



## Identifying family centred conversations in routine clinical care

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**P-6** INTEGRATION OF A MEDICAL EXAMINER SERVICE TO SUPPORT DEATHS ON A HOSPICE INPATIENT UNIT

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**Background** In response to several public inquiries, the Government reformed the process of death certification in England and Wales. Medical examiners (ME) have been recruited in hospitals to conduct independent medical scrutiny of cause of death and engage with bereaved families to understand their concerns. The ME initially contacted the hospice to expand the service to hospice deaths in the area.

**Method** From initial multi-professional discussions, a pilot programme was developed to refer all hospice inpatient deaths to the local medical examiner office (MEO). Information governance and IT support allowed note sharing between the hospital and hospice via electronic patient records, a referral algorithm was developed, and the pilot was started. Throughout the process there were multiple ongoing virtual meetings, to ensure continual improvement. These improvements included ensuring deaths could be registered within 5 days and streamlining discussions with the coroner.

**Results** Number of referrals 1/2/2021 - 8/12/21

Total deaths Coroner referral 100A/NFA 100B Inquest  
177 27 23 1 3

The pilot programme went well. The MEO has been able to support when cause of death or need for coroner referral has been uncertain, the accuracy and consistency in recording cause of death has improved (e.g. 'squamous cell lung cancer' rather than just 'lung cancer'), and importantly, it has successfully provided a separate support service for the bereaved to help navigate the process and give feedback about care provided.

**Conclusion** This has been a successful pilot programme, remarkable given the hospice is not on the site of the hospital. The ME process is now integrated into the hospice care after death procedures.

The ME is using this positive experience in the roll-out of scrutiny to all community deaths in 2022. We hope our experience can help provide insight for other hospices as they start working with their local MEO.

**P-7** DEATH, DYING AND BEREAVEMENT: CAREGIVERS AND FAMILY SUPPORT IN AN ACUTE HOSPITAL

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**Introduction** Embracing the needs of caregivers and family is fundamental to providing kind and compassionate holistic end of life care (Leadership Alliance for the Care of Dying People 2014). Caring for the dying in a hospital setting can be challenging and the physical environment can impact on caregivers and family experiences (Miller et al 2021).

**Method** A service evaluation adopting the 'Walking the walk' quality improvement design provided an experienced based approach to view the hospital through the eyes of caregivers and family visiting dying loved ones (Claire Henry Associates 2019). Following ethical approval, a review group of eight participants with personal lived experience of caring for a dying relative, including marginalised groups, was selected through purposeful sampling. Restricted by the pandemic and

infection control, the exercise was delivered virtually by presenting over one hundred photos and videos to participants. Focusing on four key areas of care (involvement in care of the loved one, access to help and support, care after death and the bereavement process), feedback and observational data was collected and coded using thematic analysis (Braun and Clarke 2006).

**Results** Generated themes reflected those within current literature. Priority areas for development included: enhancing non-verbal communication, dedicated side rooms for end of life care, provision of resources to support caregivers and family to stay at the patient's bedside including hospitality trays, access to a quiet family room space including a kitchenette and availability of washing facilities, creating a more inclusive spiritual space and improving the décor and ambience of the mortuary visiting area. Dedicated to excellence, these initiatives have been championed by the senior leadership team and hospital charity.

**Conclusion** Focusing on the things that really do make a difference and embedding improvements into practice will demonstrate, as a trust, we really are prepared to care for caregivers and family of dying patients.

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**P-8** IDENTIFYING FAMILY CENTRED CONVERSATIONS IN ROUTINE CLINICAL CARE

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10.1136/spcare-2022-SCPSC.29

**Background** Literature reports that healthcare staff wait for patients and their family network to raise questions about whether or how to talk to children and young people (< 24 years, hereafter referred to as children) about a loved one's illness and impending death. Patients and families wait for staff to raise the subject. Research indicates families and healthcare staff find these conversations difficult.

**Aim** To survey palliative care practice in an NHS hospice.

**Methods** Data was captured from a random sample of 30 patient records.

**Results** Participants ranged from 27 – 97 years, 30% female. Patients were known to the service for 4 to 534 days, 58% were receiving ongoing palliative care at the time of the survey.

Information about the patient's relationships with children was documented in 10 (30%) records; at first meeting in 4 and at subsequent contacts in six.

Palliative Care Key Information form was completed for 36% (11/30) of patients. 'Significant relationships' were

completed on 8 forms, however, only 3 records referred to children.

Documented relationships with children included parent, grandparent and great-grandparent.

Two families raised concerns about talking to children with staff. In one case there was no evidence that concerns were addressed, in the second the issues were managed by a consultant in palliative medicine and followed up during the hospice admission.

There was no documented evidence that members of staff offered to speak with children. A children's bereavement charity was reported as supporting one family, whilst another family's children received support at school and from a counselling service.

**Conclusion** Important conversations with children are not being included as part of routine clinical care. The results of this survey and the literature about the impact of timely information for children when an important adult is receiving palliative care, will be shared across our service. These discussions will inform an action plan to facilitate family-focused conversations.

**P-9 UNDERSTANDING THE EXPERIENCE OF CHILDREN WHO HAVE A PARENT WITH MOTOR NEURON DISEASE: A THEMATIC ANALYSIS**

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**Background/Aims** Children who have a parent with Motor Neuron Disease (MND) often have carer responsibilities and require extra support from others. MND is also a life-limiting disease and the children require support. Asking the children about their experiences will help healthcare professionals better understand their unique needs and may help facilitate better pre-bereavement support.

**Methods** Semi-structured interviews were conducted with three children aged 6 to 12 who have a parent with MND. The children were asked about their understanding of MND, what support they receive or would like, and their interactions with peers and healthcare professionals. A thematic analysis of the interviews was performed.

**Results** Four themes were identified: (1) perception of MND, (2) learning about MND, (3) emotional wellbeing and support, and (4) the role of a carer. The children had a limited understanding of MND, and the children felt excluded from discussions with healthcare professionals around their parent's illness and treatment. Despite its negative aspects, the children acknowledged that MND allowed the family to spend more time together. Even though the children did not self-identify as carers, they had significant carer responsibilities. They found that this negatively affected their schooling, such as completing homework. Although they felt that MND was poorly understood by their classmates, the children found young carer groups beneficial and were able to meet other young carers and relax.

**Conclusion** Thematic analysis of interviews with MND patients' children provided invaluable insight into the children's experiences and what support would be beneficial. Guidelines should be established around communication between healthcare professionals and children, and actively involving children in the care of their parent would facilitate

the family dynamic. Greater advertising of resources for young carers would allow more children to meet other young carers. Children must have an active voice in discussions around their support.

**P-10 HOW DO THE PROGNOSTIC PERCEPTIONS OF PARENTS, AND ITS CONCORDANCE WITH THOSE OF HCPS, INFLUENCE DECISIONS ABOUT GOALS OF CARE IN CHILDREN WITH LIFE-LIMITING ILLNESSES?**

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10.1136/spcare-2022-SCPSC.31

**Background** The prevalence of children with life-limiting conditions is set to increase, resulting in an increased number of parents being involved in their child's treatment decisions. These decisions are influenced by the medical information conveyed and their own evaluations of this knowledge. The aim of this review was to explore the alignment between parental and Healthcare professional (HCP) prognostic perceptions and treatment preferences, whilst presenting possible explanations for any differing opinions.

**Methods** A literature search, using the databases: Medline, Trip, PubMed, PsychINFO and EMBASE was conducted. The inclusion criterion applied was – published since 2000, written in English, focused on children of 0–18 years. Peer reviewed data on the prognostic perceptions of parents and HCPs, and their goals of treatment for children with life limiting condition were selected.

**Results** Overall, in the eleven papers included there was a lack of parental prognostic understanding with a poor alignment to the prognostic views of HCPs. Parents promoted more aggressive treatment options relative to HCPs more palliative approach. This is hypothesised to result from particularly fathers remaining hopeful for a cure. Studies showed discrepancies remained after prognostic conversations were held between parent's and HCPs, with others indicating parents' insight of there being no cure resulted before being openly disclosed by a HCP.

**Conclusions** This study postulates poor prognostic insight may arise from a lack of open communication, resulting in parents advocating for more aggressive treatment with hope of finding a cure. However, given the cross-sectional nature of the studies, this review is only able to suggest these correlations. Future studies are recommended to explore the trajectory of parental prognostic understanding and how it is influenced by communication with HCPs.

**Posters 11–35 | COVID-19**

**P-11 HAVING VISION: THE ROLE OF QUALITY IMPROVEMENT IN SUSTAINING RATES OF CORNEAL DONATION THROUGH THE COVID PANDEMIC**

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10.1136/spcare-2022-SCPSC.32

**Introduction** Normalising the discussion and practice of Corneal Donation amongst hospice inpatients has been the focus