Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

… Understanding and improving palliative and end of life care

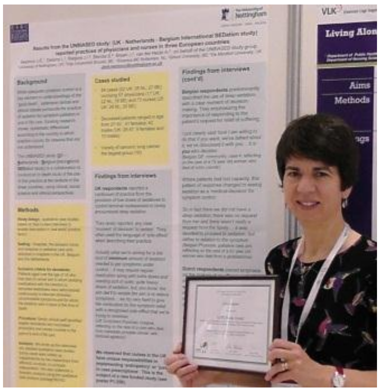
NEWSLETTER Welcome to the SRCC Newsletter, one of the ways we share information and updates.
Autumn 2013 We welcome your comments

Update

- **European Association of Palliative Care (EAPC) Conference - Prague**

  In May we were able to fund four staff members and three PhD students to attend the EAPC international conference in Prague. During the conference Jane Seymour delivered a symposium on *Palliative sedation and patient preferences* and Kristian Pollock presented on *The hospital as a place of death.* The group also highlighted studies from the Centre in two posters displays.

Becky Whittaker (centre left) with the three PhD students (Issa Almansour, Nahyeni Bassah and Louise Bramley) at the EAPC Conference.



Jane Seymour (above) receiving her prize for her award-winning poster at the EAPC Conference.

- Also in May, Eleanor Wilson was awarded her PhD entitled *A Delicate Equilibrium: Living with Huntington's Disease.* This will be available on the University's electronic these archive shortly.

- Kathryn Almack has presented her work on LGBT older people at conferences for both the British Sociological Association and the British Society for Gerontology. She was also invited to be part of a panel discussion after a screening of the documentary 'Gen Silent' at Fringe! Film Festival, London. Gen Silent explores the concerns and experiences of older LGBT people in the US facing issues around end of life care.

- We are delighted to announce that Dr. Bridget Johnston, currently Reader in Palliative Care at the University of Dundee, will shortly be joining us as Professor in Palliative and Supportive Care - more details in our Spring 2014 newsletter.

- Jane has continued her international collaboration by participating as a member and Deputy Chair of the Health Care Sciences Research Review Panel, Swedish Research Council (May to August 2013) and presented research papers to both the Karolinska Institute and Esrta Skondal University College, Stockholm. In addition Jane was invited by the National Clinical Director for End of Life Care to share her expertise at the End of Life Care Strategy Stakeholder Engagement Event, London, in July.

- In September, Beth Hardy presented at the British Psychological Society Qualitative Methods in Psychology Conference: *Pictor: Supporting patients and carers to share their experiences of complex care situations*.

- **Liverpool Care Pathway**

  Members of the group undertook a rapid review of research evidence about the Liverpool Care Pathway and its components. The review was commissioned by the Department of Health and played an important role in the Independent Review led by Baroness Neuberger. The report is published here: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212451/review_academic_literature_on_end_of_life.pdf

  After publication of the Independent Review of the LCP, researcher Ruth Parry wrote a blog post emphasising that "*ensuring dignified, compassionate healthcare and excellent communication means giving staff more time for both training and support*" http://blogs.nottingham.ac.uk/pressoffice/2013/07/17/personalised-approach-to-end-of-life-care-good-care-and-communication-take-time/

New Staff

Beth Hardy joined the Centre in June as a new Senior Research Fellow. Beth has a PhD in psychology and is a registered general nurse who has worked in a community healthcare setting since 2002, gaining her community specialist practice qualification in 2006, and working as a district nursing sister until 2012. Whilst in this role, Beth spent a lot of time working with people with complex illnesses and at the end of life, developing a specific interest in palliative and end of life care for patients and their families. Her doctoral work was inspired by her work in the clinical setting, and explores the experiences of people affected by advanced disease who are receiving community healthcare. During her PhD, Beth continued to work in out-of-hours community nursing services, and latterly worked as a haematology research nurse for the University of York. Beth is delighted to join the research team at the Sue Ryder Care Centre and excited to be involved in the dynamic and varied research being undertaken by the department.

Research Focus

Caring for frail or seriously ill older people on acute hospital wards

Kristian Pollock, Glenys Caswell, Rowan Harwood, Davina Porock

A three year study funded by the Alzheimer's Society has recently been completed. The study explored end of life care for frail older people with and without dementia in the acute hospital setting. Much emphasis has been placed on the need to accurately diagnose the point when active treatment should shift to the provision of palliative care for dying patients. However, the study findings highlight the difficulty of recognising dying particularly in this patient population experiencing a protracted decline prior to death. The study found no difference in the care and family experience of patients dying with or without dementia and that it is difficult to apply the current model of palliative care to end of life care for frail older patients in hospital settings. Uncertainty of prognosis makes clinical decision making difficult, and exacerbates problems of communication with patients and families. However, staff contact with dying patients tended to be brief, and task oriented. Some families reported feeling unsupported throughout the vigil they kept for their dying relative. Although hospital is widely considered to be an undesirable place of death, it will continue to be where most people die. For some families in this study it was preferred, and could even provide a positive experience. It is important that the hospital is adequately resourced to provide sensitive, compassionate care to dying patients and their families. This will require substantial changes in the physical environment, organisation and delivery of care, and in staff understanding of their role in supporting and communicating with patients and their family carers. For further information about the study, and the two elearning resources that will form part of its output, please contact Kristian Pollock via kristian.pollock@nottingham.ac.uk or 0115 8230810.

DECIDE

Karen Cox, Jane Seymour, Kathryn Hinsliff-Smith, Ruther Feakes, Gillian Whitworth

The DECIDE project (Everyday decision making and frail older people: Mental capacity and best interests) commenced in May and we welcome three new members of staff: Kathryn Hinsliff-Smith, Research Fellow and two seconded staff from Nottinghamshire City Care Partnerships, Ruth Feakes and Gillian Whitworth. The project is funded by NHS Nottingham City NIHR Research Capability Fund, and will be exploring the realities of everyday decision making and best interest decisions by professional carers in three settings: an acute ward, in a care home, and in the community setting. Along with individual interviews with professional carers views by informal carers are also being sought. The project findings will lead to a larger NIHR project grant application in 2014.

Practitioner Research Network Open Meetings

We convene and host regular seminars that are open to practitioners, educators, researchers and other interested parties. Over the past few months, Practitioner Research Network Seminars have included talks about: mental capacity autonomy and safeguarding, a Sikh perspective of understanding and talking about palliative care, and natural support networks and the idea of holistic care. PowerPoint presentations for all these talks and previous talks, including video recordings of some can be found at: http://www.nottingham.ac.uk/research/groups/srcc/seminars/index.aspx

The next Practitioner Research Network Meeting is on **21st November 2013** and will host Macmillan Reader in Palliative Medicine and Medical Oncology, Dr. Andrew Wilcock with a presentation entitled: *Palliative care research: national, regional and local perspectives*

Apart from our regular lunchtime seminars we organise and evening Annual Lecture. Please see updates on the website for further details and a finalised date.

To be added to our seminar mailing list please use the contact details at the end of this newsletter.

Education news

BSc Healthcare Studies (palliative and end of life care) and MSc health and Social care (palliative and end of life care).

The above pathways have a new 30 credit module structure starting Autumn semester 2013. The BSc award comprises four 30 credit modules and the MSC award four 30 credit modules in addition to a 60 credit dissertation. The MSc award is now available as a full time option over 12 months from September 2013.

The 2 core 30 credit modules for the above pathways are:

- Critical perspectives in end of life care which explores contemporary debates including ethics, decision making, withdrawing treatment and advance care planning
- End of life Care Management which focuses on the delivery and management of care including generic symptom management of complex symptoms, application of end of life care principles and using best practice tools to manage last days of life.

Please contact Becky Whittaker for further information: becky.whittaker@nottingham.ac.uk

Evaluation toolkit

The Evaluation project has been developed over three years with support from the East Midlands Strategic Health Authority and National End of Life Care programme. The Toolkit contains three validated questionnaires (Tool A, Tool B and Tool C) that can be used over a period of time to help evaluate practitioners self-assessed changes in practice after attending a range of end of life education/learning events.

The questionnaires are freely available for access and use - Evaluation Toolkit (PDF)

For more information about using the Evaluation Toolkit please contact Becky Whittaker at:
evaluationtoolkit@nottingham.ac.uk

Life Cycle Studentships: Update

With monies raised from Nottingham Life Cycle events three students have been funded to undertake full-time PhD studies. All have now completed their first year and start their second year this October.

Nayheni Bassah

Education that makes a difference in end of life care at the bedside in a resource poor context: the situation of Cameroon

Some preregistration nursing curricula do not include any palliative care contents, especially in resource constrained countries. Existing research identifies lack of palliative care knowledge and skills among registered nurses, both newly graduated and student nurses.

This study is to develop, pilot and evaluate the impact of a palliative care course on Cameroonian preregistration student nurses' palliative care knowledge and self-perceived competence and confidence in palliative care provision.

This study uses an intervention (30 hours classroom based palliative care course) delivered by nurse educators in Cameroon to second and third year student nurses of the University of Buea. Baseline assessment will be conducted on the first day of the course and the follow-up assessment will be after the completion of the course and following students' completion of their regular second semester placement. Focus group and individual interviews will also be conducted at this point to explore students' evaluation of their experiences of the course and whether they were able to implement their knowledge and skills from this course in the care of patients who need palliative care during placement. Nayheni is currently in Cameroon helping to deliver the intervention and undertaking data collection. She has been able to take 52 textbooks to help deliver the education programme. The books were funded by the Education and End of life Care budget.

Louise Bramley

Advance planning of care towards the end of life in frail older people: Implications for acute hospital care

Evidence suggests that planning care in advance at the end of life has the potential to facilitate preferred place of death, reduce unwanted hospital admissions and enhance communication between patients and their families. However, the evidence for acute hospital care assisting patients with advance care planning is inconsistent and does not currently represent the narrative of frail older people and their carers. In addition existing research has not examined how contemporary frameworks for advance planning in end of life care relate to frail older people and their carers, who may be experiencing day to day challenges of failing health and mental capacity requiring increased levels of health and social care.

My research is taking a case study approach and aims to investigate the expectations and experiences of frail older people and/or their carers of advance planning for end of life care and to examine the implications of this for acute hospital care and current contemporary frameworks for advance care planning. Following a critical review of the current empirical, policy and health professional guidance literature, serial qualitative interviews will be conducted with frail older people and/or their carers, during hospital admission and post discharge.

Following on from a challenging and successful confirmation review in July, I am now in the process of applying for ethical approval for the interview part of the study, which I aim to commence in the New Year.

Nicola Turner

Young carers caring for a parent who is approaching the end of life

My PhD Studentship is jointly funded by the Sue Ryder Care Centre and the School of Sociology and Social Policy. I aim to explore the experiences of young people who are living with and caring for a parent who is approaching the end of life. The study will adopt a qualitative approach to include in-depth interviews with young people and other family members nominated by the young person. These interviews will explore;

- Young people's understandings of the processes and practices of care in the context of a family with a parent approaching the end of life.
- how practices of care are negotiated and enacted by family members.
- how the boundaries between 'carer' and 'cared for' are understood and expressed.
- how young people who are caring for a parent who is approaching the end of life make sense of this difficult experience in relation to their own lives.
- the extent to which young people are active agents in family care-giving and the influence of wider social and cultural narratives of care.

Data gathered will then be analysed using the voice centred relational method. I have recently completed a successful confirmation review and am currently preparing to apply of ethical approval.

Recent publications

Fenlon, D., Frankland, J., Foster, C.L., Brooks, C., Coleman, P., Payne, S., **Seymour, J.**, Simmonds, P., Stephens, R., Walsh, B. & Addington-Hall, J.M. (2013) *Living into old age with the consequences of breast cancer*. Eur J Oncol Nurs, 17(3), 311-6.

Meron, T. (2013) *Medical advance directives ("living wills") – ethical issues* [in Hebrew]. In: Rubinstein, D. and Tabak, N. (Eds.) Contemporary Nursing Ethics. Tel Aviv: Dionon, pp 271-288. (PhD student)

Papavasiliou, E., Brearley, S., **Seymour, J.E.,** Brown, J. and Payne, S, (2013) *From sedation to continuous sedation until death: how has the conceptual basis of sedation in end-of-life care changed over time?* Journal of Pain and Symptom Management, http://dx.doi.org/10.1016/j.jpainsymman.2012.11.008

Seymour, J. & Horne, G. (2013) *The withdrawal of the Liverpool Care Pathway in England: implications for clinical practice and policy*. Int J Palliat Nurs, 19(8), 369-71.

Wilson, E and Seymour, J (2013) *Understanding the role of nurses in the management of symptoms and distress in the last days of life* in Streckx, S; Raus, K and Mortier, F (eds) Continuous Sedation at the End of Life: Ethical, clinical and legal perspectives, Cambridge University Press, New York pp100-115

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