Abstracts

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

1Michael Tatterton, 2Megan Fisher, 3Bluebell Wood Children's Hospice, Sheffield, UK; 2Northumbria University, Newcastle upon Tyne, UK; 4University of Bradford, Bradford, UK

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 Palliat Care Soc Pract. 2020; 14, 2632252420957997; Ullrich, Grube, Hlawatsch, et al. BMC Palliat Care. 2019; 18, 10.1136/bmjspcare-2023-HUNC.149)

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; 4Marie Curie Palliative Care Research Department, UCL, London, UK; 4Marie Curie, London, UK

Background There is evidence that gender influences many aspects of end-of-life experience (Gott, Morgan, Williams. Palliat Care Social Pract. 2020; 14, 263235242097997; 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, Karan Ornadel. Marie Curie, London, UK

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