

Aims This mixed-methods study aimed to (i) quantify the extent and risk of bias of MD in palliative care trials; (ii) explore the factors associated with MD, (iii) develop MD recommendations for patients, clinicians, researchers and policymakers.

Methods (i) Systematic review of MD in 108 palliative care trials (meta-analyses and meta-regression); (ii) individual participant-level data (IPD) meta-analysis of factors associated with MD in 10 palliative care trials (multi-level modelling); (iii) in-depth interviews with research personnel (thematic analysis).

Results (i) Systematic review: 23% of primary outcome data were missing at the primary end-point (95% CI 19, 27). Larger MD proportions were associated with increasing numbers of questions/tests asked of participants (odds ratio (OR) 1.2 per-doubling, 95% CI 1.1, 1.4) and longer study duration (OR 1.1 per-doubling, 95% CI 1.0, 1.2). There was evidence of differential rates of MD between trial arms, thus potentially introducing bias. (ii) IPD: Participants with previous MD (OR 17.2, 95% CI 8.6, 34.5) and poorer Karnofsky Performance Status (10-unit increase: OR 0.8, 95% CI 0.7, 0.9) were more likely to have MD. (iii) Interviews: themes included 'clinical vs research-role tension' and 'attention-to-detail vs attention-to-person'.

Conclusions MD pose a significant risk to palliative care trial findings but can potentially be reduced. It is therefore essential that multi-disciplinary team members can (i) critically assess the MD risk of bias and (ii) help to reduce MD – guidance on how to do these will be discussed.

0-7 HOW SYSTEM-WIDE ADVANCE CARE PLANNING SUPPORT CAN BE DELIVERED COST EFFECTIVELY

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Advance care planning (ACP) can promote person-centred care and better use of resources. ACP involving a facilitated conversation with a health or care professional is more effective than document completion alone. However, these conversations are time consuming. Evidence about how ACP support can be delivered by health and care professionals cost-effectively and at scale is currently lacking.

To explore this issue, we identified twelve international healthcare organisations with practical experience of resourcing, staffing and delivering system-wide ACP support. In each, we conducted an average 13 in-depth interviews with senior managers, ACP leads, dedicated ACP facilitators, physicians, nurses, social workers and other clinical and non-clinical staff. Data were thematically analysed using NVivo software.

Our findings emphasised the importance of strategic and dedicated day-to-day leadership for creating accountability and supporting professionals to deliver ACP support within their roles. Reliance on dedicated facilitators was not considered sustainable or scalable, although a degree of staff specialism improved efficiency and effectiveness and allowed the better targeting of training.

A lack of protected time was commonly experienced as a barrier. Incorporating ACP into existing care could mean it got 'squeezed out' or became too fragmented. Physician leadership was important, but entirely physician-led approaches were associated with late introduction and limited scope. Team-based approaches, involving nurses and social workers,

were recommended for cost-efficiency and quality of care, and were well-aligned with new models of care.

When used by experienced staff, the choice of ACP conversation tool had limited influence on the length of a conversation. Participants' informational and educational needs, however, significantly influenced the time required for a conversation. There was scope for efficiencies here from the use of decision aids, educational events and activities in the community and group-based facilitations in community and clinical settings.

Parallel session 3: No child left behind? The challenges we face in caring for children

0-8 NURSES' PERCEPTIONS OF CARING FOR CHILDREN AFTER ORGAN DONATION IN CHILDREN'S HOSPICE COOL ROOMS

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Background In Yorkshire, there were five paediatric organ donors in 2017/18. Very limited bereavement support is offered to families whose children donate organs (Berntzen & Bjørk, 2014). Changes to the Specialist Nurse Organ Donation (SNOD) role meant that SNODs felt unable to provide donor families with adequate bereavement support. This led to a broadening of hospice acceptance criteria, where deceased children, without known life-limiting conditions (Widdas, McNamara & Edwards, 2013) could use the cool bedrooms (Forrester, 2008) for post-mortem care, and their families access bereavement support offered by the hospice. Since 2017/18, a total of four children have been cared for post-donation.

Aim To explore the perceptions and experience of registered nurses involved in caring for families of children and young people who have donated organs in children's hospice cool rooms.

Methods A semi-structured focus group was conducted with nurses from the Yorkshire Organ Donation Services Team, and Martin House in March 2018. Purposeful sampling was used (Richie, Lewis, McNaughton Nicholls *et al.*, 2013), based on nurses who either:

- Whilst working as a SNOD, referred a child and family to the hospice following organ donation
- Whilst working at the hospice, cared for the body of a child after organ donation, and their family.

Results Five core themes emerged from the thematic analysis: (i) barriers that prevented families from receiving the care they need, (ii) bereavement support, (iii) impact: on families, SNODs and professionals, (iv) influencers and enablers of change, and (v) sustainability of services.

Conclusions Nurses perceived that families gained much from the bereavement support offered by the hospice, and from being able to spend time with their child's body after death. Although some of the grief experiences of families was different to what hospice nurses were used to, staff gained confidence as their exposure increased. Joint working between the

organisations enhanced bereavement care for families. Links between organisations were achieved through joint learning opportunities and hospice visits.

0-9

HOW DO UK HOSPICES SUPPORT FAMILIES WITH DEPENDENT CHILDREN? RESULTS FROM A NATIONWIDE SURVEY

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Background In the UK, 23 000 parents die annually leaving over 40,000 dependent children (Childhood Bereavement Network, 2015). Without support, the impact of parental loss on the social, emotional and physical development of children can last a lifetime (Moore & Raunch, 2010; Ellis, Dowrick, Lloyd-Williams, 2013). Children value honest communication about parental illness (Raveis, Siegel, Karus, 1999; Christ, Raveis, Siegel *et al.*, 2005), but many parents are unprepared for these conversations and would like more support (Visser, Huizinga, Hoekstra *et al.*, 2006; Semple & McCance, 2010). UK hospices contribute considerably to the end of life care of more than 200,000 patients a year (Hospice UK), of which anecdotal evidence suggests between 5%–10% have children under 18 years. To date, little data exists on the contribution UK hospices make to supporting families with dependent children.

Aim To examine the support provided by UK hospices to families with dependent children under 18 years when one parent is dying.

Method 197 UK hospices were invited to complete an online survey in March/April 2018. For pre-bereavement and bereavement, the survey asked about support delivered in terms of format, location and recipients and about processes for gathering information and for supporting staff. Region and size of hospice were collected. Responses were anonymous.

Results Response rate was 66% (130/197). All UK regions were represented. Most hospices provided in-patient and community services and were medium-sized in terms of beds and referrals. Among hospices responding, 78.4% (87/111) asked about dependent children; a substantial minority had no consistent or formal processes (21%; 24/111), and did not provide support for staff (21.5%; 20/93). For pre-bereavement and bereavement, written information, signposting to other services and one-to-one support were most delivered formats. Support was least likely to be provided in absence of the dying person.

Conclusion The research provides a comprehensive and representative account of support provided by hospices to families with dependent children prior to, and following, parental death. It identifies gaps in provision and can contribute to developing interventions that can be delivered by UK hospice staff.

0-10

CHILDREN'S PALLIATIVE CARE NURSE ROTATION POSTS: A RECRUITMENT, RETENTION AND RESILIENCE SOLUTION?

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Background The National Health Service is experiencing an unprecedented nursing shortfall. For the first time in 2017 more nurses left the profession than joined (Nursing & Midwifery Council, 2017). Within London competition for children's nurses is strong, with charitable, statutory and private organisations attracting registered staff. The need for children's palliative care (CPC) services is growing within the UK (Together for Short Lives, 2018): however, Dickson (2017) identified an 11% nursing vacancy rate here with 65% of these unfilled for 3+months. Innovative opportunities for staff development are presented as a tool to aid recruitment and retention (NHS Employers, 2015; Smith & Baltruks, 2015; The Association of UK University Hospitals, 2017).

This project adopts an iterative approach to design, implementation and review of rotation posts for CPC nurses and will measure the impact on the workforce.

Aim To create and test rotation posts for CPC nurses, subsequently enabling recruitment, development and retention of a resilient CPC nursing workforce, responsive to patient need.

Methods Initial grant application, stakeholder engagement, recruitment of project manager (PM). Literature review completed, hospice nurse survey and hospice retention data gathered, service user involvement, pilot rotation pathways with bespoke competencies developed. Pilot rotations commence September 2018. University partners to develop resilience tool and gather information on programme impact. Clinical supervision and action learning sets integral throughout.

Results Successful Burdett Trust funding bid. Appointment of PM in first recruitment drive. Cumulative enthusiasm established through wide networking. Success is reliant on flexibility and innovation. Clinical competencies gathered, scope for Pan London CPC document development. CPC nurse survey: eagerness amongst staff for new development pathways, especially senior staff. Requesting networking opportunities, good support identified as essential. Literature review: minimal evidence of which interventions influence recruitment and retention, less for hospice workforce. Retention data: shared challenges, improved reporting identified to inform workforce development.

Conclusion Collaborative working, harnessing sector wide enthusiasm, facilitates development of nurse rotation programmes.

Parallel session 4: Innovating and evaluating palliative care

0-11

THE HOSPICE ENABLED DEMENTIA PARTNERSHIP (HEDP): OVERVIEW OF EVALUATION FROM THREE YEAR PILOT PROJECT

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Background Currently over 1400 deaths a year in Northern Ireland, directly attributable to dementia yet, to date, dementia is rarely considered within a palliative care context, with limited attention directed towards the person's psychological, social, emotional and end of life needs or the support of their family carers. To address this need, Northern Ireland Hospice developed an innovative service (HEDP), based on collaborative working across voluntary and statutory