

Secondly, understanding family dynamics and children's needs, including knowledge of how children grieve and process information, was important in order to support the child at home. Professionals advocated for the children's need to know what was occurring with their parent. However, time constraints and limited resources affected their ability to engage children. There was little formal training on communicating with children, with professionals largely drawing on prior experience or doing their own research.

Thirdly, professionals embraced their own vulnerability. They experienced countertransference, and most were intentional about self-care. While there was fear of making things worse for children, there was a sense of fulfillment and comfort in being of assistance.

Discussion Professionals showed awareness of the emotional toll, and vicarious post-traumatic growth was also evident in some. There was significant countertransference, mostly in for those who were themselves parents of young children. Parentified children who were caregivers causes significant distress to the Professionals.

Significance There is a need for better organizational support to manage emotional toll and time constraints. More specialized training and resources are required, as well as enhanced partnerships with external agencies to better support affected children. Findings can contribute to the development of an interdisciplinary project aiming to address these issues.

OP-24

EMBRACE: MEETING THE CHALLENGE OF LIVING WITH SERIOUS ILLNESS, A FEASIBILITY STUDY

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Background People with serious illness face multiple losses which necessitates a new way of living. Many experience a loss of meaning and purpose. There is a need for interventions to support people exploring opportunities for growth despite their changed circumstances.

Aim to develop and test the feasibility of an intervention that is based on the principles of posttraumatic growth and seeks to foster a stronger sense of meaning and purpose and that is relevant and appropriate to palliative care settings.

Methods Using participatory action research methodology, the intervention was designed in an iterative process with both health professionals and people with lived experience of a terminal illness. Further feedback from program participants and facilitators was then used to modify and refine the program before finalisation. The face to face group program was pilot tested over six weekly sessions each for two hours. Outcome measures include the Symptom Assessment Scale, FACIT-Sp, HADS and a qualitative interview. Ethics approval was obtained. Qualitative analysis was conducted using framework analysis.

Results Three major themes:

Engagement; Self-reflection and Empowerment.

Engagement

The theme of 'Engagement' describes how participants interact with others, both in taking part in the program and with family or other people during the course of their illness. Group interaction during the program demonstrated the care participants showed towards each other e.g. dealing with the

expression of emotion; trust was demonstrated by how participants allowed themselves to display emotion as they knew their fellow group members would understand their situation.

Self-reflection

The theme of 'Self-reflection' in response to the program offered participants an opportunity to listen to other participants' stories and consider their own situation. In particular, many commented on how, despite perceiving individual differences, they could learn from the similarities of their shared experiences. Many participants were open to learning more about how to manage differently while living with serious illness, however some participants felt this was not possible. Self-reflection and being open to learning allowed participants to consider alternative views about what was important in each individual's life and one's capacity to make changes to live life in a positive manner for the benefit of the individual, their family and friends.

Empowerment

The theme of 'Empowerment' describes the realisation that participants are able to manage their life differently in a way that still has meaning and purpose. Prioritising, making choices, and setting differently configured goals for oneself became ways of living with purpose and hope. Through self-reflection and discussion with others, many participants stated how they now felt they were better able to discuss and prepare for the future with close family and friends, with some stating a new found purpose and/or determination to benefit others while the participant is able.

Conclusions The Embrace program shows promise at addressing the widespread challenge of finding new sources of meaning and purpose for those living with serious illness.

OP-25

IMPROVING PARALLEL PLANNING IN TRISOMY 18 AND 13

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Background West Midlands Perinatal Palliative Care Service (WMPPCS) is the busiest such service in the United Kingdom with 62 referrals for the 12 months 2023 to 2024 to date. A large cohort of babies with Trisomy 18 and 13 are referred to this service. These conditions are associated with poor outcomes such that colloquially has been described as 'incompatible with life'. Increasingly services involved are recognising a variety of outcomes though, and questions about what interventions should be offered are being raised. Parallel planning varies and may or may not include offers of a doctor attending delivery, subspecialist review, access to respiratory support, access to Neonatal Intensive Care Units and surgical intervention. This balance between recognising potential to survive and need best possible care, and poor average survival makes care complex to navigate.

Objectives We reviewed the number of babies with a trisomy 18 or 13 diagnosis referred to the service and reviewed what service was provided, what interventions were undertaken and for those babies that died what their length of survival was. Using this information we hope to broaden understanding of possible outcomes and precedent clinical journeys to improve and provide consistency in parallel planning for these babies.

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

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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.¹ 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.²

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.

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

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Site

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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