

be varied including very positive and very negative reactions. There was widespread individual engagement online and off-line and also endorsement by organisations such as Marie Curie and Health Improvement Scotland. The Guide for COVID-19 had 2,545 unique page reviews with users spending on average 2 minutes 50 seconds on the page. Analysis of Twitter data demonstrated a wide level of engagement with the content of both guides, and discussions occurring across a diverse range of individuals.

Conclusions There has been widespread uptake. Public reception, as evaluated in the content analysis, will guide future research to explore the Guide's impact.

Free papers 16–18 | audit

16 HOW COVID19 CHANGED DYING IN MILTON KEYNES UNIVERSITY HOSPITAL

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10.1136/spcare-2021-PCC.16

Introduction The Coronavirus pandemic (COVID19) brought unprecedented challenges to healthcare, and changed how we interact with patients. Recognising the dying patient is essential to deliver compassionate End of Life Care; allowing patients and loved ones to prepare for death, and facilitates opportunities for comfort and dignity. We have reviewed how COVID19 has influenced our approach to the dying patient.

Method We reviewed the electronic notes of all hospital inpatients who died at Milton Keynes University Hospital between 30/03/2020–31/05/2020 and compared key areas to the same period in 2019.

Results In 2020 there were more deaths (207 vs 143) and more occurred within 48 hours of admission (24% vs 18%). In 2020 more treatment escalation plans were completed (98% vs 85%), there were fewer deaths at 'arrest calls' (2 vs 7) and more deaths were anticipated (87% vs 83%). Further analysis of expected deaths occurring >48 hours of admission have shown that in 2020 (vs 2019) dying patients were more often:

- recognised as dying (84% vs 70%)
- reviewed by the Palliative Care team (74% vs 66%)
- on a personalised care plan for the dying patient (89% vs 82%)
- prescribed a syringe driver (50% vs 31%)/anticipatory medications (84–91% vs 79–85%)

However, patients:

- less frequently had visitors (44% vs 93%)
- less often discussed their preferred place of death (27% vs 43%).

Discussion We have reviewed how the pandemic changed our management of dying inpatients. Despite the increased number of deaths there were positive changes in our approach. Possible influencing factors are the perceived increased burden on ITU and encouragement of early discussion about escalation. Challenges like facilitating visitors have also been identified. It is vital that we learn from this experience to ensure our dying patients are managed compassionately, irrespective of the ongoing global crisis.

17 ADVANCE CARE PLANNING FOR ADOLESCENTS AND YOUNG ADULTS WITH CANCER: A RETROSPECTIVE BASELINE AUDIT FROM A PRINCIPAL TREATMENT CENTRE IN THE UK

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Introduction and aims Patient experiences at life's end remain poor, especially with regards to discussing and planning death.¹ Adolescent and Young Adult (AYA) cancer patients represent an important demographic with unique needs. Unfortunately, little is known about the extent of Advance Care Planning (ACP) within this group.² The aims of this study were to determine what, if any, ACP occurred with AYA patients and whether preferences for care/death were met.

Methods A retrospective case note audit was conducted of all AYA cancer patients known to the Principal Treatment Centre in Birmingham, UK, who died between 2013 and 2019. Patients whose care was provided by children's services were excluded. Case notes were scrutinised for evidence of ACP, involvement of palliative care services, and place of death. Data were entered into an Excel spreadsheet for analysis.

Results 84 AYA patients (64% male) met the inclusion criteria. 57% of primary diagnoses were oncological; 43% haematological. Evidence of ACP was recorded in the notes of 67% of patients. ACP discussions were facilitated by oncology/haematology doctors in 61% of cases and by palliative care specialists in 23%. 29% of patients died on a dedicated AYA cancer unit within a specialist tertiary care centre, 26% died at home, and 12% died in hospice. Place of death reflected a patient's ACP in 42% of cases.

Discussion and conclusions Our results demonstrate inconsistent ACP amongst AYA cancer patients. Many patients died in their preferred setting, but almost one third of case notes showed no evidence of ACP. The reasons for this are not clear. Nor is it appreciated whether the topics of death and dying were broached at all in this patient group. Further research is urgently called for to help AYA patients feel more empowered and understood as they approach the close of life.

REFERENCES

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2. Sansom-Daly UM, Wakefield CE, Patterson P, Cohn RJ, Rosenberg AR, Wiener L, and Fardell JE, 2019. End-of-life communication needs for adolescents and young adults with cancer: recommendations for research and practice. *Journal of Adolescent and Young Adult Oncology* ahead of print <http://doi.org/10.1089/jayao.2019.0084>

18 CONTINUOUS SUBCUTANEOUS INFUSIONS IN DYING PATIENTS: A CASE NOTE COMPARISON OF HOSPITAL AND HOSPICE SETTINGS

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Background In the light of the Gosport Independent Panel Report (June 2018), we conducted a comparison of continuous subcutaneous infusions (CSCI) at end of life in hospital and hospice settings.

Methods Retrospective case note review of all patients who died at a university teaching hospital and local hospice in April 2018.

Results 26/34(76%) hospice patients died on an infusion in comparison to 34/86(40%) hospital patients.

Select drug dose ranges were:

Abstract 18 Table 1

	Hospice (median) mg		Hospital (median) mg	
	Start of CSCI	At Death	Start of CSCI	At Death
Morphine	5–80 (20)	10–100 (22.5)	5–30 (10)	5–30 (10)
Oxycodone	5–80 (15)	10–200 (25)	5–20 (5)	5–50 (5)
Midazolam	5–20 (10)	5–60 (20)	2.5–20 (5)	2.5–20 (7.5)
Levomopromazine	6.25–50 (12.5)	12.5–300 (50)	6.25–12.5 (6.25)	6.25–15 (6.25)
Haloperidol	1–3 (1.5)	1.5–5 (3)	1.5–3 (3)	1.5–3 (2.25)

21/26(81%) had been on a regular opioid prior to starting an infusion in hospice, in comparison to 6/30(20%) in hospital.

Median survival after starting a CSCI: 3 days in hospice, 2 days in hospital.

Although recognition and discussion of dying was often recorded, documentation around starting a CSCI was poor in hospital. In the hospice, all patients had a documented indication and 24/26(92%) had a documented rationale for starting doses. While documentation of discussion with patients, family and between doctors was good, discussion with nursing staff was poorly documented in both settings.

Conclusions Higher drug doses used in the hospice setting could be attributed to more complex symptom control needs and interestingly did not seem to have a negative effect on survival. This comparative review highlights areas for improvement: documentation of discussion with family about starting a CSCI, indication and rationale for starting doses in hospital and documentation of discussion with the wider team in both settings. These are likely to apply to other hospices and hospitals.

Poster presentations

Poster 1 | caregivers and the family

1 WHAT IS THE EXPERIENCE OF CAREGIVERS IN RELATION TO ANTICIPATORY MEDICATIONS?

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Background More than half of patients with a terminal diagnosis want to die at home.

NICE recommend provision of injectable anticipatory medications as a way of managing symptoms and facilitating this. However, there is little published evidence regarding the experience of caregivers in relation to anticipatory medications. The primary objective of this study was to explore these experiences and secondly ways to improve practice.

Methods We developed a questionnaire with public involvement and sent it to 100 consecutive caregivers, 3 to 9 months post bereavement. Carers were identified from hospice notes as having been issued anticipatory medicines to have in the home. Data was analysed using descriptive statistics and thematic analysis of free text comments.

Results The response rate to the survey was 38%. The majority were spouses of the deceased (61%). Most patients died at home (63%) and 82% had cancer.

87% of carers said there were benefits of having anticipatory medications available. The majority were reassured that medicine would be readily available when needed to provide symptom relief. However, some people found medicines distressing as they highlighted that death was imminent. Some expressed concern about storage of medication and potential for waste.

Several people commented that they were unable retain all the verbal information given but there were mixed views on potential usefulness of having written information.

Just over half reported that the medication was used; usually for pain or agitation with good effect.

Of those patients that did require the medications the most common problems carers experienced were: delay in a health care professional attending to administer medication (29%); knowledge of the person attending (24%) and deciding when to call for help (21%).

Conclusion Most caregivers find having these medicines is a generally positive experience but some experience challenges and there are areas for practice development.

Posters 2 – 32 | Covid-19

2 NEW COVID INITIATIVE – INTRODUCTION OF THE JUST IN TIME EMERGENCY MEDICINE PACK (JEMP)

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Background During the coronavirus pandemic, it was essential to ensure access to End of life (EoL) medications while protecting the medications supply chain. Traditional Just in Case prescribing could have exhausted the national supply. Consequently, a new NHS Wales Interim End of Life COVID-19 Medicines Service was implemented to provide access to a medication box a Just-In-Time Emergency Medication Pack (JEMP).

Methods The JEMP scheme ensured that end of life medications could be delivered directly to the patient within 2 hours, 24 hours a day 7 days a week, across the whole of Wales. The JEMP contained an agreed list of medications. The Health Courier Service Wales managed a Single Point of Contact, and directed the JEMP request to the most appropriate EoL Pharmacy Hub situated at one of five strategic sites around Wales. To access the service, a healthcare professional would call a 24/7 phone line and send a digital image of the prescription for EoL medications via Hospify (like an NHS Whatsapp). The JEMP then would be delivered directly to the patient's house and the prescription would be collected.