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'PLACE BONDING'- A NEW MODEL TO UNDERSTANDING PARENTAL DECISION MAKING WHEN ACCESSING A HOSPICE

^{1,2}Helena Dunbar. ¹De Montfort University, Leicester, UK; ²Rainbows Hospice for Children and Young People, Loughborough, Leicestershire, UK

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Respite/short breaks have been recognized as an important supportive service in paediatric palliative care (Knapp & Contro, 2009; Ling, 2012). In some countries, for example the UK, hospices are key players in this delivery. Despite evidence that supports short break services in hospices (Kirk & Pritchard, 2012) the literature suggests that there is varied access and uptake of such provision (Smith, Graham, & Herbert, 2017; Devanney & Bardley, 2012; Knapp, Shenkman, Marcu *et al.*, 2009). A two-phase grounded theory study was conducted in one region in England, to explore parental experiences and perceptions of children's hospices, the barriers and facilitators to access and the characteristics which parents wanted from hospice services.

A two phase grounded theory study (Charmaz, 2014) was conducted: Phase 1 used focus groups to collect data from parents of children already accessing the hospice (n=24) and in Phase 2 semi-structured interviews were conducted with parents of children who did not use the hospice (n=7) and parents who had previous experience of using a hospice (n=7). Analysis of the data identified three main themes: Coming 'Home'; This is Living Now; and Moving Forward. A grounded theory model of place bonding was developed which illustrates the cognitive journey and characteristics which are important for parents of children with life-limiting conditions when considering/receiving hospice care for their child. Finding a place where they belonged and felt at 'home' made the decision to accept help in caring for their child with a life-limiting condition more acceptable.

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LEARNING DISABILITY NURSES (RNLDs) IN CHILDREN'S HOSPICES. CONTRIBUTORS OR GAME CHANGERS?

Sabine Schwaebisch, Rhian Simmons, Emily Molony. *Helen and Douglas House, Oxford, UK*

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Background We want to explore the versatility of RNLDs. Why and how have they become important partners in paediatric palliative care? Factors influencing this new trend (Brigham, Atkinson, Jackson *et al.*, 2000). (i) National (children's) nursing shortage (especially in paediatric palliative care (Munn, 2017). (ii) Advancement in medical practice and technology, prolonging lives and increasing complexity of needs in children with medical conditions and disabilities (Evans, 2018). (iii) RNLDs' unique passion for supporting the most vulnerable children, and increasing motivation to advance careers in this highly specialised field.

Aim Identifying and acknowledging RNLDs' contribution to paediatric palliative care and further developing their roles and skills in hospice settings.

Method Two case studies identifying best practice examples. Collective reflection by hospice-based RNLDs on experiences and learning. Systematic analysis of RNLDs' unique skills. Map these against best practice NICE guidelines (National

Institute for Health Care Excellence, 2016). Identify competencies necessary to make PPC a safe endeavour for RNLDs. Short survey: RNLD workforce in UK children's hospices. Experiences mirrored in other children's hospices (Schwaebisch, 2018, *unpublished report*).

Findings RNLDs' specialised skills can contribute to making care of children with life limiting conditions safer in key areas, including enhanced communication, management of epilepsy, acute deterioration and challenging behaviour.

These and other specialised skills can make all the difference when building therapeutic relationships with families, because they include being acutely sensitive and responsive to the needs of children with profound disabilities or critical illnesses. There are moments when advocacy for the most vulnerable can have a vital impact on holistic outcomes.

Conclusion Further exploration/research in this area is needed. The evidence collected suggests RNLDs have a positive impact within the field of paediatric palliative care. For RNLDs, paediatric palliative care is an enriching and satisfying career choice. We also suggest that the palliative field invite RNLDs as nursing partners to offer people with learning disabilities the specialist person-centred care they deserve.

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A COLLABORATIVE PATHWAY FOR MALIGNANT PLEURAL EFFUSION

¹Suzanne Ford-Dunn, ²Kate Steele. ¹St Barnabas House, Worthing, UK; ²Western Sussex Hospitals NHS Foundation Trust, Worthing, UK

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Introduction For patients with known malignancy, development of malignant pleural effusion (MPE) is a poor prognostic marker: median survival with effusion at presentation is five months (Zamboni *et al.*, 2015), but for the majority of those developing MPE during active cancer management, prognosis is much worse.

Management of pleural fluid in this setting should be individualised, depending on symptoms, functional status, prognosis and fully informed patients preferences. Pleural drainage whether single aspiration, short term drain or semi-permanent drain are all highly invasive procedures with risks attached.

Locally, patients developing MPE were frequently referred to the respiratory service for insertion of an indwelling drain inappropriately (either too unwell, or single drainage preferable, or without understanding their prognosis) and were often not known to palliative care services.

Aim To create a pathway ensuring patients developing MPE had a holistic palliative care assessment and creation of an effusion management plan appropriate to their symptoms, prognosis and informed preferences.

Method Patients developing MPE are referred to the respiratory consultant and advised they will have a palliative care review as part of the assessment process. A hospice palliative care CNS who has undertaken additional training on assessing these patients, visits at home within five days – assesses palliative care needs, discusses prognosis and options for management (semi-permanent drain/single drainage/medical management of breathlessness) with patient/family. If drainage is appropriate, the palliative care CNS liaises with the respiratory team and the patient is booked in, as well as arranging on-going palliative care support.

Results Patient and staff satisfaction results will be available at conference, along with the first six months of data from the pathway.

Conclusion Collaboration between specialties and between services can ensure patients receive timely assessment of needs and are fully informed in order to make choices about potentially invasive interventions.

P-84 IMPROVING END OF LIFE CARE FOR PEOPLE AND FAMILIES LIVING WITH DEMENTIA IN KIRKLEES, WEST YORKSHIRE

¹Jaqueline Crowther, ¹Sarah Shaw, ²Julie Allen, ¹Rachel Guest. ¹Kirkwood Hospice, Huddersfield, UK; ²Dementia UK, London, UK

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Similar to cancer, dementia is a complex, life-limiting condition, incidence also increasing with age. Both conditions require skilled care by professionals who understand the significant impact upon physical, emotional and social well-being for whole families. Recent work by Hospice UK (2015) resulted in guidance for hospices in embracing dementia care, partnership and collaboration being identified as key to success.

Kirklees has a diverse population, approximately 4600 people currently live with dementia, a figure predicted to rise to 7000 by 2030. A number of these will be living with multimorbidities necessitating support from different agencies and professionals as end of life approaches.

The Kirkwood Admiral Nurse will ensure increasing numbers of families affected by dementia are supported to access skilled, competent, compassionate care.

Aims Support people with dementia and carers make future plans for advancing illness and end of life care. Enable and facilitate workforce development, internal and external. Provide an expert resource for people with dementia, carers, hospice staff and external organisations. Develop new collaborations and partnerships extending role of hospice in dementia care. Promote role of hospice in dementia care amongst local community. Support both local and national agendas from dementia and end of life care perspectives.

Service description This innovative service is a collaboration between Kirkwood Hospice, Kirklees Council and Dementia UK. An open referral system is in place with referrals accepted from people with dementia, carers and professionals. The Admiral Nurse has a caseload of complex cases, works in an advisory, consultancy capacity and focuses on workforce development via education.

This paper describes how aims of the service have been implemented along with successes over a two-year pilot leading to a future substantive End of Life Care Admiral Nurse post at Kirkwood Hospice.

P-85 HOW A HOSPICE ADMIRAL NURSE COMMUNITY OF PRACTICE CAN IMPACT ON PRACTICE

Caroline Scates, Karen Harrison Denning. *Dementia UK, London, UK*

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People with dementia often do not receive the same access to end of life care as people dying from other illnesses (Hospice

UK, 2015). Despite dementia being acknowledged as a life limiting illness (van der Steen, Radbruch, Hertogh *et al.*, 2014) people living with this illness often do not have the same access to palliative care services as people with other life-limiting conditions, despite similar levels of complexity.

Dementia UK have experienced a growing level of interest in commissioning the model of Admiral Nursing from hospices. In 2016 an Admiral Nursing Hospice Community of Practice started exploring how Admiral Nurses can support each other, and their colleagues to ensure consistency of practice and ensure people with dementia receive good end-of-life care.

Communities of Practice have been defined as 'groups of people who share concern or passion for something they do and learn how to do it better' (Wenger & Wenger-Trayner, 2015). This Community of Practice aimed to provide peer support to hospice-based Admiral Nurses and develop a model of practice, alongside disseminating skills and knowledge to Admiral Nurses in other settings.

The Admiral Nursing Hospice Community of Practice was first convened in December 2016 and has since met regularly to develop the model of practice. There are now nine Admiral Nurses working in an end of life/hospice setting across the country with a further six posts at recruitment stage with more in the pipe-line.

The Community of Practice will continue to explore how to increase resources available for Admiral Nurses on end of life care and act as an expert reference group for Dementia UK. Currently the group are sharing practice from their settings; for example, assessment documentation, referral criteria and leaflets for family carers.

Hospice-based Admiral Nurses are an innovative way of ensuring people with dementia receive more equality from hospices, and the hospice-based Admiral Nurses will be supported by this growing Community of Practice.

P-86 THE ADMIRAL NURSE PROJECT: PROACTIVE APPROACHES TO EFFECTIVE DEMENTIA SUPPORT IN A UK HOSPICE

¹Wendy Mountford, ²Sue Read. ¹Douglas Macmillan Hospice, Stoke-on-Trent, UK; ²Keele University, Stoke-on-Trent, UK

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Background Dementia is a progressive neurodegenerative disease. There are some treatments that will alleviate some symptoms but dementia is not curable and is a terminal illness. It is estimated 850 000 people are living in the UK with a diagnosis of dementia and 670 000 are people acting as primary carer for a loved one with dementia (Alzheimer's Society, 2015).

UK hospices are being encouraged to engage in the agenda of dementia care for people who are palliative or end of life.

Aim To present the independent, interim evaluation of a service for people with dementia in a hospice setting.

Methods A qualitative evaluation approach was used within a participatory action research framework, incorporating several phases across the general participatory action research (PAR) framework (Brydon-Miller, 2004). This cyclical process was adopted, alternating continuously between enquiry and action, and between practice and innovative thinking (Hart & Bond, 1995). This alternating process enables implementation of