

interactions, department practices, and physical spaces. Similarly, factors causing separation between parents and infants should be identified and minimised where possible, and may be facilitated by palliative models of care.

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OP-28 QUALITY IMPROVEMENT PROJECT ON AFTER DEATH CARE IN BIRMINGHAM, UK

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Background After death care (ADC) refers to the time immediately after the death of a baby, child or young person (BCYP) and management of this significantly impacts the bereavement journey for families. Birmingham in the United Kingdom has the highest Muslim population in the country, a cohort for whom swift burial after death represents culturally appropriate after death care. This has highlighted for local bereavement and paediatric palliative care services the need for processes that support this, and the need to understand the issues families can face in achieving this goal.

Objectives Our service commenced routine recording of novel data in after death care to understand our service's ability to achieve cultural goals. Further aims with provision of grant funding due shortly include hosting local Muslim leaders to understand if this measure is of relevance, feedback findings and review if any other outcomes would be useful.

Methods Birmingham Children's Hospital (BCH) is a large children's hospital servicing the West Midlands (population around 6 million) with 378 beds including the largest PICU in the country. BCH bereavement and palliative care service collected time to hospital release of all deceased BCYP from 1 August 2023 to 29 February 2024, and this was effectively imbedded into ongoing hospital bereavement data collection.

Results We collected complete data for 59 of 61 deaths that occurred in the review period. The average time to release from BCH was 5.6 days with 24% released same or next day, and 51% released within four days. A coroner referral caused delays with average 7.7 days (1.8 days without referral) to release, only 3% release same or next day (62%) and 29% released within 4 days (90%). Outcomes from our engagement events will be available at the time of presentation.

Discussion It is essential data and standards are relevant to the communities we serve. Based on experiences supporting Muslim families in Birmingham we added an ADC measure to review time to hospital release of a body. Our initial data outlines the average time to release for a large hospital in the UK for the first time (that has been published). This shows what we interpret to be 62% of deaths achieving an average processing time meeting cultural goals but that unnecessary coroner referrals could potentially cause harm. We hope to engage with the local Muslim community on outcome relevance and to share our findings. We hope that this is an outcome measure that can be used to compare services, observe

changes when processes change and so delineate barriers and facilitators.

OP-29 DATA GATHERING IN A UNIQUE PALLIATIVE CARE POPULATION: CHARACTERISTICS OF PATIENTS ADMITTED TO THE ADOLESCENT AND YOUNG ADULT HOSPICE (AYAH) IN MANLY SINCE ITS OPENING IN FEBRUARY 2023

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Background The Adolescent and Young Adult Hospice (AYAH) opened in Manly, NSW in February 2023 and is the first of its kind in Australia with the purpose of caring for adolescents and young adults (16–30 years old) from NSW and ACT requiring admission for emergency or planned respite, step down from an acute hospital, complex symptom management, end of life care and post death care.

Given the uniqueness of this patient population and the facility, data is collected on all patients admitted to the AYAH in order to help improve the AYAH service and to guide future developments of similar facilities.

Method Data was gathered looking at:

- Demographics.
- Diagnosis.
- Disease modifying treatments.
- Palliative Care Outcomes Collaboration data.
- Goals of care.
- Airway, breathing, gastrointestinal, seizures, neurological status, motor, bladder, and bowel care needs.
- Seizures, agitation, hypothalamic instability, and dystonia plans.
- An estimate of global nursing hours per day for each patient formed by consensus of two senior nurses.
- Specific mental health diagnoses.

Results As of mid-May 2024, there have been 145 admissions to the AYAH for 45 different patients with an average length of stay of 9 days. Of these admissions, 4/145 were in the terminal phase with 2/4 admissions for complex symptom management and 2/4 for end-of-life care. 29/145 admissions were in the unstable or deteriorating phase with 8/29 admissions for elective respite, 16/29 for complex symptom management, 2/29 for end-of-life care, 1/29 for emergency respite and 2/29 for step down from an acute hospital. The remaining 112 admissions were classed as stable with 5/112 admissions for emergency respite, 102/112 for elective respite, 3/112 for step down from an acute hospital and 2/112 for complex symptom management. 14/145 admissions were for patients with a primary malignancy diagnosis with 4/14 for end-of-life care. 11/145 admissions were for patients with childhood dementia, 31/145 had a primary muscular pathology, 42/145 had a neurodegenerative condition, and 44/145 had a neurostatic condition. Goals of care were modified in 28/145 admissions.

The estimated average and median hours of direct nursing care per patient was 8 and varied between 4 and 18 hours. Care needs could be very high even for stable patients, with 78/145 patients requiring gastrostomy/jejunostomy feeding, 8/145 requiring home parenteral nutrition, 40/145 having seizures on at least most days, 91/145 being incontinent of urine,