

Making it real

Reflecting on the applicability of research in clinical practice

Conference and annual scientific meeting
incorporating the **AGM**

Wednesday **11 May 2011** The Stormont Hotel Belfast



Welcome

I would like to welcome you to the Palliative Care Research Society Annual Scientific Meeting and AGM in Belfast. We are delighted to be hosting our ASM in Northern Ireland for the first time and would like to extend a particular thank you to Sue Foster from the Northern Ireland Hospice for helping organise the event. We have a stimulating and comprehensive programme for you with a mix of invited speakers, proffered papers and workshops.



Dr Bridget Johnston

*Chair Palliative Care Research Society
School of Nursing & Midwifery, University of Dundee*

As the new incoming chair of the Palliative Care Research Society, I am delighted to welcome you to the 2011 Annual Scientific Meeting in Belfast. This conference provides the opportunity for palliative care researchers to share new research findings, network with colleagues and the potential for collaborative research partnerships to be developed.



Professor Barbara Jack

*Chair Elect, Palliative Care Research Society
Evidence-Based Practice Research Centre (EPRC), Faculty of Health,
Edge Hill University*

A note from your Treasurer ...

I will be leaving the PCRS Executive Committee at the May 2011 AGM, having completed two three-year terms of office, one as Treasurer. It's been a great experience being a part of the Committee and I look forward to many more years of involvement with the PCRS and to continuing to raise the profile of rehabilitation research in palliative care.

I am delighted that Dr Jane Hopkinson, Macmillan Post Doctoral Research Fellow in the Faculty of Health Sciences at the University of Southampton, will be taking over from me as Treasurer and I pass Jane, the Committee and the Society all good wishes for the future.

Dr Gail Eva

*Treasurer, PCRS Executive Committee
Department of Brain Repair and Rehabilitation, UCL Institute of Neurology*



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Programme

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Session One

09:30

District nurses' beliefs regarding referral of a patient receiving palliative care to physiotherapy

*Lesley Nelson, Southeastern Trust,
N Ireland*

*Felicity Hasson, University of Ulster,
N Ireland*

This study was conducted as an MSc research project at the University of Ulster.

Aim: To explore the perceptions and beliefs of district nurses influencing their decision to refer a patient receiving palliative care to physiotherapy.

Background: Despite increasing recognition of the benefits of rehabilitation for patients receiving palliative care there is evidence that the number of patients accessing rehabilitation is low. District nurses play a major role in accessing services for this group of patients.

Method: A qualitative descriptive study, guided by the Theory of Planned Behaviour, was conducted with a purposive sample of 16 district nurses enrolled at a university in Northern Ireland. Three focus groups were carried out, audio-recorded, fully transcribed and content analysed.

Findings: Within the framework of the Theory of Planned Behaviour a total of 9 beliefs were identified influencing the referral decisions of district nurses to physiotherapy, the vast majority of which were negative. District nurses identified a number of disadvantages to making a referral including beliefs that; physiotherapists would not have skills in palliative care, physiotherapists could foster false hope and physiotherapists

would contribute to too many professionals being involved with the patient. Several barriers to referral were identified including: a lack of contact and communication between district nursing and physiotherapy, a lack of knowledge or experience of physiotherapy, unsuitable referral systems and poor availability of services. The wishes of patients and families also had a strong impact on referral decisions which could be either positive or negative.

Conclusion: The identification of factors influencing the referral decisions of district nurses provides some insight into possible reasons why very few patients receiving palliative care currently access rehabilitation services. These findings may inform future initiatives aimed at ensuring that all patients who could benefit from palliative rehabilitation are able to access it ■

09:45

Preparing family carers for the role of supporting a dying relative: An overview of three evidence based strategies

*Peter Hudson, Queens University, Belfast
& Centre for Palliative Care c/o St Vincents
& The University of Melbourne, Australia*

Background: Despite evidence which identifies that family carers of palliative care should receive support and guidance to prepare them for their role, systematic reviews have identified a shortage of effective strategies.

Objectives: This session aims to provide an overview of three studies conducted in Australia which evaluated the effectiveness of interventions designed to prepare family carers for the role of supporting a dying relative. Multi-media resources will also be profiled to promote implementation into clinical

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practice. Methods: Study 1 examined the effectiveness of a psycho-educational group education program for family carers providing care for a dying relative at home. Study 2 evaluated 20 family meetings using recently published clinical practice guidelines. Studies 3 evaluated a two hour psycho-educational group session for carers of patients receiving care in an inpatient setting.

Results: Utilising a pre-test, post-test design, the three interventions showed a statistically significant reduction in the unmet needs of family carers. The group education interventions also demonstrated significant improvements in carer competence and preparedness for the caregiving role.

Conclusion/implications: These preliminary results indicate that it is possible to prepare family carers for the role of supporting a dying relative. These interventions should undergo further empirical inquiry ■

10:00

Understanding home and homeland at end of life – A qualitative study about older South Asians in East London

Munikumar Ramasamy Venkatasalu, University of Nottingham
Jane Seymour, University of Nottingham
Tony Arthur, University of Nottingham

Background: South Asians constitute the single largest ethnic minority group in the United Kingdom, yet little is known about their perspectives and experiences on end of life and its related care.

Aim: To explore and critically examine views and perceptions about end of life issues among older South Asians living in East London.

Methodology and methods: After gaining ethical approval, five focus groups and 29 in-depth, semi-structured interviews were conducted with total of 55 older adults (24 men and 31 women) aged between 52 to 78 years. Participants from six South Asian ethnic groups were recruited through 11 local community organisations. Constructive grounded theory as used as data analysis approach. This paper examines beliefs, attitudes and expectations of older South Asians about the place of 'home' and 'homeland' in care of the dying.

Findings: Religious practices were often seen as essential to achieving peaceful death and gave a sense of completion of religious and filial duties. The theme of 'home as a haven' describes participants' accounts of how their home is a physical place in which it is possible to perform various cultural and religious rituals. The second theme, 'reconsidering the homeland during end of their lives' provides insights into the relevance of the notion of 'diaspora' and why the place of death is perceived by many as less important than the cultural practices surrounding death.

Conclusion: Alongside vivid memories of home and homeland at end of life, older South Asians living in East London make efforts to adhere to important social and cultural values relating to death and dying, and rebuild and adapt those values during the challenges of living in an emigrant society ■

10:15

Portraying Identity: Using portraiture to aid identity reconstruction in people suffering from life threatening and chronic illnesses

Susan Carr, Prospect Hospice & Loughborough University

"I look in the mirror and I say, 'who's that?' I don't really know who I am anymore! I have lost the person I thought I was." Patient, Prospect Hospice.

Arguably life threatening or chronic illness is not just an attack on the body, it is an attack on the embodied self, and identity, shattering the means by which a person experiences the world, and by which they also are experienced, contributing to a person's sense of powerlessness and 'loss of self' (Charmaz, 1983). Therefore negatively affecting a person's ability to continue with their pre-illness activities, relationships and future plans and contributing to their 'total pain' (Saunders, 1976).

This paper will present two case studies, drawn from the author's current PhD research, looking at how working collaboratively with an artist to co-design a portrait of themselves can help people suffering from life threatening or chronic illnesses to increase their self knowledge, build new identities and improve their 'individual creative capacity' (Reeves, et al., 2010), to adapt to illness, therefore enabling the development of a more coherent sense of self and identity.

When attempting to understand the complex emotions and feelings contained within experiences of illness and loss of self, the use of portraiture as identity work, provides an intervention within which discursive knowledge and non-discursive knowledge can be reintegrated into a more coherent whole. Portraits

often capture the 'essence' or subjectivity of a person; the trace of a human presence left behind, and can enable people feeling detached from their body after invasive treatment, to recover a sense of autonomy over the bodily image they portray. This intervention also offers 'time,' for the building of a collaborative relationship, at a time when relationship is hard to sustain, acknowledging that identity is built and sustained in relationship with others ■

Session Two

11:00

Value of qualitative data in the design & evaluation of complex interventions in advanced disease

Morag Farquhar, University of Cambridge, Cambridge

Irene J. Higginson, King's College London, London

Sara Booth, Cambridge University Hospitals NHS Foundation Trust, Cambridge

Background/objectives: Qualitative methods can stand alone, be used sequentially with quantitative methods (before, or after) or concurrently. The inclusion of qualitative data in randomised controlled trials (RCTs) remains uncommon, even in complex intervention evaluation. This paper describes the value of qualitative data to the design, evaluation and remodelling of a complex intervention for breathlessness in advanced disease: the Breathlessness Intervention Service (BIS).

Methods: Qualitative observational studies and mixed method RCTs (pilot and fully powered) of BIS used within the MRC's framework for complex interventions. Qualitative data was analysed using a framework approach.

Results: Qualitative methodology was used throughout the development and evaluation of BIS. The Pre-Clinical qualitative study (stand alone) of patients with breathlessness and their carers contributed to the evidence-base for the initial service model. Phase I, a qualitative study (stand alone) of the pilot service users, informed the service's re-development. The Phase II pilot RCT collected mixed methods outcomes (concurrent) and used qualitative methods to examine the feasibility and acceptability of outcome measures. Importantly in a palliative care setting, the qualitative findings at Phase II further refined the service model and RCT protocol: both were shortened. The current Phase III is a fully powered mixed methods concurrent multiple-perspective RCT.

Implications: Qualitative methodology is intrinsic to the MRC framework (and therefore complex interventions): it can justify the need for interventions and is fundamental to their design, evaluation and subsequent remodelling. In the development and evaluation of BIS, qualitative methods were used at every phase: as a stand alone method or concurrently. Further, by embedding qualitative methods in RCT pilots, they can play a key role in testing evaluation methods, which can be crucial to the successful delivery of RCTs in a palliative care setting ■

11:15

An evaluation of an holistic assessment tool for palliative care practice

Sonja McIlfatrick, University of Ulster, Northern Ireland

Felicity Hasson, University of Ulster, Northern Ireland

Holistic assessment is a complex process which presents challenges for palliative

care practice. The need for effective and structured assessment of patients' needs has been identified. This study outlines the findings from an evaluation of a palliative care brief holistic assessment tool in Northern Ireland. A mixed method research design was employed to address the research objectives and comprised of four stages.

Stage 1: overview of the theoretical literature;

Stage 2: Analysis of piloted holistic assessment tool (n=132);

Stage 3: Discussion groups with pilot leads and assessors (n=10) to explore usability, applicability and potential service barriers and facilitators towards implementation and

Stage 4: Assessor questionnaire (n=24) evaluating the structure, format and presentation of the holistic tool.

Some of the key findings indicated that the tool did appear to enable health professionals to identify and gain an understanding of the needs of the patients, specifically in relation to the patients' physical health care needs. Analysis of the tool documentation revealed that 59 (68.8%) responses had discussed preferred priorities of care with the patient; however focus groups comments revealed participants had concerns around this. The use of clinical prognostic indicators was ambiguous. Whilst the first phase of the evaluation indicated that over half of responses (n=50 57.5%) had considered a prognostic clinical indicator for the patient as an action, the other strands indicated that there are questions around health care professional's knowledge and perceived usefulness of clinical prognostic indicators. Some positive aspects of the tool included were it was easy to understand; not time consuming & captured the needs of individuals. Negative aspects included it was repetitive and the experience of assessors

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and training required consideration. A recurrent message was a view that holistic assessment was being carried out already and that the completion of this tool was duplication and repetition ■

Session Three – Plenary Lecture

11:30–12:15

The Importance of Research in Palliative Care

*Professor Phil Larkin and
Professor Max Watson*

Workshop – Session Four

13:30–15:00

Ethnography / Observation

Erna Haraldsdottir and Catherine Walshe

This workshop will focus on the underpinning philosophy of ethnography as a research methodology and observation as a way of collecting data. Practical examples will be demonstrated and participants will have the opportunity to discuss and explore the appropriateness of this research methodology / method as well as benefits and challenges ■

Session Five

15:25

Realist review of key factors affecting implementation of the Liverpool Care Pathway

*Tracey McConnell, Peter O'Halloran, Sam Porter - Nursing and Midwifery Research Unit, Queens University Belfast
Michael Donnelly, School of Medicine Dentistry and Biomedical Sciences Centre of Excellence for Public Health, Northern Ireland*

Background: Although the Liverpool Care Pathway (LCP) has been advocated by policy as a tool to enable generalist staff to improve care for patients and their families at the end of life (NICE 2004), recent national audits in the hospital setting have shown a low percentage (20%) of patients actually benefiting from the pathway. Research to date on the LCP has focused on outcome measures but has not addressed processes affecting success or failure of implementation.

Aims: The aim of the review is to uncover the theories of how the LCP should be implemented in order to throw light on how this process could be more effective in practice.

Methods: Searches included electronic databases from 1950 to current (MEDLINE, CINAHL, BNI, Cochrane Library and Science Direct), manually searching relevant journals (1999 to 2009), snowball searching and forward citation tracking of important articles. Inclusion criteria were English language literature which focused on end of life care, integrated care pathways and implementation processes.

Results: Over sixty papers were selected for review. This resulted in identification of five broad areas: facilitation, education

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and training, audit and feedback, major cultural shift, and resources.

Discussion and conclusions: Funding needs to be in place for facilitator posts to drive implementation. Implementation is more likely to be successful when regular feedback is provided to staff on benefits of the pathway. The culture of cure in the hospital setting was found to be a key factor hindering implementation. Education and training is crucial in helping generalist staff change their perception of dying as medical failure to a natural time of life where care takes precedence over cure ■

15:40

What is good end of life care in intensive care? Relatives' perspectives and experiences

15:55

A focus group study exploring how Bolivian health and social care professionals manage end-of-life care decision making

Miss Audrey Roulston, Tommy Haynes and Dr Jim Campbell – Queens University, Belfast

Background: According to regional (1) and national (2) end-of-life care strategies, service providers should promote a 'good death' through effective management of symptoms (3); service user involvement in decision-making (4); respecting the patient's psychosocial, cultural and spiritual needs (5); and promoting effective patient-professional communication (6).

Aim: The aim of this study was to explore how Bolivian oncology professionals manage ethical and practical challenges in decision-making.

A focus group methodology was used with 17 professionals, purposively recruited from an oncology clinic in Cochabamba, Bolivia. Participants were given 24 hours to consider involvement in the study. All agreed and provided written consent. Study data were collected during three 45 minute group meetings, which were conducted in Spanish using an interpreter. Meetings were audio-recorded. Transcripts were verified by participants and translated into English, prior to using interpretative phenomenological analysis (IPA).

A questionnaire was used to collect demographic data. The results indicated that participants were at different stages of their professional career (1-16 years qualified), and the majority (n=14) were aged 20-39. Two strong themes emerged: Firstly, participants' views mirrored those in Anglo-American research literature including aspirations to improve access to cancer prevention programmes; increasing specialist education; and offering pharmaceutical and psychological support to manage distress. Secondly, the influence of culturally specific factors on decision-making. For example, end-of-life care conversations were normally conducted with family members, not patients; discussions about euthanasia were limited because of legislative and cultural taboos; and medical professionals tended to 'de-humanise' themselves to avoid becoming immersed in the patient's and family's distress.

Conclusion: In conclusion, participants identified barriers preventing patients accessing oncology services, as well as culturally specific patterns of professional decision making, not found in Anglo-American research literature. More comparative research is needed to explore cultural nuances in this important field of end-of-life care ■

16:10

Meanings of happiness across different ethnic groups living with advanced cancer

Jonathan Koffmam, Myfanwy Morgan, Polly Edmonds, Peter Speck and Irene J Higginson – King's College London

Introduction: David Cameron recently remarked that 'measuring happiness is not a distraction from the serious business of government but central to it'. Quality of life is integral to palliative care comprising freedom from distressing symptoms and enhancement of emotional and social well-being which can include the presence of happiness. To date, little research has explored the meanings of happiness during advanced illness among different ethnic groups, important as society becomes more socially diverse.

Aims: To explore meanings of happiness among Black Caribbean (BC) and White British (WB) patients living and dying from cancer in London.

Methods: 26 BC and 19 WB patients with advanced cancer recruited from palliative care teams and oncology clinics. Semi-structured interviews were conducted and analysed using the framework approach.

Results: 22/26 BC and 16/19 WB participants volunteered views on the meanings of happiness in relation to their advanced cancer. Happiness was related to three main themes. Being free of distressing symptoms, particularly pain was more common among BC participants. 'Love and belonging' was central to both ethnic groups and associated with family and friends. More BC than WB participants referred to realizing personal meaning in life; this element of happiness was associated with connection with God, prayer and the sacred world.

Conclusion: We identified that happiness was central to many patients' quality of life and is multifaceted. We also identified that some aspects of happiness are culturally patterned. Patients with advanced disease from all cultures therefore require impeccable assessment and intervention to manage physical, psychological, social support and spiritual issues that contribute to the presence of this state of being. The last two are often neglected at the end of life ■

■ 1

A study to assess whether patients with end stage chronic obstructive pulmonary disease can benefit

Kathryn Shorthose, St Margaret's Hospice, Taunton

Dr Julian Abel, Weston Hospicecare, Weston-Super-Mare

Dr Grahame Gould, Weston General Hospital, Weston-Super-Mare

Dr Alison Rich, Weston Hospicecare, Weston-Super-Mare

Sr Yvonne Moul, Weston General Hospital, Weston-Super-Mare

Introduction: It has been recognised that patients with end-stage COPD have palliative care needs at least equal to those of some cancer patients and would benefit from a more holistic patient centred approach. Non-cancer patients still comprise only a small percentage of a typical specialist palliative care (SPC) service caseload. There is little evidence of whether involvement of SPC can meet the needs of these patients.

Aim: To explore the potential benefits and applicability of SPC intervention in patients with end-stage COPD assessed as having SPC needs.

Methods: The intervention comprised community SPC input over six weeks. Study participants underwent a symptom and needs assessment and were referred to other members of the SPC team as indicated.

The intervention was assessed with interviews supplemented by three validated assessment tools applied pre and post intervention; The Hospital Anxiety and Depression Scale (HADS), the Palliative Care Outcome Scale (POS), and the Functional Assessment of Chronic Illness Therapy-spiritual well-being scale (FACIT-Sp).

Results: Twelve patients were recruited to

and completed the study.

Qualitative analysis of the interview data produced six major themes. Patients described a cycle of decreasing activity associated with dyspnoea, with resulting social isolation, anxiety and depression. The intervention of the physiotherapist, use of specific coping strategies and psychological support were key in helping patients break this cycle. The quantitative data demonstrated a significant reduction in anxiety scores on the HADS and a significant difference in the POS scores pre and post intervention.

Discussion: The study confirmed that the needs of these patients could be met by a specialist palliative care approach. Collaborative working with the respiratory team and staff education were important in ensuring that the needs of patients were met. The most valued elements of the service were the advice and support from the community nurses, physiotherapists and day hospice ■

■ 2

Supporting the chance of dying at home: the impact of a bespoke Hospice at Home service

Barbara Jack, Evidence-based Practice Research Centre, Faculty of Health, Edge Hill University

Karen Groves, Catherine Baldry – West Lancashire, Southport & Formby Palliative Care Services, Queenscourt Hospice Kathryn Gaunt, Royal Liverpool and Broadgreen NHS Trust, Liverpool Janice Sephton, Queenscourt Hospice Alison Whelan, Evidence-based Practice Research Centre, Faculty of Health, Edge Hill University

Background: Promoting the choice to die at home is central to UK policies and strategies. Supporting this are Hospice at Home services which vary in service composition and intervention. A bespoke Hospice at Home service comprising three

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elements: accompanied transfer home; multi disciplinary (including doctors) crisis intervention team and flexible sitting service was established in the North West of England and piloted for one year.

Aim: To explore the impact of a bespoke Hospice at Home service on the choice of dying at home.

Method: Retrospective cohort study and stakeholder evaluation. Data (demographic and service intervention) was collected on the 201 patients who received the service. 55 Health Care Professionals participated in semi-structured interview, focus groups and electronic open ended questionnaires.

Results: 245 patients were referred to the service, 201 received the service. 184 (92%) had cancer, 36% were aged over 80 years. 57 (28%) lived alone. 181 (90%) recipients died, 73% (132) died at home (72% (120) were patients with cancer), 6% (29) in the hospice, 12 (6.5%) care home, 1 (0.5%) on their way home, 7 (4%) hospital. 51 patients who lived alone, 69% (35) died at home. Health Care Professionals reported on the impact of the different elements of the service as helping patients to remain at home and enabling a speedier discharge home. The support for carers enabling them to continue coping was strongly reported.

Conclusions: This novel bespoke service provides different elements of a Hospice at Home service, providing a tailor made package to meet individual and local area needs. This service appears to be helping to have a major impact on place of death and is enabling patients to die in their place of choice. This paper will discuss the service and potential explanation for the results will be suggested ■

■ 3

A partnership for care: the impact of the bespoke 'Hospice at Home' service on community health care

Barbara Jack, Evidence-based Practice Research Centre, Faculty of Health, Edge Hill University

Karen Groves, Catherine Baldry – West Lancashire, Southport & Formby Palliative Care Services Queenscourt Hospice Kathryn Gaunt, Royal Liverpool and Broadgreen NHS Trust, Liverpool Janice Sephton, Queenscourt Hospice Southport

Alison Whelan, Evidence-based Practice Research Centre, Faculty of Health, Edge Hill University

Background: Promoting the choice to die at home is central to UK policies and strategies and supporting this are Hospice at Home services of which there are variations in service composition and intervention. A novel bespoke service comprising 3 elements of: accompanied transfer home; multi disciplinary (including doctors) crisis intervention team and a flexible sitting service) was developed in the North West of England following consultation and piloted for one year.

Aim: To explore the impact of a bespoke Hospice at Home service on community health care professionals.

Method: As part of pilot evaluation 55 Health Care Professionals (General Practitioners, District Nurses, Community Specialist Palliative Care Nurses and Hospital Discharge Coordinator) who had experience of the service participated in semi-structured interview, focus groups and electronic open ended questionnaires. Interviews were digitally recorded and thematically analysed, open end questionnaires were subject to content analysis.

Results: All but two respondents,

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reported on the positive impact of the service on themselves, in being able to provide additional support for the patients and the families. Additionally the access to specialist palliative care input as well as advice was positively regarded as complimenting the care they were able to provide. One GP raised the issue that this service could potentially result in GPs abdicating their responsibility for palliative care patients and resulting in them becoming de-skilled.

Discussion: Despite initial fears of the community based staff, this bespoke service by providing a supplementary palliative care service also has a positive impact on the health care professionals and was felt to impact on helping patients who wish to die at home to achieve their goal. This paper will discuss the results and explanation for the findings will be suggested ■

■ 4

Developing a bespoke 'Hospice at Home' service: Challenges and Success

Barbara Jack, Evidence-based Practice Research Centre, Faculty of Health, Edge Hill University
Catherine Baldry, Karen Groves, West Lancashire, Southport & Formby Palliative Care Services, Queenscourt Hospice
Helen Birch, Ann Shard, Queenscourt Hospice

Background: Promoting the choice to die at home is central to UK policies and strategies and supporting this are Hospice at Home services of which there are variations in service composition and intervention. A bespoke Hospice at Home service comprising 3 elements: accompanied transfer home; multi disciplinary (including doctors) crisis intervention team and a flexible sitting service was established in the North West of England and piloted for one year.

Methodology: The retrospective cohort study and stakeholder evaluation undertaken of the pilot phase, found that of the 201 patients who received the service 73% (132) died at home. 55 Health Care Professionals (General Practitioners, District Nurses, Community Specialist Palliative Care Nurses and Hospital Discharge Coordinator) participated in semi-structured interview, focus groups and electronic open ended questionnaires to identify their views on the service, its establishment and impact. In regard to the establishment of the service, the health care professionals reported that they had initially been fearful of the new service and how it could take over their role with terminally ill patients. However this fear was unfounded and they found the service to compliment the care that they could provide. This poster describes the phases of planning and designing the service, introducing the service and the pilot evaluation. Examples of good practice and lessons learnt will be presented.

Conclusions: This novel bespoke service provides different elements of a Hospice at Home service, provides a tailor made package to meet individual and local area needs. This service appears to be helping to have a major impact on place of death and is enabling patients to die in their place of choice ■

■ 5

The Preferred Priorities for Care document in Motor Neurone Disease: views of bereaved relatives

Harriet Preston, St Catherine's Hospice, Lostock Hall, Preston, Lancashire
Iris Fineberg, International Observatory on End of Life Care, Lancaster University
Pauline Callagher, MND Care and Research Centre, Royal Preston Hospital, Lancashire
Douglas Mitchell, Lancashire Teaching

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*Hospitals NHS Foundation Trust,
Lancashire*

Increasing emphasis is being placed on the need for advanced care planning (ACP) at the end-of-life. The Preferred Priorities for Care document (PPC) is a patient-held record promoted by the End of Life Care Strategy as an ACP tool to promote discussion and communication amongst patients, family and health care providers. However, little research exists into evaluating its effectiveness or exploring user views, particularly in non-malignant disease. Because the majority of patients with Motor Neurone Disease (MND) lose verbal communication, early discussion of patients wishes and preferences, a central aspect of ACP, is vital.

This study examined MND patients bereaved relatives experiences of using the PPC document and their perceptions about its impact on end-of-life care using qualitative methods. Participants were bereaved relatives or primary carers of patients with ALS known to the Preston MND Care and Research Centre in the North West of England. Semi-structured face-to-face interviews were conducted at the participant's home and thematic analysis was used to analyse the written interview data. Eleven participants were interviewed. Four main themes specific to the PPC document were identified: (I) completion; (II) document availability to others; (III) importance and influence on end-of-life experience and (IV) limitations.

Key findings adding to existing literature were that the PPC document was felt to have little impact on end-of-life care amongst this patient group and that there was a perceived lack of awareness of the document amongst Health Care Professionals (HCPs), in particular hospital staff. This lack of awareness was identified by participants as the most important area for improving effectiveness of the document. This has obvious implications

for practice looking at levels of and ways to improve awareness amongst HCPs, particularly in light of the current pressures to meet patient preferences at the end of life ■

■ 6 A narrative inquiry of personal experiences of death and dying in GP-Training Junior Doctors

*Marina Malthouse, Dorothy House
Hospice, Bath*

This research aims to examine medical culture surrounding death and dying within the daily working environment of junior doctors. Poor experiences at work have been identified as a source of distress in juniors that can affect their patient care. It can also negatively influence job satisfaction and adversely affect their personal lives. I explore personal experiences and the context of medicine's end-of-life care to raise awareness in the medical profession and argue how training and support of junior doctors should be improved.

Narrative inquiry researchers simultaneously explore sociality, temporality and place to study theoretical ideas of life alongside lived experience (1), inviting their readers to consider different ways of seeing the world. The researcher, a palliative medicine physician (also once a junior doctor) teaches, advises and supports junior doctors in palliative care in hospital and hospice. Using this narrative research methodology, I explore through interview, memories of death and dying in the professional and personal lives of twelve doctors on the GP training scheme in Bath; the current and future medical context of end-of-life care; and medical discourse of undergraduate and postgraduate medical education and professional regulation. Using writing as a method of inquiry within this methodology, I re-present these doctors

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experiences as fictional stories aiming to give these doctors an opportunity to have a voice, one that they felt was lacking in their work environment. For some, their first encounter with death was in the dissection room at medical school. For others, death and dying had already been a part of their lives. Either way, new experiences entered into their working lives as junior doctors.

This research is part of an Educational Doctorate under the supervision of Dr Jane Speedy, Director of Narrative Inquiry at the Graduate School of Education, Bristol University ■

■ 7

The presence and severity of side effects of strong opioids

*Gail Allan, Strathcarron Hospice
Ruth Isherwood, Beatson West of
Scotland Cancer Centre
Lesley Colvin, Marie Fallon, University of
Edinburgh*

Research Aims: The study assesses the prevalence and severity of side effects of strong opioids. Patients are recruited who have a history of cancer or non-cancer pain or substance misuse.

Study design and methods: An observational study which recruits patients who are prescribed strong opioids. The frequency of side effects (dry mouth, nausea, vomiting, myoclonus and hallucinations) associated with strong opioids has been recorded using Likert scales. Constipation severity has been scored. Objective measures of cognitive function are assessed using a scale which has been validated for diagnosing dementia. A subjective measure is provided using 16 visual analogue scales anchored by positive and negative aspects of emotion. Qualitative interviews with patients who have previously been opioid toxic were also carried out.

Results: Preliminary results on 50 patients are presented. 54% are female, median age is 54.7 years. The majority of patients reported 2 or more symptoms using the Likert scales. 28% of patients had 2 or more symptoms present quite often or very often over the previous week. 34% had a score of 3 or less indicating constipation. 20% were on a low (60mg or less) morphine equivalent daily dose (MEDD) and 26% were on a high MEDD (300mg or more). Patients have significant impairment of cognitive function with 52% of patients scoring less than 88/100. (This score gives 94% sensitivity and 89% specificity for dementia). Subjective assessment of cognitive function suggests patients are very aware of the impairment. Possible associations between MEDD, opioid prescribed and rate of titration of the opioids are explored.

Conclusions: The side effects of strong opioids cause a significant symptom burden demonstrated by both the quantitative and qualitative data obtained. It appears clinically significant that patients report awareness of their cognitive impairment ■

■ 8

■ 9

Systematic review of strategies to improve the recruitment of participants to research studies

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Systematic review of strategies to improve

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the recruitment of participants to research studies via healthcare professional's lessons learned for palliative care.

Background: Fewer than 50% of trials reach recruitment targets (Treweek 2010); in palliative care this may be as low as 31% (Bennett 2009). Many studies report problems with recruitment but few formally evaluate recruitment strategies despite considerable time and effort spent by researchers to improve recruitment to studies. Often researchers only have indirect access to participants through healthcare professionals who can act as "gatekeepers".

Research Aim: To identify and assess recruitment strategies to improve recruitment to palliative care studies via healthcare professionals.

Method: The review used Cochrane Methodology and is registered with the Cochrane Methodology Review Group. Searches were conducted on 4 databases for publications about recruitment of participants into research via healthcare professionals and which included a comparison. 11,941 titles were screened against inclusion/exclusion criteria - 770 were selected for full-text examination. Information was extracted from 9 publications. All processes were conducted independently by two researchers. Included paper and review reference lists were checked and citations tracked.

Results: Nine papers met eligibility criteria. Three were randomised controlled trials and six observational studies. The most promising strategy was introducing a staff member whose primary role was recruitment. Sending additional information and visiting trial centres more frequently were not effective.

Conclusion: There is a dearth of evidence to evaluate recruitment strategies. The

most promising strategy for palliative care identified from the limited evidence was introducing a staff member to identify and recruit patients. Further study is required and we are applying ■

■ 10

Qualitative methods in evidence based practice: the case of cancer cachexia care

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There is increasing acceptance of the contribution of qualitative methodologies to evidence based practice if we are to understand the complexities of health and illness and provide care in a holistic manner.

This paper aims to assert the contribution of qualitative methods in answering research questions relating to the experience of illness and care, with the exemplary case of cancer cachexia, and outline how this evidence base can inform healthcare interventions. Cancer cachexia is a distressing and devastating wasting syndrome which has profound bio-psycho-social implications for patients with advanced cancer and their families.

To date, traditional quantitative research methods have failed to provide an intervention that is effective in the treatment of cancer cachexia, underlining the indispensability of research designed to ameliorate the negative experience of this syndrome. A review was undertaken of the results of the authors' research programmes which involved the use of qualitative methods to uncover the experience of those living with cancer cachexia and those involved in providing their care.

The qualitative information revealed that a

lack of understanding of cancer cachexia by patients and their families caused considerable distress, confounded by a perceived lack of information and support from professionals. In turn, professionals require appropriate intervention tools to help recognise and respond to the needs of this population.

On the basis of this qualitative information four types of interventions can be developed which have the potential to support patients and their families and reduce the burden of this devastating syndrome. Such important interventions could not have been developed using quantitative methods given the complexities involved in the meaning of cachexia for patients and their families and the challenges of managing it in clinical practice ■

■ 11 Interventions for fatigue and weight loss in adults with advanced progressive illness

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Fatigue and unintentional weight loss are two of the commonest symptoms experienced by people with advanced progressive illness (Brunnhuber *et al* 2008; Davis & Dickerson 2000; Solano *et al* 2006) and can be of great concern to those affected and of even greater concern to formal and informal caregivers (Hopkinson *et al* 2006; Poole & Froggart 2002; Reid *et al* 2009). Altered metabolism, inadequate intake of nutrients, muscle deconditioning and poor energy management have all been implicated in the development and exacerbation of these symptoms (Carey 2000; MacDonald 2007; Radbruch *et al* 2008).

Objectives of Overview: To review

evidence to determine the efficacy of interventions used in the management of fatigue and/or unintentional weight loss in adults with advanced progressive illness by reviewing the evidence contained within Cochrane reviews.

Methods: The Cochrane Database of Systematic Reviews was hand searched by title for all reviews that may assess the effect of an intervention on fatigue and/or unintentional weight loss in adults with advanced progressive illness.

Discussion: Many studies have looked at ameliorating fatigue and unintentional weight loss through pharmacological and non pharmacological means. Systematic reviews have been conducted looking at interventions using single modalities such as exercise, nutrition, drug therapy, complementary or alternative medicine or psychosocial interventions.

This work gathers together data from a wide range of Cochrane Systematic Reviews into one overview. This overview is of benefit to clinicians, policy makers and informed consumers who are accessing The Cochrane Library for evidence on treatments to ameliorate fatigue and unintentional weight loss in adults with advanced progressive illness. Data from this overview will be used to highlight areas needing further research ■

■ 12 Using Action Research to Develop a Framework for Palliative Interventions in Respiratory Services

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Traditionally, palliative care services have been directed towards patients with malignant disease. Following publication of the Irish Hospice Foundation/HSE report "Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks" (2008) a two year research project commenced in 2010 in the Respiratory Unit, St James's Hospital, Dublin. This project is formally linked with local Specialist Palliative Care and Primary Care services and is using action research methodology to develop a model of palliative care for patients with advanced respiratory disease in a clinical setting.

Action research methodology was chosen as it is particularly suited to small scale projects that strive to bring about change which is identified locally and has application in wider contexts. The partnership and reflective nature of action research ensure that all those involved in the care of patients with advanced respiratory disease are collectively involved in the development of the project.

To date, the initial planning and action cycles have started. The key stakeholders in the provision of palliative care have been identified and the project outcomes and potential barriers have been identified through an expert focus group. Audits of patient charts in primary and secondary care have commenced and interviews with patients, family members are being conducted. A survey of the palliative care education needs of healthcare professional has demonstrated the need for further education in this area. The project is also supporting the collaboration and development of communication networks across teams and sites.

Twelve months into the project, the benefits of taking an action research approach to facilitate change in palliative care clinical practice can already be seen. This methodology enables the inclusion of all relevant stakeholders to be part of

the changing work environment. This innovative project is informing palliative support, intervention and referral pathways for people with advanced respiratory disease ■

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■ 14

Memories, Trajectories and Bereavement

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Introduction: Much attention has been given in recent years to the concept of illness trajectories and their potential use in the planning of services provided to those with life limiting illnesses. This study examines how trajectories are experienced by bereaved individuals and whether the memories retained by the bereaved or the experience of grief differ according to the disease trajectory of the deceased.

Aims and Methods: The aim is to investigate whether the trajectory of dying influences the experience of grief or the memories held by the bereaved of the death and prior biography of the deceased. One to one unstructured in depth interviews have been conducted with bereaved relatives between three months and two years after the death, followed by thematic analysis of the narratives produced.

Preliminary Results: Whilst it is possible to identify key stages in the dying trajectory as experienced by the bereaved, there is little uniformity to trajectories and key events are often not related to the medical status of the deceased. Considerable sacrifices are often made by the bereaved in order to achieve a 'good death' as defined by the deceased and there appears to be a need to integrate

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the trajectory of dying with the memories of the deceased and their prior biography.

Discussion: There are a wide variety of experiences, with differences between the medical and the experienced trajectories of dying. Research is ongoing, but it seems that the needs of the bereaved can be (willingly) overridden in the desire to provide an appropriate death and retain coherent memories of the deceased. This may have future implications for the assessment of need and the provision of services and support of the bereaved both prior to and following the death ■

■ 15

'Let me speak!: the voice of learning disability in end-of-life care'

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Background: The literature highlights concerns regarding the quality of palliative and end-of-life care offered to people with learning disabilities (Michael, 2008). The need for partnership working between the specialties of learning disability and palliative care has also been recognised to ensure that this population is not dying disadvantaged deaths (Todd, 2006).

Aims/Objectives: The aim of this study is to develop and evaluate an educational resource for specialist palliative care and learning disability services which promotes collaborative working.

Methods: This is a sequential, exploratory mixed methods research study involving three integrated phases. The study is underpinned by a transformative paradigm and is both being informed and informing a conceptual model on partnership working from previous work by Boydell *et al* (2007). The findings of two focus groups, with a total of seventeen people with learning disabilities

recruited through an advocacy group, are presented. An interview guide, adapted from the literature containing pictures and straightforward language, was used to facilitate the focus groups which aimed to elicit the views of people with learning disabilities on end-of-life care and provide a user perspective to the development of the educational resource. Data were transcribed and analysed thematically using a recognised framework.

Results: Five themes emerged which were:

- time with family and friends,
- having help and support,
- comfort at end of life,
- understanding the illness
- coping with the illness.

Conclusions: People with learning disabilities can articulate their needs for end-of-life care which need to be more fully acknowledged and addressed. Raised professional awareness of the importance of facilitating people with learning disabilities at the end-of-life to express their needs and take part in decision making is required. This study adds to the slowly developing knowledge base in this area of practice, but further research is required ■

■ 16

An exploration of how older people with primary lung or colorectal cancer view registered complement

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Background: Complementary Therapy (CT) has a supportive role for those with cancer. The importance of equal access for all patients has been highlighted by NICE guidance (1). Lung and colorectal

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are the most common cancers in Europe, with peak incidence occurring in the over 60s (2). There is a paucity of research regarding CT use by older patients with lung or colorectal cancer.

This study aimed to explore the understanding and experiences of older people with lung or colorectal cancer regarding CT services.

Methodology: A twin-site study was conducted in Northern Ireland Cancer Centre and Marie Curie Hospice Belfast. Patients, both users and non-users of registered CT (aromatherapy, reflexology, massage and acupuncture) completed an interviewer-administered questionnaire. Results were analysed using SPSS.

Results: Sixty-eight patients (37 males, 31 females) were recruited. The majority were classed as skilled manual/partly skilled/unskilled (n=46) and were ambulatory (n=38). Most had an awareness of CT and 40 patients had previously used registered CT services. Over 90% of CT users rated the quality of sessions as good/very good. Over 95% of respondents thought all patients with cancer should be offered CT. Only 38% thought it was easily accessible to older people. Lack of information and uncertainty of benefit were perceived as barriers preventing access. Of those patients who accessed CT, only eight had informed their GP. In the non-user group, no-one had discussed accessing CT with their GP/consultant.

Conclusion: This study highlights the need for timely provision of information and improved communication between patients and healthcare professionals on CT use. Future research is needed to further explore these factors and to confirm if these findings are generalisable ■

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■ 18

Achieving Effective Collaboration: Palliative Care in Intensive Care

Wendy Prentice, Caroline Rumble, Rachel Burman, Phil Hopkins, Will Bernal, Irene J Higginson, King's College London

Aim: To develop and implement an end of life care intervention for the intensive care units in a London teaching hospital.

Background: National guidance has been developed recommending the use of end of life care pathways; however there are mixed views about their relevance in the ICU setting. ICU staff in an inner city teaching hospital worked in collaboration with the palliative care clinical team and academic department in a project to develop an intervention specific to this environment.

Methods: The MRC guidance for the evaluation of complex interventions phases 0, I, II was followed. The research study involved consultation with staff and relatives and facilitated the development of an end of life care group. This included ICU clinicians, nurses and palliative care staff and acted as the main forum for discussion of consultation results, fusion of ideas and refinement of the intervention specific for the local environment.

Results: A complex intervention was developed including: amendment of an existing withdrawal document (developed by the ICU); a tool to prompt assessment of psychosocial issues and a fax proforma to inform GPs of shift to comfort care. Supported by education and awareness-raising, four piloting phases took place with ICU staff contributing to data collection, discussion of refinements and feedback of results. Initial evaluation shows good use of the documents with increasing staff awareness and ability to deal with end of life and psychosocial

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issues and increased collaboration with specialist palliative care ■

Conclusions: The collaborative development approach has given ownership of the intervention to the ICU staff necessary for effective implementation. The resulting intervention has aims and content similar to national guidance but with local relevance. By using an academic focus as a platform for the development this has facilitated increased collaboration with specialist palliative care and separate units within the Trust.

■ 19

An Ethical Analysis of the Use of Sedation in Palliative Care

*Katie Frew, Paul Paes, Julian Hughes, Northumbria Healthcare NHS Foundation Trust
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Palliative sedation is a controversial issue in palliative care (1-3). Previous research has explored aspects of administration, concerns of relatives and staff and also ethical issues, predominately in retrospective studies (3-9). One consistent feature emerging from these studies is that further empirical research regarding the intent of physicians in using sedation is advocated (3,5,6).

This research study is an ethnographic study of the use of sedation in a palliative care inpatient unit. This research sits within the social constructivist paradigm, informed by the theoretical approach of the symbolic interactionists (10-12). As the researcher has previously worked as a doctor in the inpatient unit under study, this methodological perspective is important in understanding the nature of the data and how it is interpreted. The researcher has been based in a palliative care inpatient unit as a participant observer for a period of 10

months. This has involved integrating herself into the clinical team and observing the decisions made, the motivations behind these decisions and how they are enacted in practice. As a participant observer she has been carrying out interviews with members of staff, both informally as part of her day to day observations and also formally, in qualitative in-depth interviews. These in-depth interviews are clustered around individual patients who have been observed as having received sedation.

Data is being analysed taking a constructivist grounded theory approach. Reflexivity and accepting deductive, as well as inductive, reasoning is central to this approach (11,13).

The findings of this study will address the evaluative nature of end of life decision making, acknowledge the central position of intent, and introduce the concept of narrative unity as an approach to develop sound ethical decision making in palliative care.

This is being undertaken as a PhD study through Newcastle University, supported by a robust annual progress review panel and undergraduate training programme ■

■ 20

■ 21

Cancer and beyond....Experience of using the Liverpool Care Pathway in the acute hospital setting

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Aim: To look at the experience of non-palliative care staff with regard to use of an end of life pathway based on the Liverpool Care Pathway.

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Design: This qualitative study took place in an acute hospital. It consisted of semi-structured interviews of a purposive sample of medical and nursing staff looking at the use of an end of life pathway. Specialities which took part included Medicine, General Surgery, Orthopaedics and Critical Care. The interviews were transcribed and the transcripts were analysed for emergent themes.

Results: 16 members of clinical staff participated in the study and covered all disciplines and grades. The amount of experience in the use of the pathway varied considerably amongst participants, although they were all aware of its use. The nursing participants used it more than doctors and senior doctors were involved in the decision-making process but often not directly involved in its use. This study showed the widespread use in this hospital of the pathway in non-cancer patients, especially in patients with extensive cerebrovascular accidents, heart failure, chronic obstructive pulmonary disease and those with fractured femurs and other co-morbidities. However, participants reported difficulty in diagnosing dying particularly in non-cancer patients and this was a potential barrier at times to its use. The pathway's use was also commonplace within Coronary care and High Dependency Unit.

Conclusion: This study showed that use of the Liverpool Care Pathway in non-cancer patients in this hospital was widespread but there were still potential difficulties in its use in this group of patients, especially in diagnosing dying ■

■ 22

Pathway Hurdles - Barriers to the use of an end of life pathway

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Aim: To explore the barriers to use of an end of life pathway in the acute hospital setting.

Design: Nursing and medical staff across all grades from medical, surgical (including orthopaedics) and critical care departments were invited to participate in this qualitative study using semi-structured interviews. An interview schedule with questions around participants' perceptions of the impact of the pathway and barriers to its use was used. The interviews were transcribed and analysed to find common themes.

Results: There were 16 participants in total across all grades and disciplines, seven nurses and nine doctors. Common themes were felt to be the difficulty in diagnosing dying especially in patients with a non-cancer diagnosis e.g. chronic obstructive, pulmonary disease, heart failure and extensive stroke and there also appeared to be a difference in opinion at times between doctors and nurses regarding the diagnosis of dying and hence the appropriate time to commence the pathway. Some of the junior doctors who participated in the study felt that it could be difficult to diagnose dying in a patient who they had contact with for the first time whilst on-call and weren't confident as to whether they should be making this decision at a junior grade. Overall, the perception from participants of the impact of the pathway was positive. Training in use of the pathway varied considerably amongst participants with some consultants having had no training and nursing staff on the whole tending to



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have more formal education sessions with regard to use of the pathway.

Conclusions: This study highlights findings in other studies about the diagnosis of dying, especially in non-cancer illness. It also reinforces the importance of multi-professional team decision making when diagnosing dying and the continued need for education ■

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