/ITU) critical care, as they may have been intubated
- Patients who were admitted to independent hospitals, as this group of patients were unlikely to be acutely unwell.

Sampling criteria

From the whole group a maximum of four patients per hospital were randomly selected for inclusion, and a request was made to the treating clinician to complete a questionnaire.

Hospital participation

NHS hospitals in England, Scotland, Wales and Northern Ireland were expected to participate as well as public hospitals in the Isle of Man, Guernsey and Jersey.

Data collection

Patient/carer online survey

An open-access, anonymous survey was circulated online to allow patients with PD who were admitted to hospital with dysphagia, or their carers, to provide their views on the care received as an inpatient. A link was sent to a wide group of stakeholders to disseminate via their local and national service user and carer networks.

Spreadsheet

A pre-set spreadsheet was provided to every local reporter to identify all patients meeting the study criteria during the study time period. From this initial cohort sampling for inclusion in the study took place.

Questionnaires

Two questionnaires were used to collect data for this study: a clinician questionnaire relevant to each patient and an organisational questionnaire for each participating hospital.

Clinician questionnaire

This questionnaire was sent electronically to the consultant responsible for the care of the patient at the time of their hospital admission. Information was requested on the patient's initial clerking, assessment of swallowing, ongoing care, dietary modifications, medicine optimisation, 'risk feeding' decisions, end of life care and discharge/death (if applicable).

Organisational questionnaire

This questionnaire was disseminated to each hospital with patients in the study and included questions on pathway/protocols and the provision of services relating to dysphagia.

Case notes

Copies of case note extracts were requested for each case that was to be peer reviewed. These included:

- General Practitioner (or other) referral letter
- Ambulance service patient report form/notes
- All inpatient annotations/medical notes/nursing notes/allied health professional notes
- Any operation notes/anaesthetic records/consent forms
- Fluid balance/weight/food/drug/observation and oral care charts
- Malnutrition Universal Screening Tool (MUST)
- Mental capacity assessment forms
- Advance care plans or do not attempt cardiopulmonary resuscitation (DNACPR) forms/treatment escalation forms
- Discharge summary
- Clinic letters for one year prior to the index admission

As the number of patients identified as experiencing dysphagia was lower than expected, following receipt of the first 350 sets of notes, the case note request was amended to focus on those patients where the clinician indicated that the patient had any (or all) of the following:

- Indicators of dysphagia at some point during the admission
- Required modified diet/fluids
- Missed/had altered medication

Peer review of the case notes and questionnaires

A multidisciplinary group of case reviewers was recruited to peer review case notes. The group of case reviewers comprised consultants, clinical nurse specialists and allied healthcare professionals from the following specialties: speech and language therapy, geriatric medicine, acute medicine, palliative care, neurology, nursing, dietetics, physiotherapy, pharmacy and surgery.

METHOD AND DATA RETURNS

Questionnaires and case notes were anonymised by non-clinical staff at NCEPOD. All patient identifiers were removed. Neither the clinical co-ordinators at NCEPOD, nor the case reviewers had access to patient identifiable information.

After being anonymised, each set of case notes was reviewed by at least one reviewer within a multidisciplinary group. At regular intervals throughout each case review meeting, the chair allowed a period of discussion for each reviewer to summarise their cases and ask for opinions from other specialties or raise aspects of the case for discussion.

Case reviewers answered a number of specific questions using a semi-structured electronic questionnaire and were encouraged to enter free-text commentary at various points.

The grading system below was used by the case reviewers to grade the overall care each patient received:

Good practice: A standard that you would accept from yourself, your trainees and your institution

Room for improvement: Aspects of **clinical** care that could have been better

Room for improvement: Aspects of **organisational** care that could have been better

Room for improvement: Aspects of both **clinical and organisational** care that could have been better

Less than satisfactory: Several aspects of clinical and/or organisational care that were well below the standard that you would accept from yourself, your trainees and your institution

Insufficient data: Insufficient information submitted to NCEPOD to assess the quality of care

Information governance

All data received and handled by NCEPOD complied with all relevant national requirements, including the General Data Protection Regulation 2016 (Z5442652), Section 251 of the NHS Act 2006 (PIAG 4-08(b)/2003, App No 007), PBPP (1718-0328) and the Code of Practice on Confidential Information.

Each patient was given a unique NCEPOD number. All electronic questionnaires were submitted through a dedicated online application. Prior to any analysis taking place, the data were cleaned to ensure that there were no duplicate records and that erroneous data had not been entered. Any fields that contained data that could not be validated were removed.

Data analysis

Following cleaning of the quantitative data, descriptive data summaries were produced. Qualitative data collected from the case reviewers' opinions and free-text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis. The data were reviewed by NCEPOD clinical co-ordinators, a clinical researcher and researcher to identify the nature and frequency of recurring themes.

Data analysis rules

- Small numbers were suppressed if they risked identifying an individual
- Any percentage under 1% has been presented as <1%
- Percentages were not calculated if the denominator was less than 100 except for comparison of percentage across a group
- Anonymised case studies have been used to illustrate particular themes

The findings of the report were reviewed by the SAG, case reviewers, and the NCEPOD Steering Group including clinical co-ordinators, trustees and lay representatives prior to publication. In addition, the recommendations were independently edited, and the report proofread, by two external proof-readers.

Data returns

Clinical data

In total 11,584 patients were identified as meeting the study inclusion criteria (Figure 1). Subsequently 227 were excluded, including 94 patients who were identified as not having PD. Up to four patients per hospital were randomly selected for review of their care, which resulted in a sample of 878 patients. Clinician questionnaires were sent for completion for all this sample. An initial request was made for the case notes to be returned for all 878 patients however, this was subsequently streamlined to request case notes for just those patients where the clinician completing the clinician questionnaire indicated that the patient experienced dysphagia during the admission. This resulted a total of 562 sets of case notes being requested.

In total, 505/878 (57.5%) clinician questionnaires were included in the analysis and 344/562 (61.2%) sets of case notes were peer reviewed by the case reviewers; this included 126 patients with dysphagia.

Patients were identified for inclusion using the ICD10 codes G20 (Parkinson’s disease) and G21 (secondary parkinsonism). Of the 878 patients sampled for clinician questionnaire completion, 50 had an ICD10 code of G21. While patients with both Parkinson’s disease and secondary parkinsonism were included in the study, the term Parkinson’s disease is used throughout the report.

Organisational data

Organisational questionnaires were returned from 177/283 (62.5%) hospitals.

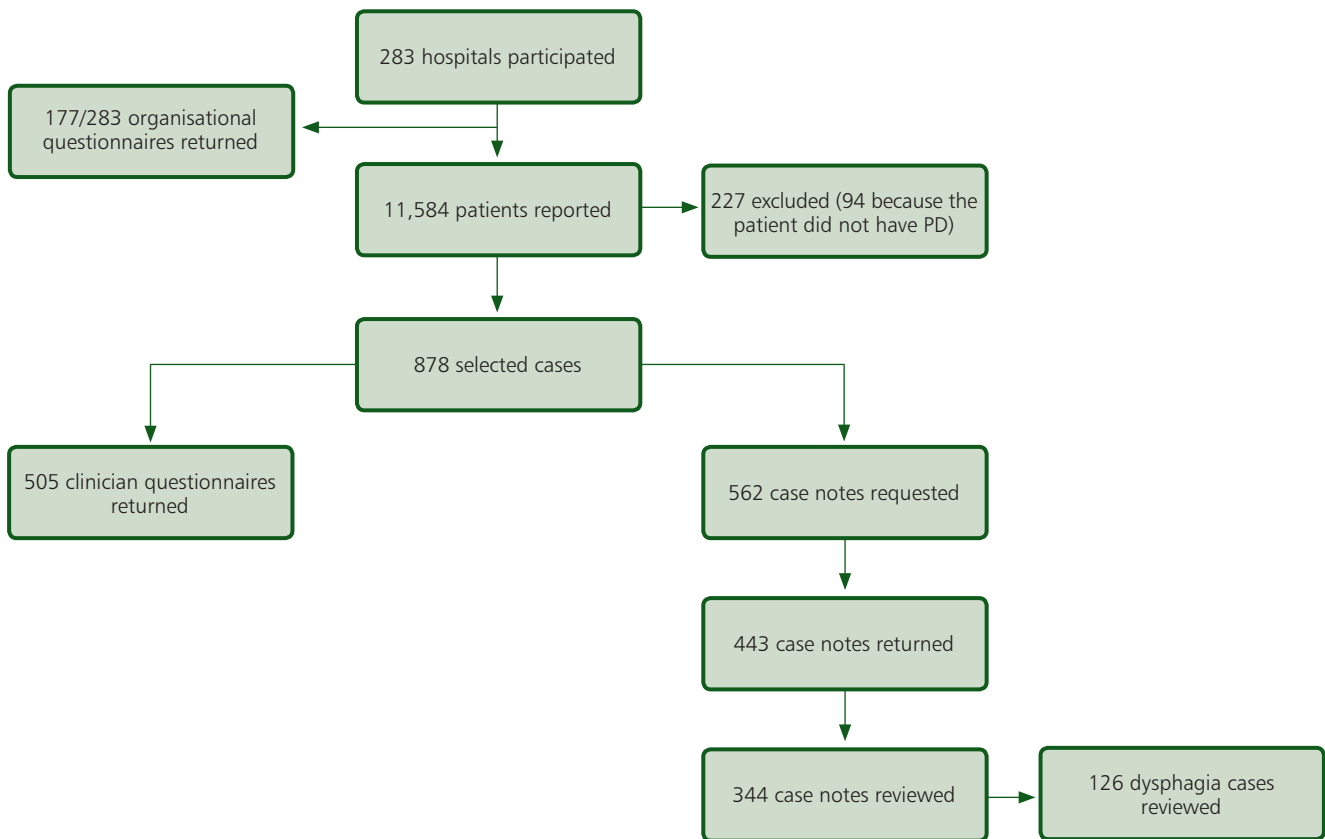


Figure 1.1. Data returns and study inclusion for questionnaires and case note review

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