



CENTRE FOR THE
PROMOTION OF
EXCELLENCE IN
PALLIATIVE CARE

INFORMING PRACTICE. TRANSFORMING CARE.



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Informing Practice, Transforming Care

Annual Report 2014-2015

Introduction

Excellence in the palliative, supportive and end of life care for patients and their families drives our work. Providing world class education and undertaking research on a multi-professional basis to inform practice are central to the delivery of CPEP's mission. An equally important role for CPEP in making a difference to the experience of patients and families is raising the profile of the importance of palliative and end of life care amongst the general public, and the wider health and social care community, both locally and nationally.

In this report we showcase activity from the past twelve months. Activity is however only one measure of our performance. A key outcome for CPEP is how much it is influencing patient care through informing practice, an outcome which is much more complex to measure. In some projects and learning events this is relatively easy to identify, but in most instances CPEPs influence is more subtle, longer term and just one part of what makes someone change their practice. We have included some examples of this outcome in the individual activities described below.

In January 2015, Christine Whitney-Cooper commenced as the Head of the School of Nursing and Midwifery at De Montfort University and immediately helped CPEP overcome the imminent risk that the retirement of Martyn Geary in November 2015 posed. We are delighted that this has led to a 2-year secondment from LOROS to support development and delivery of the Masters in Palliative Care. A key part of the development is to support international students in accessing the programme.

We should like to take this early opportunity to thank Martyn for his invaluable work in palliative care over many years and in supporting the birth and nurturing the infancy of CPEP! We wish him well for his retirement and will miss his highly professional and wise support in so many ways.

1. Raising Awareness of Palliative Care

Dying Matters Awareness: Continuing Bonds

In May 2014 as part of Dying matters Awareness week CPEP developed a mini-conference with the Leicester Cathedral Richard II team, *Continuing Bonds: An exploration of death and legacy drawing on Richard III and archaeology of the dead*. This drew on the knowledge in the disciplines of archaeology and social history to stimulate thinking about death practices, legacy and our continuing relationships with those that have died and indeed our future descendants. The lectures given by Dr Karina Croucher (University of Bradford) Professors Sarah Tarlow and Kevin Schurer (University of Leicester) and Rev Alison Adams (Leicester Cathedral) are available on the [CPEP website](#) as part of growing collaboration and focus of work in area.

In December a collaborative bid between Karina Croucher and Laura Middleton at Bradford University and Christina Faull was awarded 2 years funding by the Arts and Humanities Research Council to develop this interdisciplinary work further. The programme will commence in April 2016. In brief, we are going to examine a dialogue about death and dying between the clinical and historical disciplines. The aim of the project is two-fold:

- * to demonstrate tangibly how archaeology can inform our current attitudes to death and dying, and thereby help shape policy and practice;
- * to explore the value of collaboration between health care professionals and archaeologists.

The diverse methods of dealing with death and the dead uncovered by archaeologists will bring a different perspective to our current attitudes and therefore contribute towards a necessary re-examination of today's taboo status of death as an inevitable human experience. The project will test out this approach with both lay audiences and with students and professionals in health, social and spiritual care, including nursing students, spiritual care practitioners, counsellors, and medical students. It will seek to

use materials to prompt reflection and examination of participants' own familial and cultural approaches to death, commemoration and continuing bonds with those that have died. It will also draw on the past to explore the concept of ancestors, and how this relates to contemporary considerations of legacy, continuing bonds, and the prospect of ourselves as ancestors of future generations. This will be achieved through a series of thematic workshops with the stakeholder groups and an action research approach, with each workshop informing future workshops, as well as working towards an exhibition intended for the public. Stakeholder workshops will run in conjunction with two 'Dying Awareness Week' events on the theme of Continuing Bonds, which will include a public audience, and will be the primary dissemination event for exhibition materials.

Towards the close of the project, an exploratory workshop will be held with secondary teachers, to assess the viability of introducing material into schools as part of a 'Death Education', with this the focus of work beyond the current project. The project will provide a foundation for further interdisciplinary approaches to fundamental issues of life and death, demonstrating how disciplines which are apparently diverse can aid, inform, and mutually benefit from each other.

CPEP Annual Lecture

We were honored that Professor Irene Higginson, internationally renowned researcher in Palliative Care and Director of the Cicely Saunders Institute at Kings College London, gave a lecture in the 'Distinguished Lecture' series at DMU on November 12th 2014 titled *Hospices & Universities Working Together: Does it raise the game? Reflections from Creating the Cicely Saunders Institute*. The lecture was well attended and evaluated. It helped us see how innovative the CPEP collaboration is within academia and the Hospice movement and the lecture served to set a new level for vision and aspiration for CPEP

CPEP Website

The CPEP website has been revised this year with the support of Wendy Padley, research assistant, and Jamil Anait. Our aim is to provide material of interest to stimulate thinking about the last part of life as well as information to help people access courses and evidence that will improve their practice and care for patients and their families.

2. Research Activity at DMU and LOROS

People

Dr **Richard Kitchen** completed his 2 year **medical education fellowship** funded by the East Midlands Health Care Workforce Deanery. His qualitative work, exploring decision making by surgeons and anaesthetists about frail patients has been submitted as his dissertation for a Masters in Medical Education at De Montfort University, supervised by Professor Faull and Dr Simon Moralee. Richard took his findings in a poster presentation titled *How do surgeons and anaesthetists make decisions about surgery for patients who are frail, and what factors influence these decisions?* Richard presented his work at the Palliative Care Congress and the Association for Palliative Medicine Medical Education Special Interest forum.

Dr **Lynn Furber, Senior Lecturer at DMU and Nurse Researcher at UHL** was funded by a HOPE Against Cancer research grant to conduct a 12 month study: Enhancing consultations in oncology using a consultation tool: A pilot qualitative study. The study is in the final stages of data analysis. Lynn is in the process of producing an National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB) bid which will be submitted in September 2015 to carry this work forward as a cluster randomised controlled in Leicester and in Nottingham. Lynn is working with a group of researchers from the University of Leicester, University of Nottingham, University of Lincoln and Imperial College London.

Lynn is Co-Investigator on a project which was submitted to NIHR RfPB in January of this year. This project is led by Mr David Bowrey a Consultant Surgeon with the University Hospitals of Leicester NHS Trust and is currently under review with an expected outcome in July 2015. The project is called: *A qualitative study to determine the patient and general practitioner factors that influence the time to diagnosis for patients with newly diagnosed oesophageal and stomach cancer.* We should know the outcome of this application in July of this year.

Lynn has also been selected as a committee member of tEACH (Teaching: European Association of Communication in Healthcare). She hopes to use this group to raise the profile of DMU and CPEP and develop other research collaborations in Europe and the USA

Dr **Zoebia Islam** is **Senior Research Fellow** at LOROS and Honorary Lecturer in CPEP and the Mary Secole Centre at DMU. Zoebia is a social scientist and combines her LOROS post with continuing her role in research in mental health in Birmingham Mental Health Foundation Trust and the University of Warwick. Zoebia has become instrumental in developing and delivering the research module on the LOROS/University of Northampton Foundation Degree in Palliative and Supportive Care. A bid to Marie Curie Cancer Care exploring the experiences of advance care planning of South Asian patients family and their health care professionals and developing and evidence based learning programme was unsuccessful in the second stage but has recently been revised and submitted to the NIHR Research for Patient Benefit. Zoebia is also leading the development of research at LOROS on meeting the needs of young adults in transition in palliative care.

Helena Dunbar is the Rainbows Hospice Scholar. Her PhD work is entitled *What are the palliative care needs of children in the East Midlands?* Helena is has competed 2 phases of data collection and is currently beginning her analysis

Rachael Carroll is a nurse researcher for the ENRICH project in University Hospitals of Leicester (see below). Rachel has also commenced a PhD entitled *An exploration of the role and characteristics/attributes of the Health Care Assistant in acute care – a constructivist inquiry*

Jayne Brown is also providing doctoral supervision to **Jo Bird** who is looking at how the concept of compassion develops in student nurses; **Mandy Gamble** who is completing her thesis entitled: *How do patients with a long-term condition, their carers and case managers experience community based case management?*; and **Cheryl Utrecht** who is exploring the development of professionalism in student nurses; Sue **Sloan** who is exploring the role of facilitation in the leadership programmes;

Masters students **Liz Darlison** has graduated having completed her Masters dissertation in which she interviewed the family carers of people who have died from mesothelioma about their experience of end of life care. Titled

A qualitative study to explore carer perception and experience of end of life care following an individual's death from mesothelioma

Jayne has also supervised four pre-registration students through their final dissertation focusing on palliative care.

Projects

The **EnRICH Project (Enhancing Relationships in Care in Hospital)**, led by Jayne in collaboration with Sheffield University and University Hospitals of Leicester, is funded by the Burdett Trust for Nursing for 2 years, ending in March 2016. It focuses on improving care for older people in acute hospital wards and builds on Jayne Brown's seminal work with the Senses Framework. Two PhD studentships (Rachel Carroll and Sue Sloan above) have been awarded to support the project.

A group of six lecturers from De Montfort University and the education team at LOROS are working with Jayne on **Short Courses in Palliative Care: Developing an Evaluation Tool for Health Care Managers**, commissioned by the University of Nottingham.

The aim of the study is to develop a valid and reliable questionnaire to assist managers and educationalists in evaluating learning and its effect on patient care resulting from staff undertaking short courses in palliative care. Data analysis is now being undertaken and the project should be completed by the end of the year

Jayne has been successful in gaining a small grant £50,000 from Shaw Health Foundation for a 12 month project to explore care home managers' contribution to quality care and resident, family carer and staff wellbeing.

Christina has led a national study **Exploring the experiences of families and health professionals supporting a patient with MND who requests that their ventilation be withdrawn.** Findings from this work have been presented at international and many national conferences to the diverse groups of professionals who support patients with MND.

Further funding from the Motor Neurone Disease Association has supported actions resulting from the research and National Guidance and Audit are in the consultation phase.

As doctors hear about this project they are contacting Christina for guidance in care and the Association for Palliative Medicine of Great Britain and Ireland now have a position statement on this area of care; both being examples of how our research is influencing care for patients.

LOROS is working with Dr Ruth Parry and team from the Sue Ryder Centre for supportive and palliative care at the University of Nottingham on **VERDIS: Video-based communication research and training in decision-making in supportive and palliative care.** Funded by the Health Foundation this 2 year project is giving new insights into doctor-patient consultations. The project has developed real-life materials for teaching which are just commencing piloting. Several national and international presentations have been given and detail can be found on the project [web page](#).

Summary of grant seeking activity

Funder	Project and role	Outcome	
NIHR RfPB	Thinking ahead in dementia care CF Co-applicant	Unsuccessful	To be submitted elsewhere
Marie Curie Cancer Care	Improving nurses' symptom related ethical decision making in the last days of life: an educational intervention study in 4 sites JB Co-applicant	Unsuccessful	
Marie Curie Cancer Care	Understanding the experiences of End of life care planning of Black, Asian and Minority Ethnic (BAME) communities and the health care professionals that support them: The EPIC Study (Enabling preference, independence and choice) CF Chief investigator	Un successful	Now submitted to the NIHR RfPB
AHRC August 2014	Continuing Bonds: Exploring the meaning and legacy of death through past and contemporary practice CF Co-applicant	Successful	To commence April 2016
Health Foundation November 2014	VERDIS: Video-based communication research in assessment and management of pain CF Co-applicant	Successful	Work has commenced
NIHR RfPB Jan 2015	Internal and external barriers to initial consultation for patients with newly diagnosed oesophageal and gastric cancer. LF and Cf Co-applicants	Awaited	

Publications

Books and Chapters

Liz Darlison Consultant Nurse at Mesothelioma UK and Ali Pilsworth from the LOROS Education team have been busy writing book chapters for the new Palliative Care at a Glance Series published by Wiley. The Chapters focusing on difficulties breathing (Liz) and advanced communication (Ali) will be published later this year (2015)

Christina Faull and Kerry Blankley 2015.. Palliative Care. 2nd Edition Oxford University Press.

A short textbook aimed at student and junior clinical practitioners of all disciplines. A key text for our masters and other teaching programmes.

Papers

Anquinet, L., Seymour, J. van der Heide, A., Deliens, L., Brown, J., Payne, S. Making sense of continuous sedation in end of life care for cancer patients: An interview study with bereaved relatives in three European countries. *Supportive Care in Cancer* — impact 2.649

CLIPSHAM, L. ISLAM, Z. FAULL, C. (2014) "I'd want somebody to get it right for my kids": Experiences of hospice inpatient nurses in supporting children before the death of a parent. *International Journal of Palliative Nursing*. In press.

FAULL, C. ROWE-HAYNES, C. OLIVER, D. (2014) The issues for palliative medicine doctors surrounding the withdrawal of NIV at the request of a patient with MND: a scoping study. *BMJ Support Palliat Care*, doi:10.1136/bmjspcare-2013-000470.

MARKHAM, S. ISLAM, Z. FAULL, C. (2014) I never knew that!: Why do people from Black and Asian Minority ethnic groups in Leicester, access hospice services less than other groups? A discussion with community groups. *Diversity and Equality in Health and Care*, Volume 11, Numbers 3-4, September 2014, pp. 237-245(9).

PARRY, R. PINO, M. FAULL, C. FEATHERS, L. SEYMOUR, J. (2014) Evidence-based guidance for the design of video-based research. Society for Research in Rehabilitation, *Clinical Rehabilitation*. *Submitted*

Seymour, J., Rietjens, J., Bruinsma, S., Deliens, L., Sterckx, S., Mortier, F., Brown, J., Mathers, N., van der Heide, A. Continuous sedation in end of life care for cancer patients: a qualitative interview study of physicians' and nurses' practice in three European countries. *Palliative Medicine* — impact 2.609.

Seymour, J., Rietjens, J., Bruinsma, S., Deliens, L., Sterckx, S., Mortier, F., Brown, J., Mathers, N., van der Heide, A. Continuous sedation in end of life care for cancer patients: a qualitative interview study of physicians' and nurses' practice in three European countries. *Palliative Medicine* — impact 2.609.

Wilson, E., Morby, H., Brown, J., Payne, S., Seale, C., Seymour, J. Administering anticipatory medications in end of life care: A qualitative study of nursing practice in the community and in nursing homes'. *Palliative Medicine* – impact 2.609

3. Education Activities

Working with pre-registration nursing students

Two preregistration nursing students are members of the CPEP operational group. This year they undertook a survey of their peers to seek views on *if and how* palliative care education might be further developed at De Montfort. As a result of this we have offered a number of initiatives to the school.

We now have a regular monthly programme of 'drop in sessions' for students from any year of study. These are facilitated discussions based on issues the students bring from their clinical placements. Attendance is growing slowly but those that have come have found them very valuable. We would like to see such groups embedded more formally in the curriculum.

Masters level learning

This year has seen a fall in student numbers with only 3 new students entering the programme during the academic year. Disappointingly, this has resulted in only 2 modules running (individual study (2 students) and communication skills (7 students) this year) whilst a further 3 students are undertaking their dissertation. Throughout the year there have been several discussions and developments relating to the sustainability of the programme. Particular opportunities in relation to opening the programme to international students have been discussed. Whilst early discussions focused around the possibility of attracting students from India, currently, the area demonstrating most interest in this programme is Saudi Arabia. Proposals have focused on a post-graduate diploma qualification in palliative care to include practice placements. Discussions relating to the details and feasibility of this are continuing.

In addition, opportunities for partnership working between DMU, LOROS and the children's Diana service are in the preliminary stages to consider the possibility of offering a paediatric/transition module within the current programme. Further meetings to move this forward are planned in the near future.

CPEP awards for Excellence in Palliative Care

The first awards were made in 2014. The applications for the awards were of a very high standard and we congratulate the very worthy winners.

RCN-CPEP Award.

The winner of the RCN-CPEP pre-registration nursing award was Holly Smith. Holly demonstrated how she was able to make a difference to the care of a patient on an acute hospital ward through application of principles of holistic palliative care.

LOROS-CPEP Award

The LOROS-CPEP award winner for postgraduate student excellence in palliative care is Elaine Wright. Elaine has demonstrated a consistently high standard of work on the Masters Programme and used her learning from the programme to make a difference to the care of young people with cancer.

This report was written by the CPEP Operational Group, June 2015.

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