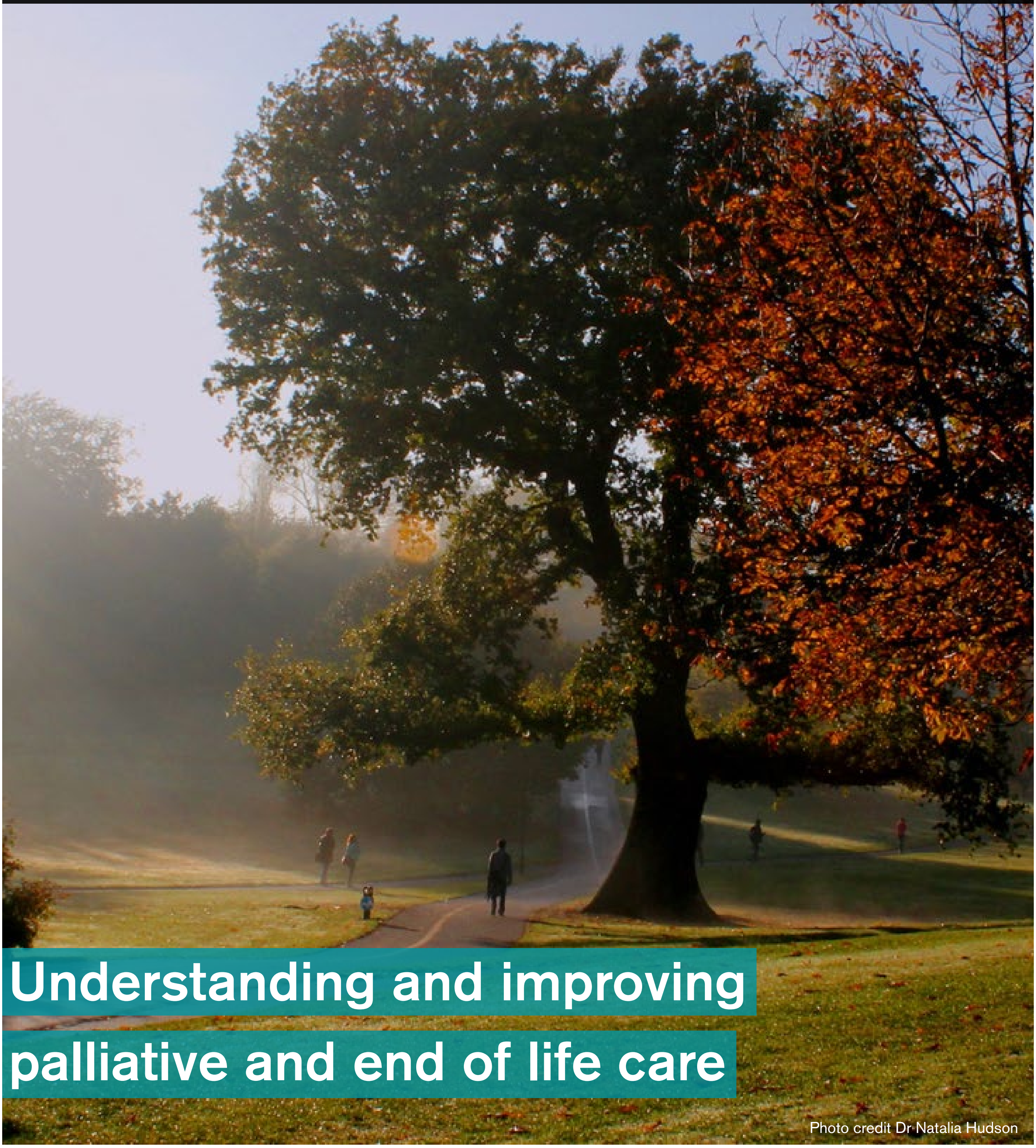
The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Sue Ryder Care Centre @Nottingham

Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care Newsletter Autumn 2014



Understanding and improving palliative and end of life care

Photo credit Dr Natalia Hudson

Welcome back Jane!
Jane Seymour's academic visit to the United States.

New staff
Welcome to Melanie Narayanasamy.

Research news
A round-up of current research and dissemination.

Welcome back Jane!

Brian Cassel and Jane Seymour.

Professor Jane Seymour travelled to Virginia Commonwealth University in Richmond, Virginia, USA, between April and August for a summer-long appointment as a VCU Global Visiting Scholar.

The Global Visiting Scholar Awards program, offered by the Global Education Office at VCU, supports departments or schools in hosting an international scholar for a semester or academic year who will contribute to enriching the learning and scholarship of the unit.

Jane's award was entitled "*What Can Be Done to Improve Care for People with Advanced Disease? A Comparison of US and UK Policy and Practice.*" It was offered in partnership with the Division of Hematology, Oncology and Palliative Care at the VCU School of Medicine.

J. Brian Cassel, Ph.D., Senior Analyst and Assistant Professor in the Department of Hematology, Oncology and Palliative Care at the Massey Cancer Center, was Jane's host for the duration of the award. Brian said of the visit: "*It is a wonderful opportunity, thanks to the Global Education Office, to host Professor Seymour... it has been great to hear Jane's reactions to, and insights about, palliative care and hospice in the US as she looks at what we do here through a 'UK lens.'*"

Brian Cassel had previously travelled to London in early 2012 on a Fulbright Scholarship grant to collaborate with researchers to measure the economic impact of end-of-life care in the US and UK and "*had the opportunity to look at the UK approach through a 'US lens,'*" he explained, "*it has been very interesting to compare notes.*"

Jane says of her visit "*I am grateful for the opportunity afforded by the VCU scholarship to spend time in the USA. I found it fascinating to reflect on the different histories and developmental patterns of palliative and hospice care in the two countries and am looking forward to going back to the US in February 2015 to present a comparative paper about our observations at the annual conference of the American Academy of Hospice and Palliative Medicine in Philadelphia.*"

Overseas visits and visitors

Louise goes Stateside

Louise (5th from right) joins international colleagues for a working lunch in Wisconsin.

In May of this year, Louise Bramley travelled to Wisconsin in the USA to learn more about an advance care planning intervention called Respecting Choices©. Respecting Choices© is being used as part of the ACTION project, a European funded mixed methods study, to assess whether an advance care planning intervention improves the quality of life and symptoms of patients with advanced cancer. The trip was a fantastic opportunity to work with colleagues from across Europe and learn about how the intervention works in the USA.

Visiting academic

Dr Kathryn Hinsliff-Smith, a Research Fellow within the centre, welcomed Dr Camilla A. Schneck from the Universidade Federal do Rio Grande do Sul, Brazil in September. This two week visit was as a result of Kathryn attending a British Council funded evidence based practice workshop on healthcare and it is hoped that further partnerships will develop around palliative and end of life care.

Dr Camilla Schneck with Dr Kathryn Hinsliff-Smith.

Education

Education

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 two 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 at:
becky.whittaker@nottingham.ac.uk

Congratulations to Ruth Parry!

Ruth Parry has been awarded a prestigious National Institute of Health Research Career Development Fellowship which will begin in 2015.

The fellowship includes funding to support her to work alongside a junior researcher on a programme of research on "*Enhancing staff-patient communication in palliative and end of life care*". In the first stage of work, they will video-record the work of physiotherapists and occupational therapists who are specialists in palliative and end of life care. The recordings will be analysed using an approach to studying language and social interaction which is called conversation anlaysis (see http://ruthparry.org.uk/conversation_analysis.html).

Analysis will focus on identifying the particular challenges and communication skills entailed in providing physical care in ways that communicate and respect dying people's dignity, autonomy and hopes. The findings will be combined with those from research Ruth is currently leading on hospice doctor-patient communication (see www.nottingham.ac.uk/research/groups/srcc/projects/video-research.aspx). Ruth will then design evidence-based online communication skills training resources for nonspecialist NHS staff, and evaluate effects of the training on practice behaviours.

For more information about the study, email
ruth.parry@nottingham.ac.uk

ESRC Festival of Social Sciences

As part of the Economic and Social Research Council's Festival of Social Sciences, the Sue Ryder Care Centre hosted a film screening of GEN SILENT, a critically acclaimed US documentary, which explores real-life issues facing older LGBT people in later life and towards the end of life. It features six individuals who discuss their personal experiences, feelings, and concerns as they face their various situations.

There was a short introduction by Dr Kathryn Almack, University of Nottingham, who has led the first study of its kind in the UK to explore the end of life experiences and care needs in the lives of older lesbian, gay, bisexual and transgender (LGBT) people (funded by Marie Curie Cancer Care Research Programme). Kathryn also chaired a Q&A discussion panel after the film to explore the UK context of issues raised in the documentary.

SRCC represented at EAPC 2014

Three members of the SRCC team presented posters at the 8th World Research Congress of the European Association for Palliative Care in Lleida, Spain at the beginning of June this year.

Kristian Pollock, Beth Hardy and Anne Patterson each presented posters based upon research projects in which they have been involved. The posters detailed research on Planning for End of Life: The Translation of Policy in Real World Settings; 'Self' and 'Dyadic' Managing in the Last Year of Life and Respecting 'Significant Others': End of Life Care and Quality of Dying for Lesbian, Gay, Bisexual and Trans (LGBT) People.

Staff

New staff

Melanie Jay Narayanasamy

Melanie studied and worked at the School of Sociology and Social Policy for nine years.

She gained a PhD in 2014 looking at decision making in mental health services using Grounded Theory.

Maintaining an interest in healthcare and health services research, Melanie sought work opportunities in the School of Health Sciences and was pleased to land a two year contract with Professor Bridget Johnston working in the Sue Ryder Centre.

She began in August and is assisting Bridget on a number of projects, including using the Patient Dignity Question as an intervention in acute palliative care settings.

Events

Practitioner Research Network – Open Meetings

We are pleased to announce dates for the Research Seminars for the forthcoming year. These seminars are open to practitioners, educators, researchers and other interested parties.

Seminar	Speaker
4 December 2014	Beth Hardy Ruth Feakes and Gill Whitworth, (Nottingham CityCare)
29 January 2015	Kristian Pollock
26 March 2015	Marco Pino and Ruth Parry
Annual Lecture 13 May 2015	This is an annual evening lecture and this year's speaker will be Richard Harding (Cicely Saunders Institute, Kings College London)
16 July 2015	Hannah Rumble, University of Exeter
24 September 2015	TBC
26 November 2015	Caroline Nicholson, King's College London

All seminars begin at 12.30pm with lunch and presentations commencing at 1pm. There will be time after the talks for discussion and networking. The current schedule of speakers is shown above and titles will follow in due course.

Details about the seminar series are also advertised via email – if you would like to be included on the email list for such events please contact
ann.gibbons@nottingham.ac.uk

VERDIS: preliminary stakeholder consultation completed

SRCC researchers, Ruth Parry and Marco Pino are carrying out a video-based research project at the LOROS hospice to explore decision-making and empathy in real-life, video-recorded consultations involving experienced palliative care consultants, hospice patients, and their significant others.

Video-recording can be a highly valuable resource to understand doctor-patient communication in palliative care and to design teaching materials for advanced communication skills training, but this kind of study implies approaching people at a time of heightened vulnerability. We carried out a preliminary stakeholder consultation in which we asked ten patients, five relatives, four nurses, seven doctors and five communication skills educators about their views on acceptable and feasible approaches to collecting video-recordings of hospice consultations for research and teaching about expert communication skills.

The stakeholders found that video-based research could be a very useful way of gaining new insights into and improving doctor-patient communication in palliative care. They also expressed concerns about the possible risks associated with recruiting patients at a time where they are likely to be in a very fragile position, the possibility that the presence of a camera may alter doctors' and patients' communication in a detrimental way, and participants' loss of control over future uses of their own image (including after the patients' death). The stakeholders also suggested several safeguards on how to video-record hospice consultations in a safe and respectful way, which is being used alongside published guidelines to design the protocol of the main study.

We are happy to report that we are currently in the process of video-recording consultations at the hospice and starting to explore doctor-patient communication around end-of-life issues.

Find out more at **www.nottingham.ac.uk/research/groups/srcc/projects/video-research.aspx**

The Last Outing research project

Dr Kathryn Almack and her team (Dr Anne Patterson and Dr Meiko Makita) have been working to maximise the impact of findings from The Last Outing Project (Exploring end of life experiences and care needs in the lives of older LGBT people).

They have been commissioned to feed project findings into the Government review of choice in end of life care. The review is being undertaken by an independent programme board, chaired by Claire Henry, the Chief Executive of the National Council for Palliative Care. The information gathered will outline the kinds of choices that people would like to be able to make at the end of life and information about the funding, systems and processes that would be needed to enable choices to be acted upon.

Kathryn is also an invited member of an external advisory group, established by the Care Quality Commission (CQC), to provide expert input and critical comment into their 'Inequalities and Variations in Provision of End of Life Care' themed programme.

DECIDE research project

In the last six months the DECIDE project (Everyday decision-making and frail older people: Mental capacity and best interests) led by Professor Karen Cox, submitted their final report to the funders NUH Charity.

The study undertaken by Dr Kathryn Hinsliff-Smith assisted by Ruth Feakes and Gillian Whitworth from Nottinghamshire CityCare Partnership, involved interviewing healthcare professionals and informal carers about their experiences of caring for frail older people with cognitive impairment alongside the Mental Capacity Act.

This work has led to submission of an NIHR grant in October around patient centred care. An executive summary of the DECIDE project can be found on the SRCC website.

Details about all SRCC research projects can be found at **www.nottingham.ac.uk/research/groups/srcc**

Publications

Recent publications

Goldberg SE, Whittamore KC, Pollock K, Harwood R, Gladman J. Caring for cognitively impaired older patients in the general hospital: A qualitative analysis of similarities and differences between a specialist Medical and Mental Health Unit and standard care wards. International Journal of Nursing Studies. 2014; 51(10):1332-43.

Hardy, B., King, N., & Rodriguez, A. The Experiences of Patients and Carers in the Daily Management of Care at the End of Life: Findings from a Phenomenological Study. International Journal of Palliative Nursing. In Press.

Pollock K. Patient's Trust. In: Cockerham WC, Dingwall R, Quah S, editors. The Wiley-Blackwell Encyclopedia of Health, Illness, Behavior and Society. London: Wiley-Blackwell; 2014. p. 3040.

Wilson E, Pollock K, Aubeeluck A. The challenge of providing care to those with Huntington's disease: an overview of complex care provision British Journal of Neuroscience Nursing. 2014;10(3):139-43.

Wilson E, Aubeeluck A, Pollock K. Applying a healthcare model to Huntington's disease: the key worker approach. British Journal of Neuroscience Nursing. 2014;10(5):1-4.

If you would like an electronic copy of any of these papers, and are unable to access them yourself, please email a request to **ann.gibbons@nottingham.ac.uk**

For further information please contact:
Dr Ruth Parry, Principal Research Fellow
Sue Ryder Care Centre
School of Health Sciences
The University of Nottingham
Queen's Medical Centre
B Floor, South Block Link Corridor
Nottingham, NG7 2HA

e: srcc@nottingham.ac.uk
w: **www.nottingham.ac.uk/research/groups/srcc**

If you require this publication in an alternative format, please contact us:
t: +44 (0)115 951 5559
e: alternativeformats@nottingham.ac.uk