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CENTRE FOR THE
PROMOTION OF
EXCELLENCE IN
PALLIATIVE CARE
INFORMING PRACTICE TRANSFORMING CARE

LOROS
Hospice Care for Leicester, Leicestershire & Rutland

CENTRE FOR THE PROMOTION OF EXCELLENCE IN PALLIATIVE CARE

Informing Practice, Transforming Care

Annual Report 2013-2014

Introduction

The last twelve months have been a time of much ‘building’ for CPEP. New researchers have taken up roles in the centre; we have developed the operational team and set foundations for regular events. We have hosted a national study day for the Association for Palliative Medicine, held a very successful research conference for local nurses and AHPs, and we now have two Professors.

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.

The CPEP operational group has two lay members; a carer and a person with cancer. Both bring considerable talents from past professional lives too, and we wish to acknowledge their valuable input to CPEP in focusing and supporting the work. We have also had a vibrant and energising input from a group of pre-registration nursing students. It is wonderful to see their interest in palliative care and hear their thoughts on influencing the understanding of their peers and the care they provide.

“As a patient it is always good to share a journey with professionals who care, as in CPEP, but particularly so when benefits can come from this association for other people with secondary/terminal illness. I perceive also that the involvement of both De Montfort University (students and lecturers) and LOROS (end of life experts) brings very different perspectives to a combined aim – the improvement of expectations of patients and their carers at a very challenging time. “ Diane Miller, CPEP patient representative.

In this report we showcase activity from the past twelve months. Activity is only one measure of our performance. A key measure for CPEP is how much it is influencing patient care through informing practice. There are some references to this in the individual activities below. 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. One piece of work we are doing is developing the East Midlands Toolkit for evaluation of end of life care learning events to see if reflection by managers of the impact on the learner's practice is a valid form of evaluation.

1. Raising Awareness of Palliative Care

Care and Compassion May 2013

Dr Prasad, the City CCG End of Life Care Lead and Dr Richard Wong, Geriatrician at University Hospitals of Leicester, were asked by CPEP to share their passion for improving end of life care and describe the *Deciding Right: Planning Your Care in Advance* initiative that has begun in Leicester City and across the County. Professor Faull was interviewed on local Radio about the initiative hopefully bringing to a broad audience the concept of thinking ahead about what is important for individuals and their families in care towards the end of life.

An information stand about CPEP and palliative care attracted many people attending the discussion event held by the Faculty of Health and Life Sciences at DMU amongst them a person living with cancer who then came forward to become a member of the operational group. Diane Miller, a retired head teacher had already had a role as a patient spokesperson with Macmillan.

City CCG GP Mentors

Leicester City Clinical Commissioning Group (CCG) together with Macmillan commissioned a programme for improvement in the end of life care provided for their patients lead by Willowbrook GP, Dr Rish Prasad. Four GP’s have been recruited to be mentors to practices in their locality to support them in implementing the locally enhanced service. Professor Faull and the team at LOROS support the GP mentors. Their honorary appointment with CPEP supports a longer-term relationship with both educational and research ambitions.

Some highlights of their work are:

- Near a 238% increase in numbers of patient identified as being in the last year of life and on a GP palliative care register
- Emergency health care plans written for over 1000 patients to help them achieve their preferences at the end of life
- 86% of patient dying in their stated place of preference
- Audit and reflection on 1232 patients who have died in 12 months, compared to 87 in the previous 12 months.

2. Research Activity at DMU and LOROS

People

Dr **Richard Kitchen** is near completion of 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?* to the Palliative Care Congress and is now developing an e-learning education intervention which will be accessed through the LOROS website.

Karen Lord, **Macmillan Clinical Academic Nurse Researcher** was appointed in January 2013. This is a permanent post jointly appointed to the UHL palliative care service and CPEP. Karen is working with Professor Jayne Brown on *Implementation of a relationship centred care model for integration of palliative care - using Mesothelioma as an exemplar, and is* currently seeking funding.

Dr **Lynn Furber, Senior Lecturer at DMU and Nurse Researcher at UHL** has recently been awarded a HOPE Against Cancer research grant to conduct a pilot study: Enhancing consultations in oncology using a consultation tool: A pilot qualitative study. This study continues to enhance a profile of work looking to improve the consultation experience for patients diagnosed with cancer and their doctors. Lynn is also working with a group of researchers from the University of Leicester, University of Nottingham, University of Lincoln and Imperial College London to extend this work further.

Dr **Zoebia Islam** was appointed as **Senior Research Fellow** at LOROS in May 2013 and is an 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 undertaken work on developing mental health services for diverse minority ethnic communities and transition from children's to adult mental health service, which has subsequently led to a European project. Zoebia has become instrumental in developing and delivering the research module on the LOROS/University of Northampton Foundation Degree in Palliative and Supportive Care and is developing research at LOROS on meeting the needs of disadvantaged communities and the transition of young adults in palliative care.

Two **PhD Students** started with CPEP in the autumn, supervised by Jayne Brown. **Helena Dunbar** is the Rainbows Hospice Scholar. Her work is entitled *What are the palliative care needs of children in the East Midlands?* **Getrude Chickura** is exploring the feasibility and acceptability of the 3,2,1 tool in working with families where cancer may be inherited. 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. In addition **Liz Darlison** is completing 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.

A highlight of the year for CPEP was the invitation from DMU for Christina Faull to become an **Honorary Professor in Palliative Medicine.**

Research Conference

In March, CPEP, supported with funding from Macmillan, held a very successful conference entitled *Research into Practice: A Conference for Nurses and Health and Social Care Professions with an interest in Palliative and End of Life Care.*
The aim of the conference was to spread the word about palliative and end of life research being undertaken by nurses and allied health professionals in the region and the difference it is making to care. Over 60 delegates of all types of profession including ward clerks, health care assistants, student nurses, staff nurses, physiotherapists, senior nurses and psychologists attended the conference. There were a good range of presentations from those given by academics such as Professor Jane Seymour of the University of Nottingham, Professor Jayne Brown, and Dr Lynn Furber. Clinical academic Dr Karen Lord also gave a paper as did nurse consultant and Masters student Liz Darlison. Discussion was lively and vital and the feedback from the conference delegates was extremely positive. One delegate explained:
"Today has reasserted that I want to be the best nurse I can be but more importantly, it made me realise that it is possible and if I am determined enough I can get to where I want to be and be actively part of research." This response really summed up what the day was about.

Projects

Completion of ***A baseline evaluation of end of life care in primary care in Leicester City***. The funding allowed recruitment of two part-time researchers. The Primary Care end of life care project in Leicester city, linked with LOROS and CPEP has led to conference poster presentations for primary care both regionally and nationally and at the national UK Palliative Care Congress.

- Transforming health care through clinical template design and training
- Deciding Right: Right Care, Right Plan, Right Patient; An Individualised Approach To Palliative Care
- "Deciding Right" Project, Right Care, Right Plan For the Right Patient

The **EnRICH Project** (**E**nhancing **R**elationships **i**n **C**are in **H**ospital), led by Jayne in collaboration with Sheffield University and University Hospitals of Leicester, is funded by the Burdett Trust for Nursing for 2 years, commencing April 2014. It focuses on improving care for elderly in acute hospital wards and builds on Jayne Brown's seminal work in the SENSES framework (Jayne gave a key note paper on this at Birmingham City University **Enriching lives: A relationship-centred approach to quality care**). Two PhD studentships have been awarded to support the project.

A group of 6 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. Ethical approval has been obtained, a literature review undertaken and the team are currently recruiting participants.

Evaluation of the Trainee Assistant Practitioner (AP) Role was completed in September 2013. This was a collaborative service development project between LOROS and the Leicester Partnership Trust, funded by the Healthcare Workforce Deanery. Findings suggest that both the Hospice and community settings were convinced of the value and utility of the role and are looking to recruit APs as part of their long term staffing but both see a different focus for the role and are not yet ready to embrace the concept of shared posts working across organisational boundaries.

A poster presentation of the findings P*roviding a Seamless Service* was taken to the Help the Hospices Conference in October 2013 and can be viewed at http://www.loros.co.uk/media/uploads/files/research/taps_poster.pdf

Jayne has been disseminating findings from the work based at Nottingham University, the European project on **Sedation at the End of Life**. A poster was taken to the Palliative Care Congress *Nurses' Roles In Anticipatory Prescribing In End Of Life Care* and several papers have been published or await decision:

In press

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* – accepted – 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* – accepted – impact 2.609.

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 – under review – impact 2.649

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

Published

Raus, K., Brown. J., Seale,C., Rietjens, J., Janssens, R, Bruinsma,S., Mortier,F., Payne, S. and S Sterckx, S. (2014) Continuous sedation until death: the everyday moral reasoning of physicians, nurses and family caregivers in the UK, The Netherlands and Belgium. *BMC MEDICAL ETHICS. 15:14 http://www.biomedcentral/com/1472-6939/15/1*. Impact -1.71

Papavasiliou, E.S., Brearley, S.G., Seymour, J.E., Brown, J., Payne, S.A., on behalf of EUROIMPACT (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* published online 08 April 2013. Impact 2.601

Papavasiliou, E., Payne, S., Seymour, J., Brown, J.(2012) Continuous sedation (CS) until death: Mapping the literature by bibliometric analysis*. Journal of Pain and Symptom Management* J Pain Symptom Manage. (Impact Factor2.601)2013 Jun;45(6):1073-1082.e10. doi: 10.1016/j.jpainsymman.2012.05.012. Epub 2012 Sep 29.

Abarshi, E.A, Papavasiliou, E. Prestn, N., Brown, J. Payne, S. EUROIMPACT (2014) May The Complexity of Nurses' Attitudes and Practice of Sedation at the End of Life: A Systematic Literature Review. Journal of Pain and Symptom Management 47(5): 915-925

Christina's work on evaluating an innovation in **developing volunteers to support care of the dying in care homes (VALE)** was taken as a poster to the Help the Hospices Conference and the Palliative Care Congress. Findings indicate that in care homes where residents had used VALE, the service had undoubtedly added value to the care home. As far as can be inferred from the comments of staff and volunteers, VALE was also valued by, and made a difference, to residents and their families. However there are a numbers of obstacles in developing a VALE service for care homes requiring a very responsive service. VALE is not just useful for those residents with no visitors. It is also likely to be needed alongside family visitors and on occasion volunteers may have a very important role in their interaction and support of family. The poster and findings, including the full report, can be viewed at the VALE: Volunteers with Dying Patients in Care Homes section of our website.

Christina is leading 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 are emerging and include international and national conference presentations and the paper:

- Faull C, Rowe-Haynes C, Oliver D. 2013. The issues for palliative medicine doctors surrounding the withdrawal of NIV at the request of a patient with MND: a scoping study. BMJ Supportive and Palliative Care doi:10.1136/bmjspcare-2013-000470

As doctors hear about this project they are contacting Christina for guidance in care, an example 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 will give us new insights into doctor-patient consultations and directly inform our communication skills teaching both through providing an evidence base but also in providing real-life materials for teaching. An oral presentation of the initial work in consulting with stakeholders about the trial design was presented at the national Palliative Care Congress.

Book chapters

Title/ description	Authors
The ‘At a Glance Series: books are intended for students who are visual learners. – Published by Wiley.	
-**Communication skills in palliative care**	Alison Pilsworth, Martyn Geary and Jayne Brown
- Breathing Difficulties	Liz Darlison and Jayne Brown

Summary of Grant seeking activity

Funder	Project	Outcome
HOPE against cancer	Implementation of a relationship centred care model for integration of palliative care - using Mesothelioma as an exemplar	Unsuccessful
HOPE against cancer	Developing a Palliative Care Self-Management Programme: HELP (Help, Education, Learning, Positivity)	Unsuccessful
Roy Castle	Implementation of a relationship centred care model for integration of palliative care - using Mesothelioma as an exemplar	Unsuccessful
Dimbleby Cancer Care	Developing a Palliative Care Self-Management Programme: HELP (Help, Education, Learning, Positivity)	Unsuccessful
NIHR RfPB	Thinking ahead in dementia care	Awaited

Marie Curie Cancer Care	Improving nurses' symptom related ethical decision making in the last days of life: an educational intervention study in 4 sites	Outline successful full application may 2014
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)	Outline successful full application may 2014
Association for Palliative Medicine	Decision making with frail patients with surgical problems	Unsuccessful

3. Education Activities

University Certificate in Continuing Professional Development (UCPD) End of Life Care

Unfortunately, since April 2014 this programme is no longer funded under the Learning Beyond Registration contract. Combined with the fact that extremely low numbers of people applied to undertake either of the two modules which comprise the award, LOROS and DMU have decided no longer to run the programme. This is particularly disappointing in light of the evaluations undertaken using the evaluation toolkit from the last Fundamentals in Palliative Care module. Attendees at the course reported higher levels of confidence in issues relating to end of life care immediately after attending the course. Whilst all the competences show high percentage improvements, the symptom management competency shows the highest percentage improvements in scores at 32.5%. Some of the comments from students include:

"I will be able to put all areas of my new found knowledge into my area of work and share this with my colleagues."

“This has been very helpful in understanding myself and my own practice and how to be more effective in the palliative care process with my patients.”

The reason for the low numbers of applications over the last year is difficult to assess. There is a 15 credit degree level module offered by DMU as part of the BSc (Hons) Health and Professional Practice programme which addresses similar areas of content. It is possible that practitioners have chosen to undertake that module as opposed to the 30 credit equivalent with in the UCPD End of Life Care programme,

Masters level learning

The MSc Palliative Care was validated in January 2010. Students can pursue the full 180 credit programme or, if they wish, opt to take individual 15 or 30 credit modules up to a maximum of 45 credits on a Continual Professional Development (CPD) basis. During the academic year 2013-2014 fourteen students actively pursued one of the two routes with the vast majority enrolled on the full MSc programme. Seven people exited the programme with either institutional credits for CPD modules, a Postgraduate Certificate or Postgraduate Diploma in Palliative Care. The flexibility afforded by the programme means that all these individuals could return to the programme if they so wished to accumulate further module credits to achieve the full MSc award. The backgrounds of individuals continue to be extremely diverse which adds greatly to the quality and depth of learning fostered by the programme. A number of General Practitioners have attended the programme over the last year as well as Specialist Nurses in Palliative Care, Community Nurses, Occupational Therapists and practitioners working with teenagers and young adults.

The next year looks to be even busier. A number of people are currently applying to begin the programme in September 2014 and four current students will move into their final 60 credit dissertation module.

National Study Day

CPEP hosted a national study day for the Association for Palliative Medicine of Great Britain and Ireland *Addressing the challenges in care needs of teenagers and young adults.* The conference, attended by 35 people, was a successful opportunity for adult and paediatric palliative care services to discuss the growing challenges of children with life limiting disease living in to young adulthood.

CPEP awards for Excellence in Palliative Care

The Royal College of Nursing have agreed to support a CPEP preregistration award for excellence in palliative care nursing. LOROS has endowed an award for post-registration/graduate excellence. The first awards are intended to be made in 2014.

Looking Ahead

CPEP needs to consider its role in the strategic plan for DMU as a truly international university, building influential global relationships to enrich our research, teaching and cultural collaborations.

We are honored that Professor Irene Higginson, internationally renowned researcher in Palliative Care and Director of the Cicely Saunders Institute at Kings College London, will be giving a ‘distinguished lecture’ at DMU on November 12th. Her title ***Hospices & Universities Working Together: Does it raise the game? Reflections from Creating the Cicely Saunders Institute*** will hopefully inform the thinking of both the CPEP operational group and LOROS and DMU as to the ambition, potential and strategy for CPEP.

This report was written by the CPEP Operational Group, June 2014.

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