

Cover Sheet

Trust Board Meeting in Public: Wednesday 12 July 2023

TB2023.66

Title: End of Life Care Lead's Annual Report

Status: For Information

History: This is an annual report to the Trust Board

Board Lead: Chief Medical Officer

Author: Dr Mary Miller, Consultant in Palliative Medicine

Confidential: No

Key Purpose: Strategy, Performance

Executive Summary

1. This paper updates the Trust Board about Oxford University Hospital's results from the National Audit of Care at the End of Life, 2022. OUH benchmarks above the national average results for patient care and care of those important to the patient. OUH benchmarks at the national average in the staff survey.
2. To build on these results, OUH workplan for 2023/4 includes bringing the patient's voice about preferences for goals of care to their final admission, learning from the qualitative feedback offered by those important to the patient and supporting staff education in care at the end of life.
3. Two examples of work to improve care at the end of life in OUH are discussed. There are many more but these highlight the desire across disciplines and departments to improve care delivered to dying patients and those at the bedside in our Trust.

Recommendations

The Trust Board is asked to:

- Note the results of the National Audit of Care at the End of Life (NACEL).
- Note the ongoing work on implementation of the electronic Recommended Summary Plan of Care and Treatment (ReSPECT) in OUH. (2019, 2021 & 2022 recommendation). There is a system wide aspiration to implement ReSPECT across the ICS. ReSPECT will bring the patient's voice to the conversation about care at the end of life.
- Note that a task and finish group will be convened in Q2 to review the qualitative feedback and identify key learning to be disseminated to staff. (2022 recommendation).
- Note that work is planned on Q2/Q3 to provide online learning modules through My Learning Hub to support staff in recognising dying, conversations at the end of life and communication skills training (2021 & 2022 recommendation). Education will support staff to deliver care of good quality with confidence.

End of Life Care Lead's Annual Report

1. Purpose

This paper:

- 1.1. This paper appraises the work undertaken in adult end of life care (EOLC) in OUH. Further information about care at the end of life is provided over the year by other papers including paediatric deaths, learning from deaths co-ordinated by the mortality review group, learning disability mortality review (LeDeR), palliative care department (RIPEL), and feedback from Medical Examiners, patient experience team and resuscitation team.
- 1.2. Reports on OUH's results from the National Audit of Care at the end of Life (NACEL) 2022 benchmarked against the UK results.
- 1.3. Describes a sample of quality improvement work undertaken in OUH in 2022/23.
- 1.4. Outlines goals to improve EOLC for 2023/24

2. Background

- 2.1. The palliative care department has provided an advisory liaison service across OUH for 30 years. The service continues to grow and evolve and is working across all four hospital sites. In 2022/23, the liaison service saw approximately 50% of all adult patients who died in OUH. Advice regarding the care of dying patients and those important to the patient makes up just over 50% of the workload of the liaison team.
- 2.2. From 2014/15, with the support of the CEO, CMO and the Chair of the Board, the palliative care department acquired charitable funding for a large QI project, 'Improving Care of the Dying in OUH', that it undertook between 2016 and 2020.
- 2.3. Following the pandemic, an EOLC role was re-established in April 2022. Dr Mary Miller currently holds this role. The role is funded by Sobell House Hospice Charity with a commitment to fund until April 2025.

3. National Audit of Care at the End of Life (NACEL) 2022

- 3.1. Final results with national recommendations are expected in late July/August 2023. This paper reports interim results for the 2022 audit.

- 3.2. NACEL's aim is to improve the quality of care delivered to people during the last admission leading to death in hospital and to improve support of those important to the patient by measuring and reporting current care.
- 3.3. The audit monitors progress against the five priorities for care set out in One Chance to Get It Right, NICE Guideline (NG31) and NICE Quality Standards (QS13 and QS144).
- 3.4. NACEL is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government. The first audit took place in 2018. Due to the pandemic, the audit was not undertaken in 2020. This is the fourth audit run by NHS Benchmarking.
- 3.5. Components of the fourth round of NACEL were completed by the EOLC lead, the HPCT team and the patient experience team. Components included:

An **Organisational** review of activity data, the specialist palliative care workforce and staff training.

40 Case Note reviews were examined spread across most OUH departments, including the inpatient specialist palliative care beds, over the 4-week audit period. This sample represents approximately 1.5% of deaths in OUH in 2022/23.

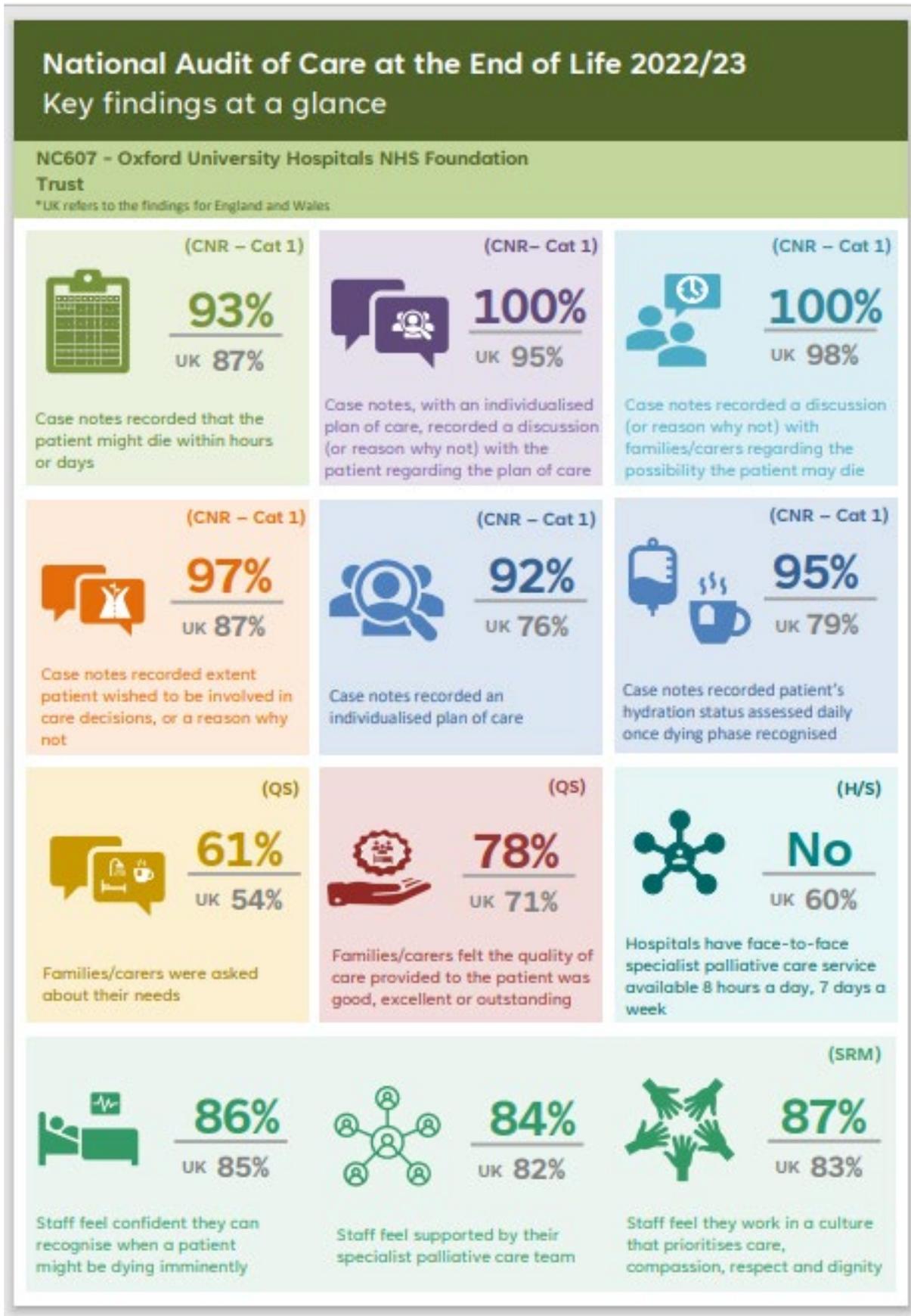
A **Quality Survey** to gain feedback, from relatives, carers and those important to the person who died, on both the care we delivered to the dying patient and the care and support those important to the patient received. From 286 invitations, **64** responses were received (**22%** return rate). This sample represents approximately 2% of all deaths in OUH in 2022/23. There is a free text option to offer feedback. **41** qualitative comments were returned, **16** were complimentary about care. **25 raised concerns** about care the patient received or the support the respondent received.

A **Staff Reported Measure** was completed by 255 OUH staff online.

- 3.6. Key results: Infographic

OUH care (numerator) is rated better than the national average in all but one metric as displayed in the infographic.

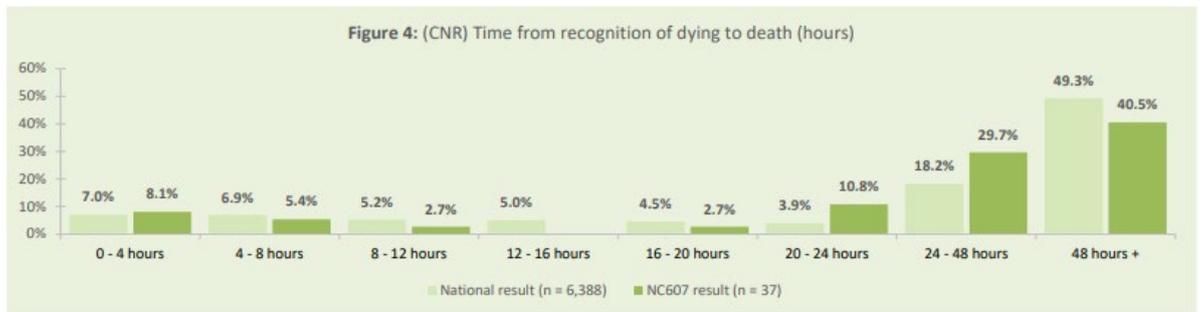
The standard is that hospitals have face to face specialist palliative care services available 8 hours a day 7 days a week. OUH offers a 6 day a week service since April 2023.



3.7 Key results: Area of concern 1 – Bringing the patient’s voice to decisions.



21.6% of patients in the audit sample were recognised to be dying within 12 hours of admission.

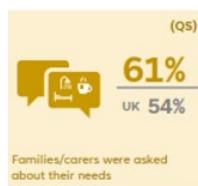


29.7% of patients died within the following 24 hours. For many patients during their final admission, they will be too ill to take part in acute advance care planning.

The Recommended Summary Plan of Care and Treatment (ReSPECT) offers an opportunity to discuss and record a patient’s wishes, preferences and goals of care prior to their final admission.

The Director of Clinical Informatics and the senior digital solutions lead are supporting development work to roll out an electronic ReSPECT form in OUH.

3.8 Key results: Area of concern 2 - Needs of families and others important to the patient.



OUH scores 61% for ‘Needs of families and others’, UK score is 54%.

Though OUH rating is better than the UK average, feedback from those important to the patient (OUH Quality Survey results) rates OUH care much lower than self-assessed scores in the Case Note Review (CNR). This disparity between evidence gathered by healthcare staff on the quality of care and feedback reported by those important to the patient is seen nationally.

Satisfaction with care reported by those important to the patient in annual quality surveys fell sharply in the pandemic and has not returned to the pre pandemic baseline. Visiting restrictions have been cited as a reason for dissatisfaction. In this audit, 37.5% of 'Families and others' reported that visiting restrictions were in place in OUH at the time of the patient's final admission leading to death.

In addition to quantitative scores, qualitative comments from the Quality Survey were returned to OUH for the first time. 16/41 comments were complimentary about care received. 25/41 raised concerns about care.

3.9 Key results: Area of concern 3 – Staff training

Our staff results are 2 – 4% above the UK average. However, of the 255 staff who completed the survey, 40% had not had training specific to end of life care in the preceding three years.

In August 2022, the EOLC lead presented a paper at Clinical Governance Committee. The committee supported a plan that EOLC eLearning be in place for clinically facing staff in OUH. Preparatory work in selecting modules to deliver education using a tiered approach has been undertaken.

3.10 OUH's case note review audit results, sampling the standard of care during the patient's final admission leading to their death, are good and above the national average. Work is underway to introduce an electronic ReSPECT process to ensure the patient's voice is part of the conversation about their care.

OUH's quality survey audit results, sampling the views of those important to the patient, are better than the national average. Work is planned to identify learning from the qualitative feedback comments.

OUH's staff survey results are in line with the national average. Work is underway to make training in end of life care available to staff in OUH.

4. Audit, Research and Quality Improvement work

Providing care of high quality to people approaching the end of their lives is important to staff in OUH. There are many examples of individual and collaborative projects across professions and departments in OUH. Two examples have been selected as examples for your attention, one medical and one surgical. These examples describe work supported by the EOLC Lead.

4.1 Patients with Parkinson's Disease (PD) dying in OUH.

Staff in OUH were uncertain how to provide care at the end of life to patients dying of PD or who had PD as a co-morbidity.

A Medicines Information Leaflet (MIL) to support the provision of care at the end of life for people with PD was developed (Appendix 1). Care was audited in 2021/22 against the standards developed in the MIL by two IMT doctors. 58% of people whose deaths were expected were prescribed medication that was likely to exacerbate their PD. Findings were published. (Appendix 2).

Teaching was undertaken with medical and nursing staff. A powerplan for Parkinson's Disease appropriate anticipatory medications at the end of life (as per NICE guidance) is in development.

A further review of care in 2022/23 is reaching completion.

4.2. Patients prescribed a continuous subcutaneous infusion (CSCI) via a syringe driver.

Two Foundation Year doctors on the Surgical Emergency Unit noted that they and colleagues found it difficult to prescribe parenteral subcutaneous infusions to be delivered via a syringe driver.

They surveyed practice in the unit in 2022/23, finding that prescriptions were relatively rare, one every five days. Involvement of the liaison palliative care team reduced errors from 58% to 0% (Appendix 3).

Findings were reported to SEU governance committee. Advice was developed and incorporated into the SEU Foundation Year handbook to support better care for patients in whom a CSCI is indicated.

5. Goals for 2023/24

- 5.1. The National Audit of Care at the End of Life (NACEL) is planning to pilot a survey of deaths in the Emergency Department, aiming to understand the quality of care delivered to dying patients in the context of the current healthcare climate. OUH will explore the option of being a pilot site.
- 5.2. NACEL will pilot quarterly case record reviews to understand seasonal effects on the quality of care and to enable more timely reporting. OUH will explore the option of being a pilot site.
- 5.3. Task and finish working group will collate learning from the qualitative feedback in the 2022 audit to identify and disseminate learning to OUH staff
- 5.4. Add agreed elearning modules on My Learning Hub. Report access to modules quarterly.
- 5.5. Restart quarterly EOLC meetings in OUH.

6. Recommendations

- 6.1. The Trust Board is asked to:

6.1.1 Note the results of the National Audit of Care at the End of Life (NACEL).

6.1.2 Note the ongoing work on implementation of the electronic Recommended Summary Plan of Care and Treatment (ReSPECT) in OUH. (2019, 2021 & 2022 recommendation). There is a system wide aspiration to implement ReSPECT across the ICS. ReSPECT will bring the patient's voice to the conversation about care at the end of life.

6.1.3 Note that a task and finish group will be convened in Q2 to review the qualitative feedback and identify key learning to be disseminated to staff. (2022 recommendation).

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Thank you for feeding back any comments or concerns to
Mary.miller@ouh.nhs.uk

Appendix 1

<http://ouh.oxnet.nhs.uk/Pharmacy/Mils/MILV11N10.pdf>

MIL

Oxford University Hospitals 

NHS Foundation Trust

Volume 11, No. 10

December 2021

This Medicines Information Leaflet is produced locally to optimise the use of medicines by encouraging prescribing that is safe, clinically appropriate and cost-effective to the NHS.

Care at the end of life: Dying with Parkinson's disease

Parkinson's disease and related Parkinsonian syndromes

This document sets out guidance for symptom management of a patient when a diagnosis of dying has been established by the multidisciplinary team.

Introduction

This guidance applies to patients who have been recognised to be dying with a likely prognosis of hours /short number of days. Patients are likely to be bed bound, sleeping for long periods and unable to take oral medications.

Background information

Patients may have a diagnosis of Parkinson's Disease (PD) or related Parkinsonian syndromes (Multiple System Atrophy, Progressive Supranuclear Palsy, Corticobasal Degeneration, and Lewy Body Dementia).

As patients approach the end of their lives the goal of care is symptom management rather than the maintenance of mobility. Therefore, lower doses of dopaminergic medications may

Medications to be avoided where possible

are antipsychotics: both typical (e.g., haloperidol) and atypical (e.g., risperidone, olanzapine), antiemetics: (e.g., metoclopramide), and other medications with anti-dopaminergic activity.

Medication for management of PD

Amantadine, MAO-B inhibitors, COMT inhibitors and anticholinergic medication should be deprescribed in the last week or two of life.

1. Continue levodopa (L-dopa) and dopamine agonists for as long as possible. Consider switching L-dopa to equivalent dose of orodispersible preparations (Madopar) if the patient can swallow (Dissolve in water or squash). If the patient has a nasogastric tube (NGT) in

Appendix 2: <http://dx.doi.org/10.1136/spcare-2023-PCC.88>

Dying with Parkinson's disease: a survey of clinical practice

Rebecca A. Frake¹, Eliana M.C. Tacconi¹, Mary Miller^{1*}

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Background
Symptom management at the end of life in patients with Parkinson's disease (PD) or an atypical PD syndrome is challenging. These patients experience common end of life symptoms, such as pain and agitation, and are prone to rigidity if sufficient dopamine therapy is not maintained, which can increase discomfort and make personal care more difficult. Swallowing is often impaired at the end of life, common practice is to convert dopamine therapy to a dispersible preparation or transdermal patches that deliver the dopamine agonist rotigotine. Converting oral dopamine therapy to rotigotine is an imprecise process, some patients are prescribed rotigotine in excess of their needs, which can increase delirium and agitation. A further challenge is that several medications commonly used in end of life symptom management have anti-dopaminergic activity. Using these medications risks increasing symptom burden in patients with PD.

Aims
To understand current clinical practice in providing care to those who die with PD in the acute hospital setting. The survey focused on three key questions:
1. Is adequate dopamine therapy maintained?
2. Is dopamine therapy appropriately adjusted in response to symptoms?
3. Are anti-dopaminergic medications used in symptom management?

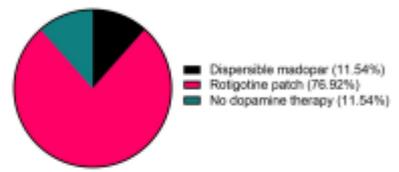


Figure 1: Dopamine therapy maintenance
At the time of death, 12% were receiving dispersible madopar, 77% had transdermal rotigotine patches, 12% were not prescribed dopamine therapy (2 patients died in ED shortly after admission, 1 patient was not receiving any dopamine therapy prior to admission).

Methods
Acute hospital inpatient deaths in Oxford University Hospitals NHS Foundation Trust (OUH) where PD or an atypical PD syndrome was entered on the Medical Certificate of Cause of Death (MCCD) were collated over a 12 month period (2021/22). A data collection form was tested, refined and a convenience sample (60% of deaths) was selected. Electronic patient records were reviewed, with anonymised data collected and stored on secure NHS drives. Data was analysed by all authors. Ethics approval was not sought as the survey examined routine clinical practice.

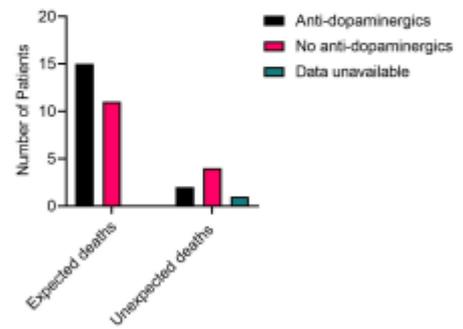


Figure 2: Use of anti-dopaminergic medications in end of life symptom management.
Anti-dopaminergic medications (metoclopramide, haloperidol, levomepromazine) were prescribed for 58% of patients recognised to be dying and for 29% of patients where dying was not recognised.

Results
55 patients had PD or an atypical PD syndrome on their MCCD over the 2021/22 12 month period, **2% of adult inpatient deaths** in OUH.
31 patients had idiopathic PD, 1 had progressive supranuclear palsy and 1 had multiple system atrophy in the sample.
79% were recognised by the medical team as dying. In all expected deaths where practically feasible, **appropriate dopamine therapy was maintained** using dispersible madopar or rotigotine patches (Figure 1). The medical and/or nursing notes mentioned delirium and/or agitation in **50% of expected deaths but no dopamine therapy prescription adjustments** were identified.
Anti-dopaminergic medications were prescribed for symptom management in 58% of expected deaths and 28% of unexpected deaths (Figure 2). In expected deaths, management **advice was sought from the palliative care team (79%), inpatient PD specialist nurses (7%) and on-call neurology registrar (4%).**

Conclusion
Good clinical practice was identified - maintaining adequate dopamine therapy for patients with PD at the end of life. However, improvements were needed – the need to review and possibly adjust dopamine therapy in agitated/delirious patients and the adaptation of anticipatory medications to manage symptoms at the end of life to ensure no/least risk of unwanted anti-dopaminergic effects.
We developed local guidelines on caring for patients with PD at the end of life, wrote a Trust safety message and undertook educational events.

Appendix 3 <http://dx.doi.org/10.1136/spcare-2023-PCC.76>

Pilot study of syringe driver prescribing practice highlights challenges faced by non-palliative care teams

Hannah Chase¹, Elizabeth Good¹, Mary Miller²

Background: Data about continuous subcutaneous infusion (CSCI) prescribing is limited. Further data is needed to understand current practice.¹

Aim: To observe the CSCI prescribing data on the Surgical Emergency Unit (SEU) in the John Radcliffe Hospital, Oxford.

Method:

- Data was collected prospectively initially (07.10.22 - 03.12.22), with retrospective data added to increase sample size (01.08.22 - 06.10.22). The Pallaborative Northwest guidelines were used.²
- Patients receiving a first CSCI as an inpatient on the SEU wards were identified and their electronic patient records reviewed for the CSCI indication, composition, complications, and any documented communication regarding CSCIs with the patient and their family.
- Data was anonymised and stored on NHS drives.
- Ethics permission was not sought as routine practice was observed.
- Data was analysed by all authors.

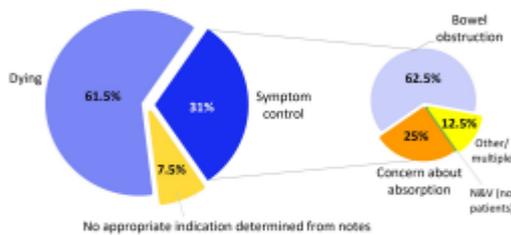
RESULTS

CSCI Prescribing Frequency

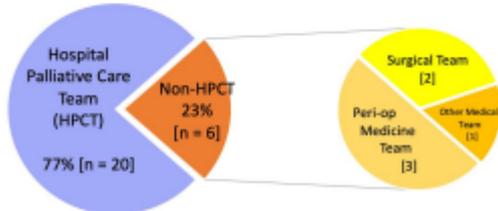
During the 4 months, 26 CSCIs were initiated in greater than 1000 admissions on SEU - 1 every 5 days.

Indication for CSCI

Documented (31%) or determined from patient records (69%):



Team recommending CSCI



Based on who recommended the CSCI, what percentage were stopped or amended within 24 hours due to prescription concerns?

- Non-HPCT recommended (n=6): 50%**
Reasons: CSCI not indicated; patient sedated; concern about dose
- HPCT recommended (n=20): 0%**

References:

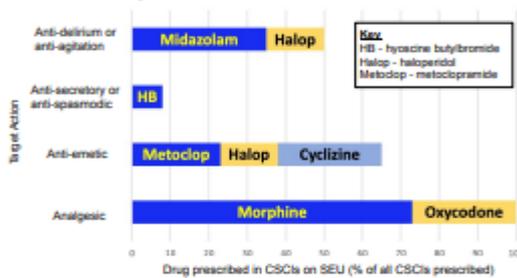
1. Baker, J., Dickman, A., Mason, S. et al. An evaluation of continuous subcutaneous infusions across seven NHS acute hospitals: Is there potential for 48-hour infusions? *BMC Palliat Care* 19, 99 (2020). <https://doi.org/10.1186/s12904-020-00811-3>

2. Benson S, Cadwallader C, Cooper M et al. Best Practice Guideline for the Use of Continuous Subcutaneous Infusions in Palliative Care. Pallaborative Northwest, May 2022. <https://pallaborative.org.uk/clinical-standards-and-guidelines/>

¹ Foundation year doctor, General Surgery, Oxford University Hospitals NHS Foundation Trust

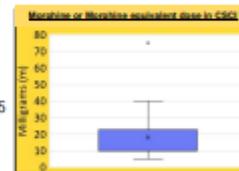
² Consultant palliative medicine, Department of palliative care, Sir Michael Sobell House, Oxford University Hospitals NHS Foundation Trust

CSCI Prescription Constituents



Opioid dosing:

The median morphine dose was 10mg/24 hours (IQR 10mg/24 hrs),
The median oxycodone dose was 7.5 mg/24 hours (IQR 10mg/24 hrs).



Patient and Family Communication

Commencing a CSCI was discussed with **23% of patients** and **42% of families**

Nursing Care of CSCIs

All 26/26 had appropriate (5-6) time checks in 24 hours and only 1 of those had partial data on checks

Conclusion

- CSCI prescribing on SEU is an infrequent event.
- Staff need support from HPCTs to guide initiation, indication and medication dosing of CSCIs.
- The opportunity to explore patient and family understanding and involve them in conversations about care when initiating a CSCI does not currently appear to be maximised.
- Further larger scale data collection is planned in the deanery.

