

### 0-12 USE OF SUBCUTANEOUS FUROSEMIDE IN THE COMMUNITY SETTING IN END-STAGE HEART FAILURE

<sup>1</sup>Fiona Hodson, <sup>1</sup>Chris Doyle, <sup>2</sup>Stefan Karwatowski, <sup>2</sup>Mohammed Albarjas, <sup>1</sup>Joy Ross. <sup>1</sup>St Christopher's Hospice, London, UK; <sup>2</sup>Kings College Hospital NHS Foundation Trust, London, UK

10.1136/bmjspcare-2019-HUKNC.12

**Background** The benefits of integrated cardiac and palliative care support for patients with end-stage heart failure (ESHF) is well recognised (Jaarsma, Beattie, Ryder *et al.*, 2009; Hospice UK, 2017). Where patients are deteriorating or wish to avoid hospital, subcutaneous furosemide has been trialled to treat fluid overload resistant to oral diuretics (Zacharias, Raw, Nunn *et al.*, 2011).

**Methods** A case series is presented from a service evaluation of an integrated model of care for ESHF patients. 4/89 patients attended ambulatory hospital services for IV diuresis, 3/89 received IV/SC diuretics in the hospice. 13/89 were considered for continuous subcutaneous diuretics at home; this was administered to 7/13.

**Results** Average age 80 ( $\pm 14$ ) years. Four patients had left ventricular dysfunction, three had right sided heart failure. Average baseline eGFR 40 (22–70). Due to immobility and frailty, weight was not used to monitor outcome; blood pressure and renal functions supplemented clinical assessment. Average Systolic Blood Pressure 108 ( $\pm 14$ ) mmHg. Doses ranged between 80 mg and 230 mg of furosemide per 24 hours, depending on previous oral dose. 2 patients had subsequent dose reductions and 2 dose increments according to clinical response. Patients were treated for a median (range) 16 (1–48) days. 6/7 patients demonstrated symptom benefit. Three were successfully converted back to oral diuretics, one with addition of oral metolazone. One patient developed an abscess at the infusion site which necessitated A&E attendance and this subsequently healed well.

There were challenges in supporting District Nurses to continue to administer and monitor infusions and in obtaining medication supplies from community pharmacy.

**Conclusion** Subcutaneous furosemide infusion in the community did improve symptomatic burden and improve quality of life in our patient group, avoiding hospital admission and enabling patients to spend quality time at home. Ongoing work is needed to further evaluate which patients will benefit most from this intervention.

### 0-13 THE CARIAD STUDY

Marlise Poolman, Jessica Roberts, Julia Hiscock, Annie Hendry, Stella Wright, Clare Wilkinson. Bangor University, Wrexham, UK

10.1136/bmjspcare-2019-HUKNC.13

**CARer-ADministration of as-needed sub-cutaneous medication for breakthrough symptoms in homebased dying patients: a UK study (CARIAD)**

**Background** While the majority of seriously ill people wish to die at home, only half achieve this. The likelihood of someone dying at home often depends on the availability of able and willing lay carers to support them. Whilst this often involves giving medication, people in the last days of life may be unable to take oral medication. Regular medications can be administered using a syringe driver. When top-up medication

is required for breakthrough symptoms, a clinician must travel to the home to administer as-needed subcutaneous medication. **Aims** To determine if carer-administration of as-needed subcutaneous medication for four frequent breakthrough symptoms (pain, nausea, restlessness and noisy breathing) in home-based dying patients is feasible and acceptable in the UK.

**Methods** Adult patients anticipated to be in the last weeks of life who were likely to lose the oral route and expressed a preference to die at home were recruited with their carers to an external randomised pilot trial across three UK sites (North Wales, South Wales and Gloucestershire). Patient/Carer dyads randomised to the intervention arm received a manualised training package delivered by their community nursing teams. Dyads in the control arm received usual care. Carers in both arms completed carer diaries and outcome measures.

**Results** Forty dyads were recruited. The main outcomes of interest are feasibility, acceptability, recruitment rates, attrition and selection of the most appropriate outcomes measures.

**Conclusions** Findings will inform a definitive Phase III randomised controlled trial.

This study is funded by the National Institute for Health Research (NIHR) HTA (Grant Reference Number 15/10/37). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

## Parallel Session 4: Rehabilitation and Meeting Unmet Needs

### 0-14 REHABILITATIVE PALLIATIVE CARE – RESEARCH AND PRACTICE

<sup>1</sup>Karen Clarke, <sup>2</sup>Olivia Beeny-Bennett. <sup>1</sup>St Michael's Hospice, St. Leonards-on-Sea, UK; <sup>2</sup>St Wilfrid's Hospice, Eastbourne, UK

10.1136/bmjspcare-2019-HUKNC.14

**Background** In order to transform end of life care (Leadbeater & Garber, 2010) these two studies look at the implementation of rehabilitative palliative care in a hospice in-patient unit (IPU).

**Aim** Using action research, to integrate rehabilitative palliative care identifying the facilitators and barriers from the health care professionals' (HCPs) perspective.

**Methods** Implementing rehabilitative palliative care, PhD.

Using participatory action research (PAR), to plan and implement a rehabilitative approach in an IPU. Concurrent analysis was used to inform the PAR cycles and thematic analysis (Braun & Clarke, 2013) was used to identify the facilitators and barriers.

Rehabilitative palliative care in hospices: The HCP perspective, MSc.

Using exploratory qualitative interviews, to explore the views and experiences of HCPs working in hospices on rehabilitative palliative care. Iterative categorisation technique (Neale, 2016) was used to develop key themes.

**Results** Due to strategies undertaken through PAR, rehabilitative palliative care was implemented into practice on the IPU and acknowledged throughout the hospice as a valid approach to care. A co-operative inquiry group of nine people (clinical, support staff and volunteers) was responsible for collectively developing an understanding of rehabilitative palliative care

and planning how to implement it. Engagement of senior managers and the wider MDT were key change facilitators, as was a comprehensive education programme for staff and volunteers. Both research projects identified a number of organisational and operational challenges in terms of: concept, lay/external perceptions, alignment with current models of care and a tradition of 'over-caring', risk aversion, strategic direction, senior/management engagement, insufficient time and/or resources, variable condition of patients, poor team working/communication.

**Conclusion** PAR can be used to integrate rehabilitative palliative care, and HCPs want to engage with and implement the concept in their practice. The combined results of these two research studies show how research can drive a change in practice successfully through a top down and bottom up approach.

### 0-15 AN EXERCISE AND NUTRITIONAL REHABILITATION (ENERGY) TRIAL IN PATIENTS WITH INCURABLE CANCER

<sup>1,2</sup>Charlie Hall, <sup>1</sup>Jane Cook, <sup>1</sup>Honor Blackwood, <sup>1</sup>Erna Haraldsdottir, <sup>1</sup>Duncan Brown, <sup>3</sup>Matthew Maddocks, <sup>4</sup>Liz Dixon, <sup>5</sup>Richard Skipworth, <sup>1,2</sup>Marie Fallon, <sup>1,2</sup>Barry Laird. <sup>1</sup>St Columba's Hospice, Edinburgh, UK; <sup>2</sup>The University of Edinburgh, Edinburgh, UK; <sup>3</sup>Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, London, UK; <sup>4</sup>Southampton Clinical Trials Unit, Southampton, UK; <sup>5</sup>Royal Infirmary, Edinburgh, UK

10.1136/bmjspcare-2019-HUKNC.15

**Background** Rehabilitation is an essential component of palliative care (Tiberini & Richardson, 2015), however, data on efficacy and key components are lacking (Salakari, Surakka, Nurminen *et al.*, 2015). There is a strong argument that any rehabilitation programme should combine exercise and nutrition, which together may improve physical function and quality of life, but this needs careful evaluation (Payne, Larkin, McIlpatrick, *et al.*, 2013; Chasen, Bhargava, MacDonald, 2014). This is being done through the ENeRgy trial which compares an Exercise and Nutrition based Rehabilitation programme with standard care, in patients with incurable cancer. The trial was funded by Marie Curie and the Chief Scientist Office.

**Aims** The primary aim was to assess the feasibility of an Exercise and Nutrition based Rehabilitation programme. Secondary aims included assessment of quality of life (patient and partner-carers), functional and nutritional status, contamination of the control group, health economic impact and survival.

**Methods** A single centre, randomised, unblinded feasibility trial was undertaken. Patients were randomised to receive an exercise and nutrition based rehabilitation programme (intervention) or standard care (control). Eligible patients were:  $\geq 18$  years, Karnofsky Performance Status  $\geq 60$ , with a diagnosis of incurable cancer; not undergoing anti-cancer treatment.

**Results** 45 patients were recruited from a mixture of hospices and a cancer centre. Challenges included optimising patient recruitment, compliance with the components of the rehabilitation programme, and the establishment of a clinical research team within an independent hospice. Patients' overall experience of the rehabilitation trial was positive and nurtured a positive, empowering impression of the hospice setting. Key themes and some preliminary data will be presented.

**Conclusions** The ENeRgy trial is an important step in assessing the feasibility of an outpatient, hospice based rehabilitation programme for patients with incurable cancer and will inform future work in this area.

### 0-16 SUPPORTING FAMILY CARERS OF PEOPLE WITH MOTOR NEURONE DISEASE: ADAPTATION OF THE CSNAT INTERVENTION

<sup>1</sup>Gail Ewing, <sup>2</sup>Sarah Croke, <sup>2</sup>Christine Rowland, <sup>2</sup>Gunn Grande, <sup>2</sup>Alex Hall. <sup>1</sup>University of Cambridge, Cambridge, UK; <sup>2</sup>University of Manchester, Manchester, UK

10.1136/bmjspcare-2019-HUKNC.16

**Background** Family carers play a vital role in supporting people with Motor Neurone Disease (MND) but face substantial physical and mental demands in doing so. Timely support from healthcare professionals is crucial to enable carers to fulfil their caregiving role and to look after their own wellbeing. The Carer Support Needs Assessment Tool (CSNAT) intervention is an evidence-based approach for person-centred assessment and support. This project aimed to: (i) adapt the CSNAT intervention to the context of MND care; (ii) test implementation of the adapted CSNAT-MND intervention within specialist MND services.

**Methods** Stage 1: focus groups and interviews with 14 bereaved and 19 current carers to explore support needs (met and unmet) and supportive inputs at key stages of the patient's illness. Stage 2: workshops with 24 practitioners and 19 carer advisers to adapt the content of CSNAT intervention and its delivery within MND care. Stage 3: implementation of CSNAT-MND in three specialist MND services; interviews with practitioners and carers exploring their experiences of the intervention.

**Results** Content of CSNAT-MND included an additional domain on support with relationships. Intervention implementation adapted to (1) legitimise assessment of carer support needs as part of routine care in MND by practitioners, (2) delivery of a stand-alone introduction stage of the CSNAT-MND intervention and (3) provide a dedicated assessment and planning conversation at a subsequent contact. This basic model was then suited to fit the working practices of three different MND services. We will present challenges of tailoring and implementing the CSNAT-MND intervention in real life practice.

**Conclusion** Implementation of the CSNAT-MND requires the establishment of a clear protocol defined at service level. This project provides insights into how carers of people with MND want to be assessed and supported, how this process can be delivered, and the feasibility of implementing the CSNAT-MND in practice.

### 0-17 LEGAL NEEDS TOWARDS END OF LIFE: DEFINITION, EXPERIENCE AND IMPLICATIONS FOR POLICY AND PRACTICE

<sup>1</sup>Colette Hawkins, <sup>2</sup>Helen Close, <sup>3</sup>Margaret Kirby, <sup>4</sup>Hannah Hesselgreaves, <sup>2</sup>Charlotte Rothwell, <sup>5</sup>Sarah Beardon, <sup>5</sup>Hazel Genn. <sup>1</sup>St Oswald's Hospice, Newcastle, UK; <sup>2</sup>Newcastle University, Newcastle, UK; <sup>3</sup>Legacare, Newcastle, UK; <sup>4</sup>Northumbria University, Newcastle, UK; <sup>5</sup>University College, London, UK

10.1136/bmjspcare-2019-HUKNC.17

**Background** Life-limiting illness generates an array of challenges for patients and carers but little is known about legal issues. There is no definition of legal issues in this context and limited integration of care across health, social, advice, legal and charitable sectors although all contribute to holistic care.