



End of life care & practitioner development and wellbeing

BPOS 2015 Annual Conference
Thursday 19th & Friday 20th March 2015
Rose Bowl Building, Leeds Beckett University



WILEY

Welcome

A very warm welcome to Leeds Beckett University for our 2015 Annual Conference. We have a diverse and engaging range of high-quality oral and poster presentations from research groups in the UK and Canada. We also have three excellent keynotes speaking on the conference themes of end of life care and practitioner development and wellbeing, as well as difficult-to-choose-between parallel workshops on acceptance and commitment therapy and challenging clinical issues and decisions in end of life care. I hope you find this year's conference informative, thought-provoking, and value for money.

I would like to say several Thank Yous. Firstly, I would like to thank the BPOS Executive Committee for helping to organise and host this conference, and our Scientific Committee (Iain Lawrie, Eila Watson, Lorraine Warrington & Melissa Pilkington) for peer-reviewing all submitted abstracts. Secondly, I would like to thank the Leeds Beckett Psychology students who have kindly volunteered to help steward the conference: Sarah Asquith, Mollie Price, Fiona Brook, Amy Toynton & Joseph Kilbride. Thirdly, I am very grateful to our keynote speakers and workshop facilitators for taking time out of their busy schedules to contribute to our conference: thank you to Mike Bennett, Stephen Barclay, Max Henderson, Nick Hulbert-Williams, Iain Lawrie, Lynne Russon, Chris Hosker, Adam Hurlow, Janet Holt & Stephen Evans. Finally, I would like to thank all our delegates for choosing the BPOS conference to disseminate their work and keep up-to-date with colleagues' work.

We will be holding the BPOS Annual General Meeting at 11:45am on Friday 20th March. Whether you are a BPOS member or not, please do come along to find out what we have been doing over the past year and how you can get more involved, and to give us your feedback.

I look forward to meeting and catching-up with many of you over the next couple of days.

Dr Laura Ashley, BPOS Chair



Keynote Presentations



Professor Mike Bennett is the St Gemma's Professor of Palliative Medicine and works clinically as a Consultant at St Gemma's Hospice in Leeds. He is based at the Academic Unit of Palliative Care at the University of Leeds since his appointment in 2011. His main research interests are in pain management in advanced disease, and evaluating decision making and interventions at the end of life.

Mike trained in internal medicine and pain management in Birmingham and Leeds (awarded FRCP & FFPMRCA) before becoming Clinical Senior Lecturer in Leeds 1997–2007. After winning a Churchill Fellowship in 2006, Mike spent time in Houston, USA and in Edmonton, Canada observing academic palliative medicine, before moving to Lancaster University to become Professor of Palliative Medicine (2007–2011).

Mike has been Cochrane Field Editor for palliative and supportive care, has chaired the National Cancer Research Institute palliative care studies group from 2008 and has chaired scientific and organisational committees for several research congresses of the European Association for Palliative Care (EAPC). He chairs the Cancer Pain Committee for the International Association for the Study of Pain (IASP).

In his keynote presentation, Mike will talk about research-based commissioning for palliative and end of life care.

In this lecture I will describe what patients and carers want at the end of life, the evidence that supports the effectiveness of palliative care services, and then the current picture in Leeds in relation to access to services. I will show how research at the Academic Unit of Palliative Care aims to influence commissioning and service provision to improve end of life care, particularly regarding management of pain.



Dr Stephen Barclay is HEFCE Clinical Senior Lecturer in General Practice and Palliative Care, and General Practitioner and Honorary Consultant Physician in Palliative Medicine. Stephen's pre-clinical training was in Cambridge and his clinical training in Oxford, from where he qualified in 1981. After GP training in Bristol he started GP work in a market town practice in the Cambridgeshire Fens and then in 1990 moved to a GP practice in Cambridge. He continues to work clinically in General Practice. He has worked clinically in the Arthur Rank House Hospice in Cambridge since 1995, and was appointed as Honorary Consultant Physician in Palliative Medicine in 1996.

Funded by a NHS R&D Health Services Research Training Fellowship 1998 – 2001, he undertook the City University MSc course in Advanced Social Science Research Methods and Statistics. His 2005 MD thesis from the University of Cambridge "General Practitioner provision of Palliative Care in the United Kingdom" was awarded the Ralph Noble prize. In 2006 he was awarded a Department of Health / Macmillan Post-Doctoral Research Fellowship, leading a programme of research "Towards an intervention to optimise Primary Palliative Care: identifying patients and understanding their preferences."

He has been Clinical Lead for the Cambridge and Peterborough CCG (previously Cambridgeshire PCT) since 2009, and is currently Clinical Lead for the Cambridge and Peterborough Palliative Care Coordination System. He is deputy Chair of the NIHR Research for Patient Benefit East of England funding committee. He is a member of the national Macmillan MACPACC research collaborative, GP Advisor to NICE on Palliative Care in QOF and was a member of the 2012 NICE Topic Expert Group that developed Quality Standards for End of Life Care in the NHS. In 2011 he was appointed HEFCE Clinical Senior Lecturer in General Practice and Palliative Care, and continues to lead a programme of research and teaching.

In his keynote presentation, Stephen will explore the rhetoric-reality gap of palliative care policy and practice.

This presentation is designed to stimulate debate and discussion. Issues to be addressed include: how important is place of death to patients? How involved do GPs want to be in palliative care, and how adequate is their knowledge-base? How appropriate is the current focus on "avoidable and inappropriate" hospital admissions close to the end of life? How patient-centred is the emphasis on encouraging patients to hold more open conversations about the end of life? It will conclude by asking the questions "What do we mean by palliative care?" and "Who are our Palliative Care patients?" So come prepared to be provoked and challenged, to disagree, and above all to think about these contested issues!



Dr Max Henderson is a Senior Lecturer in Epidemiological and Occupational Psychiatry, King's College London.

In his keynote presentation, Max will talk about work and mental health in health professionals.

We know that working in the health service can be tough. But can this lead to mental ill health? And if so what are the risks, what is the impact and what can we do about it? In this session I will describe the prevalence of mental disorders in health professionals, and what risks that presents not just to them but to the wider health service. I will briefly describe the evidence based models linking work and mental illness and what their limitations are, but show that "stress at work", "burnout" and are less helpful. I will look at whether there are specific risks to working in the healthcare sector, and in cancer and end of life care in particular. Using examples from our service in London, the Practitioner Health Programme, I will describe strategies we can consider to optimise the health of health professionals, at the individual, team and organisation level. I will argue that we need to look at this at the policy level too, and why now is an excellent time to do this. Finally I will consider how we can translate lessons learnt for health professionals to enhance overall outcomes for our patients and their families.

Workshops

Acceptance and Commitment Therapy (ACT): an experiential introduction to the framework and its relevance for cancer care

Dr Nick Hulbert-Williams

Acceptance and Commitment Therapy (ACT) is an evidence-based, psychological intervention which is gaining in popularity and reputation. One of the 'third-wave' therapies, ACT builds on earlier principles of Cognitive Behavioural Therapy (CBT), but draws more heavily on the behavioural psychology theories of Relational Frame Theory (RFT) and functional contextualism. In comparison with CBT and other similar models, ACT provides a fundamentally different perspective of psychological wellbeing, placing distress and suffering as normal responses to significant life events, and not as something unusual, or to be 'fixed'. It focusses far less on challenging problematic thoughts, and instead aims to build psychological flexibility. Although not yet widely used in cancer settings, there is a growing appreciation for why this model might be more appropriate to the needs to cancer patients, and a growing evidence base for its effectiveness within this patient group. In this experiential workshop, I will provide participants with a hands-on, brief introduction to the ACT framework. Though not a comprehensive training, we will cover all six core components of the ACT model-- mindfulness, acceptance, cognitive defusion, self-as-context, values and committed action--to give you a full appreciation of the nature and scope of the intervention and how it might apply within the oncology setting.

Nick is a Coaching Psychologist and Reader in Psychology at the University of Chester (UK) where he Directs the Chester Research Unit for the Psychology of Health (CRUPH). Nick has been researching the psychological impact of cancer diagnosis and treatment, and the consequences for both patients and their family members, for the past 10 years. He is currently leading a programme of work dedicated to developing clinically and cost effective interventions for cancer patients, the focus of which is primarily on 'third-wave' interventions such as Acceptance and Commitment Therapy (ACT). Nick has received extensive training in ACT and is currently working with colleagues in CRUPH and one of the founders of ACT to develop a framework for Acceptance and Commitment Coaching. Nick is past Chair of the British Psychosocial Oncology Society (BPOS), is a member of the UK National Cancer Research Institute Psychosocial Oncology and Survivorship Clinical Studies Group, sits on the editorial board of the European Journal of Cancer Care, and is a member of the International Psycho-Oncology Society Research Committee. He is a member of the Professional Advisory Board for 'Maggie's Centres', a UK Charitable Trust dedicated to providing holistic psychosocial care to those affected by cancer.

Panel Debate: Challenging clinical issues and decisions in end of life care

Chair: Dr Iain Lawrie, Consultant and Honorary Clinical Senior Lecturer in Palliative Medicine, The Pennine Acute Hospitals NHS Trust / The University of Manchester

Panel

- **Dr Lynne Russon, Consultant in Palliative Medicine, The Leeds Teaching Hospitals NHS Trust**
- **Dr Chris Hosker, Consultant in Liaison Psychiatry Service, The Leeds Teaching Hospitals NHS Trust**
- **Dr Adam Hurlow, Consultant in Palliative Care, The Leeds Teaching Hospitals NHS Trust**
- **Dr Janet Holt, Registered Nurse and Senior Lecturer, School of Healthcare, University of Leeds**
- **Stephen Evans, Partner, Hempsons (Health and Social Care Lawyers), Harrogate**

The panel debate will cover the following topics:

1. DNACPR (do not attempt cardiopulmonary resuscitation): what do patients and families need, want and have a right to know?
2. How far should we go to honour patient requests for treatment of limited benefit late in life?
3. Euthanasia and assisted dying

It is expected that delegates will come with questions to put to the panel and join in the debate.

General Information

Venue

Floor 4 of the Rose Bowl building, Leeds Beckett University

The main conference room: 408

Two rooms for poster viewing: 407 & 463 (these rooms are opposite each other)

Workshop rooms: 412 (ACT) & 408 (panel debate)

Tea/coffee breaks and lunch: served in 412

BPOS AGM: 408



Main entrance



Back entrance

The Rose Bowl

Leeds

LS1 3HB

Local taxi company is Amber Cars: 0113 2022117

Conference dinner

The Restaurant Bar & Grill

The Old Post Office, 3 City Square

Leeds

LS1 2AN

A 10-15 minute walk from the Rose Bowl and 1-2 minutes from the train station

Oral presentations

Please ensure that presentations are uploaded onto the computer in room 408 before the start of each session. Speakers have 12 minutes for their presentation, followed by 5 minutes for questions.

Poster presentations

All posters can be put up from 8:30am onwards on Thursday 19th March and should be removed during the final tea/coffee break on Friday 20th March. Posters have been allocated a number (see Posters section further on in the programme). Posters will be available for viewing during tea/coffee and lunch breaks and during the pre-dinner drinks (see programme overview, next page).

Workshops

The 2-hour workshops will run in parallel. Please choose one of the two to attend – you do not need to choose in advance.

Photographs

We will be taking photographs throughout the conference. These may be used by BPOS and Leeds Beckett University for publicity purposes (e.g. in newsletters, on websites). If you object to your photograph being taken and used in this way, please inform the conference stewards.

Queries

If you need assistance with anything during the conference, please don't hesitate to ask our conference stewards: Sarah Asquith, Mollie Price, Fiona Brook, Amy Toynton and Joseph Kilbride.

Programme Overview

Thursday 19th March

- 09:00 **Registration and Tea/coffee**
- 10:15 **Welcome** (Laura Ashley)
- 10:30 **Keynote: Professor Mike Bennett** (Chair: Eila Watson)
Research-based commissioning for palliative and end of life care
- 11:30 **Tea/coffee**
- 11:45 **Oral Presentations: Survivorship needs, outcomes and interventions** (Chair: Sue Williamson)
1. Morven Brown, Mark Pearce, Simon Bailey, Roderick Skinner
The long-term psychosocial impact of cancer – the views of young adult survivors of childhood and adolescent cancer
 2. Eila Watson, Emma Frith, Beth Shinkins, Peter Rose
Quality of life, unmet needs and psychological morbidity in prostate cancer survivors: implications for redesigning follow-up
 3. Abigail Albutt, Louise Wem, Lisa Copeland, Peter Gardner, Galina Velikova, Patricia Holch
Individual-based vs group-based psychoeducation sessions for breast cancer survivors following radiotherapy: impact on health-related quality of life and self-efficacy
 4. Brooke Swash, Ros Bramwell, Nick Hulbert-Williams
Unmet psychosocial needs and their psychological impact in haematological cancer survivors
- 13:00 **Buffet Lunch, Poster Viewing & Networking**
- 14:15 **Workshops** (choice of two)
1. Acceptance and Commitment Therapy (see page 6)
 2. Panel Debate: Challenging clinical issues and decisions in end of life care (see page 7)
- 16:15 **Tea/coffee**
- 16:30 **Keynote: Dr Stephen Barclay** (Chair: Iain Lawrie)
The rhetoric-reality gap of palliative care policy and practice
- 17:30 **Poster Viewing, Networking & Pre-Dinner Drinks**
- 20:00 **Conference Dinner** at The Restaurant Bar & Grill, Leeds City Centre

Friday 20th March

08:30 **Registration and Tea/coffee**

09:15 **Keynote: Dr Max Henderson** (Chair: Annabel Price)

First look after our own: work and mental health in health professionals

10:15 **Oral Presentations: Lesser heard voices and issues** (Chair: Carey MacDonald-Smith)

1. Nick Hulbert-Williams, Catrin Plumpton, Rhian McHugh, Joanna Semlyen, Paul Flowers, Lesley Storey, Emma Ream, Richard Neal

What are the experiences of cancer care in gay, lesbian and bisexual patients, and how do these differ from heterosexual cancer patients?

2. Carolina Casañas i Comabella, Mary Boulton, Eila Watson, Bee Wee

Distance caregivers in palliative care: a hidden population with specific needs

3. Samantha Flynn, Nick Hulbert-Williams, Lee Hulbert-Williams, Ros Bramwell

Cancer experiences in individuals with an intellectual disability: results from a grounded theory study

4. Simon Pini, Siobhan Hugh-Jones, Peter Gardner

The education engagement, coping and well-being of teenagers with cancer

5. Beverly Horne, Fiona Kennedy, Kate Absolom, Simon Pini, Julia Brown, Galina Velikova

Exploring sexual function assessment through cognitive interviews with cancer patients in REPORT-UK (Real-time Electronic Patient Outcome Reporting of adverse events in UK cancer trials)

11:45 **BPOS Annual General Meeting (AGM) & Tea/coffee**

12:30 **Buffet Lunch, Poster Viewing & Networking**

13:30 **Oral presentations: Health care professionals' roles, skills and education** (Chair: Chris Hosker)

1. Janet Ellis, Sana Haddad, Kaitlin McGarragle, Dong-Hyun Yoon, Rachel Ehrlich, Jeff Myers, Yaseen Al-Allaq, Michael Hawkins, Margaret Fitch, Paul Karanicolas

Examining the impact of ESAS screening on patient outcomes

2. Lucy Grant, Sara Lister, Theresa Wiseman

The development of an educational program for healthcare professionals to improve supportive care when a parent has cancer

3. Ana Martins, Susie Aldiss, Faith Gibson

'It's like a relationship, a trust, and that's what we've got with the key worker'

4. Peter Branney, Karl Witty, Alan White, Kate Bullen

"I suspect that they knew [I had penile cancer]": reflections on health professionals by men diagnosed and treated for penile cancer

5. Claire Stewart, Stephanie Archer

The curriculum vs reality: discrepant discourses in palliative care experience, education and training

15:00 **Tea/coffee**

15:15 **Conference Awards & Closing Remarks**

15:30 **Close of Conference**

Posters

- 1. *Psychological well-being in carers of someone with cancer: a process review***
Jenny Young, Austyn Snowden
- 2. *A mixed-methods evaluation of anxiety in prostate cancer patients: neo-adjuvant hormones and radical radiotherapy***
Sarah Thomason, Santhanam Sundar, Heather Buchanan
- 3. *Developing a system for cancer patients to report symptoms and side-effects of treatment online (eRAPID): Patient experiences from a usability study***
Lorraine Warrington, Kate Absolom, Patricia Holch, Andrea Gibson, Beverley Horne, Robert Carter, Leon Bamforth, Galina Velikova
- 4. *Consider Levitiracetam as a potentially reversible cause of significant fatigue in patients with a stable primary brain tumour***
Julia Day, Harriet Ingle, Sharon Tuck, Sara Erridge, Sharon Peoples, Robin Grant
- 5. *Eating As Treatment: a stepped wedge multi-centre trial of a psycho-nutrition intervention to improve outcomes in head and neck cancer patients undergoing radiotherapy***
Ben Britton, Amanda Baker, Judy Bauer, Luke Wolfenden, Chris Wratten, Patrick McElduff, Gregory Carter
- 6. *Supervised exercise for older women treated for breast cancer. Preliminary results from a pilot randomised controlled trial***
Kevin Kipling, Serena McCluskey, Marilynne Kirshbaum, Ged Garbutt, Daniel Boduszek
- 7. *Illness representations and psychological wellbeing in cancer patients and survivors: a systematic review of prospective and interventional studies***
Samantha Carruthers, Louise Bryant, Laura Ashley
- 8. *"You're actually mourning a loss": breast cancer patients' experiences of a camouflage based support service for treatment-related hair loss***
Melissa Pilkington, Nichola Rumsey, Daryl O'Connor, James Brennan, Diana Harcourt
- 9. *RESTORE: an exploratory RCT of a web-based intervention to enhance self-efficacy to self-manage cancer-related fatigue: findings from a qualitative process evaluation***
Michelle Myall, Carl May, Chloe Grimmett, Lynn Calman, Alison Richardson, Christine May, Claire Foster
- 10. *The AVALPROFS study: Assessing the VALue of PROgression Free Survival***
Susan Catt, Valerie Jenkins, Lucy Matthews, Mairead McKenzie, Jackie Garth, Lesley Fallowfield
- 11. *An exploratory study of Reiki experiences in women living with cancer***
Maxine Stead, Marilynne Kirshbaum, Serena McCluskey

- 12. *Developing and piloting a questionnaire to investigate important psychosocial outcomes in survivors of childhood and adolescent cancer***
Morven Brown, Mark Pearce, Roderick Skinner
- 13. *Instruments to record acute and late adverse events (AE) associated with radical prostate cancer treatment for remote monitoring in clinical practice: A systematic review of randomised controlled trials (RCT)***
Patricia Holch, Ann Henry, Kevin Franks, Susan Davidson, Jacki Routledge, Leanne Shearsmith, Alex Gilbert, Emma Ingleson, Abigail Allbut, Galina Velikova
- 14. *Predictors of distress in lung cancer patients: a systematic review***
Rhian McHugh, Margaret Cousins, Nick Hulbert-Williams
- 15. *Caring for cancer patients with an intellectual disability: attitudes and care perceptions of UK oncology nurses***
Samantha Flynn, Debbie Stevens-Gill, Ros Bramwell, Lee Hulbert-Williams, Nick Hulbert-Williams
- 16. *The relationship between changes in ESAS and corresponding changes in health-related quality of life***
Janet Ellis, Kaitlin McGarragle, Sana Haddad, Dong-Hyun Yoon, Rachel Ehrlich, Jeff Myers, Yaseen Al-Allaq, Michael Hawkins, Margaret Fitch, Paul Karanicolas
- 17. *Advanced cancer and sexuality - the hidden dilemma***
Miriam Coleran, Declan Walsh, Eileen Mannion, Dymphna Waldron
- 18. *Exploring the understanding, perceptions and experiences of palliative care amongst women with advanced gynaecological cancer***
Claire Stewart, Stephanie Archer
- 19. *Communication in advanced cancer care: designing a video-based research study***
John Curtin, Helen Walthall, Bee Wee, Eila Watson
- 20. *Fatigue in advanced cancer: why is it under-reported and poorly managed?***
John Curtin, Helen Walthall, Bee Wee, Eila Watson
- 21. *An exploration of gender differences in posttraumatic growth in survivors of colorectal cancer***
Katie Redwood, Kate Jenkins, Catherine Brignell
- 22. *"We feel forgotten and feel like we represent the lack of hope. When we are remembered, we are recognized as losing the battle": A focus group study of the experiences of women diagnosed with secondary breast cancer and their psychosocial support needs***
Ann Baker, Ceri Phelps



Follow us on Twitter @BPOSUK

www.bpos.org