

P-128 **'HOLDING FAMILIES IN UNCERTAINTY' THE ROLE OF CHILDREN'S HOSPICES IN PROVIDING PERINATAL PALLIATIVE CARE**

^{1,2}Michael Tatterton, ³Megan Fisher. ¹Bluebell Wood Children's Hospice, Sheffield, UK; ²Northumbria University, Newcastle upon Tyne, UK; ³University of Bradford, Bradford, UK

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Background Perinatal palliative care (PPC) describes the holistic and supportive management of a fetus, neonate or infant (baby) with a life-limiting or life-threatening condition (LLLTC). It offers psychological and emotional support to families and supports the clinical needs of babies. Children's hospices (hospices) provide a range of PPC services, however, little is understood about the role of hospice care and how it contributes to effective PPC (Tatterton, Fisher, Storton, et al. J Nurs Scholarsh. Early view. 1– 10. 2022).

Aim To understand how children's hospice services support families during the perinatal period, and how they perceive the impact of, and barriers and facilitators to providing PPC.

Methods An electronic survey was sent to all 54 children's hospices in the United Kingdom in June 2022. In the survey, hospices were asked if they would be willing to host a focus group to explore the experiences of staff members. Invitations were sent to those hospices who indicated a willingness to take part in September 2022. Qualitative data were analysed using framework analysis.

Results Thirty hospices responded to the survey, representing 54% of the sector. All regions of all four countries were represented. Eighteen practitioners participated in three focus groups. Hospices took a range of approaches to providing PPC, working with NHS Teams, most commonly fetal medicine and neonatal services. Care was usually provided from the point of diagnosis or recognition of a LLLTC. Advance care plans were an important element of effective perinatal palliative care, strengthening parent – professional and inter-professional relationships (Tatterton & Fisher. Palliat Med. 2023; 0:0). Six themes were identified from focus group transcripts: early referral, joint working, care planning, focus of care, perceptions of hospice care by neonatal staff and neonatal staff education.

Conclusions The family-centered approach to care, from a broad, biopsychosocial perspective means that hospices make an important contribution to both the clinical needs of babies, and psychological needs of families antenatally, in the neonatal period and after death.

P-129 **GENDER ROLES, NORMS AND IMPACT ON EXPERIENCES OF PEOPLE AFFECTED BY DYING, DEATH AND BEREAVEMENT – A SERVICE EVALUATION AND QUALITATIVE STUDY**

¹Bethan Edwards, ²Ellie Wagstaff, ³Nicola White, ⁴Briony Hudson. ¹Marie Curie, Cardiff, UK; ²Marie Curie, Edinburgh, UK; ³Marie Curie Palliative Care Research Department, UCL, London, UK; ⁴Marie Curie, London, UK

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Background There is evidence that gender influences many aspects of end of life experience (Gott, Morgan, Williams. Palliat Care Social Pract. 2020; 14, 2632352420957997; Ullrich, Grube, Hlawatsch, et al. BMC Palliat Care. 2019; 18, 1–10). There is a need to understand whether gender inequity

exists in palliative care services and how to adopt gender sensitive practices to improve end of life experiences for all.

Aims To explore gender differences in use of palliative care services, time from referral to death, preference for place of death and place of death and also to explore palliative care staff's views on the impact of gender on palliative care access and experiences.

Methods Service evaluation of routinely collected data from hospices and community nursing services across the UK (Jan 2019 to December 2022), summarised using descriptive statistics. Focus groups with palliative care staff from hospices and community nursing teams in Scotland and Wales, analysed using thematic analysis.

Results 90,614 data points were analysed. A roughly even split between male (51%) and female (48%) patients was observed. The majority of patients were white British (82%). Large amounts of missing data relating to personal characteristics were observed. No differences were noted in other variables explored. Focus group explored the influence of gender for patients with palliative care needs and their informal carers, including family and gender norms around caring and accessing support. The limited diversity among palliative care patients, inexperience around supporting people who were transgender and factors other than gender that influence experiences were also discussed.

Conclusions While quantitative data suggests limited differences in access to care, qualitative data suggests differences in the experiences of palliative care for people of different genders. An intersectional mindset is needed to ensure everyone has the best possible end of life experiences. To enable explorations of intersectionality, we must support staff to improve the collection of personal characteristics in practice to support future research and service delivery.

Patient care

P-130 **MORE THAN SKIN DEEP: ADDRESSING THE INFORMATION GAP DESCRIBING CHANGES ON DARKER SKIN AT THE END OF LIFE**

Devi Sagar, Nadia El-Gazar, Imogen Pinnell, Kate Maitland, Karon Ormadel. Marie Curie, London, UK

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Background To provide equitable care for people approaching death it is important that we understand how to provide the best skin care for people with darker skin tones. Healthcare professionals, carers, and people important to the dying person need help to recognise normal skin type, rashes, signs of acute inflammation, pressure damage, and changes at the end of life in patients with darker skin tones.

Aims To see what information exists documenting changes in darker skin tones that is relevant to people approaching death to update resources to ensure the information, support and services we provide are fully inclusive.

Methods Online databases were searched for articles published in the last five years describing skin changes in people of darker skin tones relevant to end-of-life care, including skin appearance at the end of life, development of pressure damage, sepsis, signs of infection, erythema and cyanosis. We consulted healthcare professionals, looked for existing guidance

available on skin changes in people with darker skin and we consulted the Ubele Initiative.

Results Preliminary searches found few articles covered descriptions of skin changes at the end of life and contained outdated terms. No studies described the appearance of skin in people with darker skin at the end of life. Information about skin changes relevant to end of life care in people with darker skin found in resources from Wounds UK, National Wound Care Strategy, Mind the Gap and UK Sepsis Trust was used to update resources and website information which were reviewed by experts by experience and professionals.

Conclusion There is a significant lack of robust evidence, information, and guidance on changes of skin tone in people with darker skin at the end of life. There is a need for co-produced, evidence-informed practical guidance for healthcare professionals and informal carers supporting people at the end of life.

P-131 HEARING THE FAMILY VOICES

¹Huw Owen, ²Tracy Jones, ³Andy Goldsmith. ¹Tŷ Hafan and Tŷ Gobaith, Cardiff and Conwy, UK; ²Tŷ Hafan, Cardiff, UK; ³Tŷ Gobaith, Conwy, UK

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Background Service user involvement in design, implementation and evaluation of services is becoming increasingly commonplace (Omeni, Barnes, MacDonald, et al. BMC Health Serv Res. 2014;14, 491). Research also shows that service user involvement has a positive impact on the organisation and the service users (Gordon, Franklin, Eltringham. Res Involv Engagem. 2018; 4, 11; Minogue, Boness, Brown, et al. Int J Health Care Qual Assur Inc Leadersh Health Serv. 2005;18(2-3):103-12).

Aims To evaluate and understand what matters to the families, what families with children and young people with life-limiting conditions need to live the best life they can, and what role do the children's hospices in Wales play in providing this support?

Methods Nov. 2019 – Jan. 2020: Online survey to gather views of families using both children's hospices in Wales. January 2020 – February 2020: Ten in depth interviews conducted to supplement the findings of the online survey.

Results Hospice services provide essential support to families and are the main places that families access the support they need. Access to respite/short break care is essential to family coping and wellbeing. Complexity of condition has an impact on care and family life. Support for young people leaving hospice services is lacking and there is a need for bereavement support and counselling.

Conclusion Children's hospices in Wales are often the only places where families can access the tailored support that they need to care for their child. Including families in service design, implementation and evaluation at all levels is crucial to providing excellent services.

P-132 TRANSFORMATION OF TRANSITION WITHIN CHILDREN'S HOSPICE

Lavinia Jarrett, Anna Sillett, Claire Collins, Paul Packman. Demelza Hospice Care For Children, Sittingbourne, UK

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Background With more children with life-limiting conditions surviving into adulthood (Jarvis, Roberts, Flemming, et al. *Pediatr Res.* 2021; 90(6): 1120-1131) approximately 25% of the overall children's hospice caseload was of transition age. Families expressed how challenging and stressful this period was, both practically and emotionally. A significant need to transform support was overwhelmingly apparent, particularly in the absence of a national framework alongside a lack of investment and resource. It also became clear there is disparity between services available to a young person (aged 18) in a children's hospice compared to accessing services from an adult hospice.

Aims To build a transition service informed by a steering group involving hospice Clinical Services Leads and representation of families, to facilitate and inform a review of the current offer of support; to ensure quality improvement and equity of service, with an identified caseload. To review multi-professional approaches and service availability within differing referral criteria.

Methods

1. Extensive research and information gained from the National Institute for Health and Care Excellence, Together for Short Lives and Hospice UK, alongside the lived experiences of families.
2. Development and implementation of unique Transition Framework.
3. Restructure and recruitment of designated posts.
4. To work collaboratively with adult services.

Results Contacting families to provide bespoke support has been key to understanding the needs of families, putting the voice of the young person at the centre. Creating opportunities for peer-to-peer support and developing these support programmes has been invaluable in connecting families, through hybrid engagements and collaborative working.

Conclusions Transition support has been transformed, with increased understanding of legislation, defined support service offer and enhanced communication with social and health providers. Needs of young people have been identified, and support given to all family members moving into adult services. Access to psychosocial Family Support defined after young person's 18th birthday with start of transition plan in place from 14 years old.

P-133 "I'M NOT ALONE": THE IMPORTANCE OF RESIDENTIAL TRIPS FOR BROTHERS AND SISTERS

Paige Fontana, Lavinia Jarrett, Jane O'Neill. Demelza, Hospice Care for Children, Sittingbourne, UK

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Background You may have special memories from a school trip, whether a first stay away or trying something new. These opportunities are crucial for siblings living with a young person with a serious or life-limiting condition. For the past two years, we have organised a three-day residential for siblings transitioning to secondary school. The need grew after the pandemic with lockdown affecting the mental health of those living with siblings with disabilities, who have missed out on important opportunities to meet others.

Aims The focus was to provide a fun space, create new friendships, meet others in similar situations and build