

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

Christine Mott*, Sinead McAndrew. *Acorns Children's Hospices and Birmingham Women's and Children's Hospital UK 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

Anushka Thevamanoharan*, Abigail Franklin. *Manly Adolescent and Young Adult Hospice, Sydney, Australia*

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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,

and 12/145 requiring recurrent intermittent urinary catheterisation. 60/145 patients had seizure plans, 13/145 had dystonia and agitation plans and 6/145 patients had hypothalamic instability plans. 55/145 admissions had an underlying mental health diagnosis.

Discussion Many patients admitted to the AYA had a neurodegenerative or neurostatic condition with significant admissions for elective respite. 7 patients have died, all from cancer. This review highlighted the importance and availability of clinical psychology and psychiatry support given that 38% of our admissions had a mental health diagnosis. Nursing requirements between patients varied widely and could be very intensive. This information may be useful to those looking at setting up similar services in the future.

OP-30 A REASON TO LIVE: HOW ADOLESCENT AND YOUNG ADULT PALLIATIVE CARE MADE A YOUNG MAN A FIGHTER

¹Azhani Amiruddin*, ²Abigail Franklin*. ¹NSW Health, Manly, Australia; ²Manly Adolescent and Young Adult Hospice, Manly, Australia

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Background/Rationale The Manly Adolescent and Young Adult Hospice (AYAH) was developed by NSW Health to provide specialized support to adolescents and young adults (AYAs) aged 16–30 with life-limiting illnesses. This case review focuses on Bodhi, an 18-year-old transgender male with hereditary spastic paraplegia, who presented to AYA for multiple admissions (Spray, 2024). The review explores the importance of multidisciplinary psychosocial involvement throughout palliative care and the progression towards end-of-life care. Bodhi and his family have provided permission to discuss his case to highlight the importance of AYA palliative care awareness.

Methodology Bodhi first presented to AYA as a 17-year-old young man with significant low mood, emotional lability, a history of suicide attempts, and suicidal ideation. These concerns were exacerbated by physical symptoms of nerve pain and functional dystonia. He regularly ruminated on seeking Voluntary Assisted Dying (VAD) upon turning 18. To support Bodhi and his family, integration between community and inpatient care was essential for a seamless transition. Regular handovers and involvement in Bodhi's clinical formulation were reflected, discussed, and disseminated through weekly multidisciplinary meetings, which were then communicated to external facilities.

Impact on Practice The psychological case review was conceptualized using a Contextual Schema Therapy framework, an integrative model combining aspects of cognitive, behavioural, and psychodynamic therapies to identify gaps in Bodhi's care. The identified gaps were:

1. Poor pain management
2. Significant existential distress
3. Distress around themes of feeling 'defective.'

These concerns were gradually addressed during Bodhi's respite and symptom management admissions through a combination of medical and psychosocial interventions.

Psychological input focused on addressing individual existential distress using tools such as Voicing My Choices (Samson-Daly et al., 2023). The Clinical Psychologist utilized

Acceptance and Commitment Therapy (ACT) to help Bodhi identify goals and accomplish bucket list tasks. Coordination between AYA Clinical Psychology, social work, psychiatry, and grief counselling ensured a seamless transition of care and provided Bodhi and his family with a sense of purpose as his disease progressed.

Discussion (Lessons Learned, Future Direction) This case illustrates the importance of addressing both physical symptoms and psychological distress within AYA palliative care. By developing a relationship with Bodhi through multiple admissions, he was able to reframe his psychological distress and gain a sense of agency over his medical condition. As a result, Bodhi declined pursuing VAD and chose to die peacefully at home with the support of community palliative care. His legacy continues through his surviving family.

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OP-31 PALLIATIVE MEDICINE IN AUSTRALIA AND NEW ZEALAND: THE BIRTH OF A NEW DISCIPLINE

^{1,2}Ofra Fried*. ¹James Cook University, Hermit Park, Australia; ²Specialist Palliative Care, Rural Telehealth (SPaRTa), Townsville, Australia

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Background Contemporary Palliative Care arose in the mid-20th century, initially in the UK, in response to health care that was increasingly aimed at treatment and cure, but with a correspondingly decreasing focus on addressing patient and family suffering, particularly at the end of life. In Australia and New Zealand, Palliative Care Services developed later; Palliative Medicine was only formally recognized as a specialist discipline in the early 2000's.

My PhD research explores the social history of these developments through the experiences and insights of the first cohort of doctors designated as Palliative Medicine Specialists by the Royal Australasian College of Physicians (RACP).

Study objectives

1. Document the experiences of the first cohort of doctors, the RACPs 'Foundation Fellows', who became Palliative Medicine Specialists in Australia and New Zealand.
2. Analyze and interpret the social history and development of Palliative Medicine in Australia and New Zealand.
3. Seek an informed insight into what might be of most benefit for the future of palliative practice in a rapidly changing health care and social environment.

Methods Narrative Inquiry, consisting of an Electronic Survey posted to all RACP Foundation Fellows, and a series of 25 Narrative Interviews conducted in person or via Zoom, and analyzed inductively according to Narrative Methodology.

Results Survey response rate 39%, of whom 58% agreed to be interviewed.

Analysis of demographic data.

Exploration of interviewees' motivations, their values, and their struggles and achievements.

Developing a narrative of discipline development for Palliative Medicine.