

**Results** In total 25 babies were referred with Trisomy 18 and 6 with Trisomy 13 from November 2021 to May 2024 (2 years 7 months).

There was a variance in approach to care during pregnancy including whether or not subspecialty reviews were offered. After birth there was a variance in approach to formalising diagnosis if amniocentesis had been declined. At birth different approaches to care were offered including around access to NICU admission, provision of respiratory support and other resuscitation measures. Interventions provided included surgery before and after formalised diagnosis. Prognosis varied, with a large cohort not surviving to delivery (8 trisomy 18; 1 trisomy 13), many having short lives (11 trisomy 18; 4 trisomy 13) a cohort continuing to survive at time of writing (6 trisomy 18; 1 trisomy 13).

**Discussion** Our findings support clinicians having an open mind in their approach to families with a baby diagnosed with or highly likely to have trisomy 18. True parallel planning, a cornerstone of palliative care, should include planning for both the best and worst possible outcomes. Families need to be aware of the possibility of IUPD but also extended time at home together to help them navigate choices effectively. Care that supports both pathways should be carefully considered, alongside an understanding of the family's goals and preferences.

#### OP-26 THE ROLE OF CROSS SERVICE SUPPORT IN CARING FOR A PATIENT WITH CHILDHOOD DEMENTIA

<sup>1,2,3</sup>Abigail Franklin\*, <sup>4</sup>Gail Hilton. <sup>1</sup>Northern Sydney Local Health District, Manly, Australia; <sup>2</sup>HammondCare, Sydney, Australia; <sup>3</sup>Clinical Lecturer Macquarie University, Sydney, Australia; <sup>4</sup>Childhood Dementia Initiative, Sydney, Australia

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1/2900 babies born have one of the over 100 neurodegenerative genetic disorders associated with developing a Childhood Dementia Syndrome. Patients suffering from Childhood Dementia Syndromes usually have normal development initially, before developing symptoms before the age of 18 years old, which progress over years, or potentially even decades.<sup>1</sup> Around 90 patients die each year in Australia from a Childhood Dementia. Given the progressive, life-limiting nature of the diagnosis, these patients and their families may receive care in Children's or Adolescent and Young Adult Hospices, whether for elective respite, complex symptom management or end of life care as well as from community palliative care teams and hospital palliative care consultation services.

A Childhood Dementia Initiative report of 2024 noted key issues including a severe lack of knowledge and understanding and a chronic absence of expert care. These then lead to increased parental burden, disempowerment of families, risk to children's safety and neglect and inequity of care.<sup>2</sup>

This presentation will highlight the role of cross-service care for patients with a Childhood Dementia Syndrome. This includes Dementia Support Australia, Childhood Dementia Initiative, NDIS, Community Specialist Palliative Care team, outpatient specialist medical consultant teams and the specialist multidisciplinary team at the Adolescent and Young Adult Hospice (including clinical psychologist, psychiatrist, occupational therapist, physiotherapist, art and music therapists, speech pathologist, dietitian and bereavement support worker)

with a case presentation of a 20 year old with a Childhood Dementia Syndrome.

#### REFERENCES

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#### OP-27 BEREAVED PARENT EXPERIENCES OF NEONATAL PALLIATIVE CARE IN THE NEONATAL INTENSIVE CARE UNIT (NICU)

Caroline Wells\*. Sydney Children's Hospitals Network, Sydney, Australia

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#### Site

Paediatric Palliative Care Service, The Women's and Children's Hospital, Adelaide

**Background** Neonatal palliative care (NPC) is a holistic model of care from the time of diagnosis of a life limiting condition, that focuses on the infant's quality of life and support of the family (Catlin & Carter, 2002; Kain & Chin, 2020). Learning directly from bereaved parents' lived experience has the potential to improve infant care, better support family-centred care and decision making, and address parental distress (Quinn & Gephart, 2016). There is a paucity of interview based qualitative studies of bereaved parent experiences of neonatal palliative care in NICU.

**Study Objectives** To explore bereaved parents' experiences of neonatal palliative care in the Neonatal Intensive Care Unit (NICU), which aims to inform and improve the delivery of family-centred palliative care.

**Method** An exploratory qualitative design was employed using a phenomenology methodology. Parents of an infant who had died in the NICU at the Women's and Children's Hospital (WCH), Adelaide, and were 6–12 months bereaved participated in semi-structured interviews to explore experiences. Interviews via videoconferencing or phone call were audio-recorded and transcribed. Inductive thematic analysis was conducted to generate themes.

**Results** Six parents (four mothers and two fathers) participated in five interviews. Four themes characterised parents' experiences of neonatal palliative care: hope and fragility, decision making role and responsibility, 'taking... in' of their baby, and being together and separate. Parents maintained hope when faced with uncertainty and infant fragility. A high priority was placed on decision making regardless of the scope of options, opportunities for deep infant connection and sharing the infant with family. Families wanted to be together, but many factors contributed to separation.

**Discussion** By elucidating parents' most pertinent experiences of neonatal palliative care the findings from this study can inform family-centred care delivered by staff. Clinicians can recognise hope as a preference and coping strategy for parents to manage uncertainty. Decision making is integral to the parent role and parent autonomy, so clinicians should empower, collaborate and support parents in decision making, regardless of the scope of choices. Given the central importance to parents of 'taking...in' their infant and family visiting, these opportunities should be actively facilitated by staff

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.

## REFERENCES

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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,