

Abstracts: Improving end-of-life care in the 21st century symposium

SESSION I IMPROVING END-OF-LIFE CARE FOR ALL

Chairman: Professor Scott A Murray, St Columba's Hospice Chair of Primary Palliative Care, University of Edinburgh, Scotland, UK

Illness trajectories at the end-of-life: implications for improving clinical care

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Abstract

Background What matters in the care of persons who are living with eventually fatal chronic illnesses is certainly not just their current status – what matters most is their experience over time. Much of 'end-of-life' care standards and practices have arisen from the assumption that affected patients are distinct from others and that their course is fairly uniform decline.

Methods or theme A better concept might well be to use the population segmentation approach that successful businesses use to tailor products to their clientele. Building on observations about the predictability of the timing of death and the clinical needs of people in various situations, we have split the population as a whole into segments, including characterizing the populations coming to the end of life.

Results We proposed eight population segments for tailoring care, and three of these focus upon people coming to the end of life. Those population segments have differing priorities for care, which dictates different quality measures, payment approaches, and modes of delivery of care. The three trajectories for those coming to the end of life include (a) a brief progressive course of decline, typical of cancer, (b) a crisis and relapsing course, typical of heart failure and emphysema, and (c) a long dwindling course, typical of frailty and dementia.

Conclusions Recognizing the course of individuals over time allows conceptualizing categories that serve to organize patient care better than our common use of diagnoses or settings of care.

References

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Gold Standards Framework of care in primary care

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Abstract

Background Findings from Gold Standard Framework Scotland. Lessons learned for patients and carers, clinicians, services and future policy in Scotland. Identification of patients wrt 3 illness trajectories. Assessment of need – linked to patient and carer experience. Service – developments and barriers. Opportunity in Scotland wrt policy.

Methods or theme Extrapolating impact on patient and carer of disease, service provision and holistic impact along the three trajectories. Current situation following GSFS project – with regard to recommendations, policy and practice. Data from GSFS giving indication of how well co-ordinated palliative care services in the community can avoid crises, anticipate and meet need.

Conclusions Palliative and end of life care requires well co-ordinated cross-boundary services with an informed and involved family.

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- 5 ISD statistics. Long-Term Condition Steering Group
- 6 Cancer Care Research Centre. *Phase 2: Patient experience research (late 2005-March 2006)*. University of Stirling
- 7 Scottish Public Services Ombudsman (SPSO) reports

Sponsors None.

Declaration The author has declared a current personal/non-specific research interest in the Cancer Care Research Centre at the University of Stirling.

Care of the dying: the challenges in implementing end-of-life pathways

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Abstract

Background The Liverpool Care of the Dying Pathway (LCP) has been developed to transfer best practice from hospice into acute hospital settings. The LCP has been adapted for use in the community, nursing home and hospice settings have also been developed. The LCP is used as a framework of care and documentation in the last hours and days of life and is initiated when the patient enters the dying phase. It contains three sections, initial assessment, ongoing care and care after death. The LCP framework is part of the Department of Health 'end-of-life' initiative and is currently being disseminated throughout the UK. Collaborations with a number of European countries have been established to translate and implement the LCP.

Methods or theme A major development in England has been the undertaking of a National Audit Care of the Dying – Hospitals. The audit has included more than 60% of hospital trusts and forms a major component of a National Continuous Quality Improvement Programme in care of the dying.

Conclusions This paper will overview care of the dying and the challenges including benefits and pitfalls in implementing end-of-life pathways.

References

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- 2 www.mcpcil.org.uk

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Declaration No conflict of interest declared.

SESSION 2 SYMPTOM MANAGEMENT

Chair: Dr Ilona Shilliday, Consultant Nephrologist, Monklands Hospital, Airdrie, UK

Nausea & vomiting – 'popper and parachutes'

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Abstract

Background Traditional consensus-based guidelines for management of nausea and vomiting in advanced cancer are based on the neuropharmacology of the emetic pathways.¹ Evidence supporting their clinical efficacy in palliative care is sparse^{2,3} and alternative approaches have been suggested, which may be equally effective.⁴

Methods or theme Many of the drugs used in the management of nausea and vomiting are old drugs. The rapid growth in knowledge of neurotransmitter receptors over recent years has left many gaps in our knowledge of the drugs used, which may partly explain the modest success of current guidelines. In order to develop better management guidelines and to assess the place of newer treatments, an understanding of our knowledge gaps is required as well as a re-appraisal of old evidence.⁵

Evidence from relevant clinical trials is sparse, and there is a bias of published evidence towards newer drugs, funded by pharmaceutical companies. Basing management primarily on the availability of published evidence from clinical trials may be equally inappropriate.⁶

This overview of the management of nausea and vomiting in palliative care will critically appraise some of these issues, and encourage a balanced approach to management, taking into account laboratory evidence, clinical trial evidence, case-report and anecdote.

References

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- 6 Smith G, Pell JP. Parachute use to prevent death and major trauma related to gravitational challenge: systematic review of randomised controlled trials. *BMJ* 2003;**327**:1459–61

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Symptom control in patients with renal impairment and end-stage kidney disease. Which symptoms? Which drugs? Which doses?

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Abstract

Background Many palliative care patients have impaired renal function; these plus those with end-stage-renal-disease (ESRD) have altered handling of many drugs. This can lead to inadequate treatment of symptoms, especially pain through fear of prescribing and toxicity due to the effect of drug handling on renal failure.

Methods or theme The measurement of renal function through creatinine is crude and underestimates impairment; the introduction of eGFR reporting has improved the situation. Guidelines for drug dosing in ESRD are helpful but must be regarded with caution. The spectrum of renal impairment discussed varies from mild, though acute renal failure to both the dialysed and non dialysed patient with ESRD. Pain and other symptoms are common and significant in the ESRD population. Prescribing to relieve these must take into account the effect of renal failure on drug handling and treatment must be monitored carefully for toxicity.

The principles of the WHO analgesic ladder can be used for pain management, but modifications are necessary and no single drug has ideal characteristics; step 3 opioids will be discussed in detail. For non-pain symptoms, choice of therapy will depend on many other patient factors in addition to evidence for efficacy. Drugs to be avoided or modified will be identified.

Conclusion Factors affecting treatment decisions include: severity of the symptom, toxicity of the drug, prognosis, co-morbidity, size and age of the patient, their preference and other medication. Methods to reduce toxicity include use of short acting/normal release preparations and titration for the individual with close monitoring. Drug doses may be reduced or the dose interval increased.

References

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**SESSION 3
WHAT'S BEST FOR PATIENTS?**

Chair: Dr Patricia Cantley, Consultant Physician, Medicine for the Elderly, Lothian University Hospitals Division, Edinburgh, Scotland, UK

Narratives at the end of life

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Abstract

Background In a paper entitled *Patient stories, narratives of resistance and the ethics of humane care*, Eliot Mishler tells this story: 'A woman diagnosed and treated for breast cancer had a recurrence several years later and was briefly hospitalized for further treatment. Much to the distress of the Resident assigned to her, she refused the pain medication he prescribed although she was experiencing persistent pain. He was insistent and kept pressuring her. She tried explaining to him that the medication dulled her ways of thinking, experiencing and responding and she wished to stay alert to what was happening to her and able to relate to family members and friends. He was angry with her and referred to her as a difficult patient in his notes on her chart.'

She learned about this from ward nurses who had their own difficulties with the Resident. Acting as patient advocates, a role that nurses often adopt, they took her side in this argument. Her daughter-in-law, another ally, brought her a small, rubber doll dressed in a doctor's white coat with an attached stethoscope. They treated the doll as a ritual object, sticking pins into it as if, through their actions, they could ward off danger. The doll and their ritual practice also appeared in the chart, an item inserted without comment by the nurses who knew full well that the Resident would see it.'

Methods or theme A story is subjective, image-rich, action packed, and laden with emotion. It conveys the illness experience in context. It depicts heroes, villains, and fools. It suggests meaning and motive in a sequence of actions. It fuels the moral imagination. Above all, a narrative invites an interpretation – from which there is always much to learn, perhaps especially when we don't agree what the story means. This presentation will 'show rather than tell' how narrative analysis can help us in end-of-life care by talking through this story, hopefully with much audience participation and discussion.

Sponsors None.

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Challenges of high quality end-of-life care in care homes (nursing)

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Abstract

Background Over the last ten years policy changes for the care of older people have meant that 23% of older people aged 65 years or older will die in a care home in the UK.¹ However, research has shown that staff in independent care homes (nursing) are isolated from innovation in palliative care.^{2,3}

Methods or theme The Bridges Initiative (1999–2004) was a five-year action research study funded by St Columba's Hospice, Edinburgh, undertaken to try to bridge the gulf between hospice and care homes.^{2,4}

Although there are many positive aspects for being cared for in a care home (nursing) in the last year of life, there are also challenges. Three main challenges are highlighted: living–dying continuum; a pervading culture of functional rehabilitation; isolation and lack of good role models and training around palliative care. An intervention study to address these challenges involving care homes (nursing) in Midlothian will be highlighted.

Conclusions Although demographics are often highlighted as the challenge facing us in the end-of-life care of older people, Philp would argue it is the ignorance and prejudice among practitioners and the general public that is the greater issue 'failing to apply evidence to develop best practice and failing to spread good practice'.⁵

References

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SESSION 4 PUTTING IT INTO PRACTICE

Chair: Dr Kirsty Boyd, Consultant in Palliative Medicine, Royal Infirmary, Edinburgh, Scotland, UK

Do Not Attempt Resuscitation (DNAR) discussions – when and how to discuss

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Abstract

Background In 2006 NHS Lothian¹ implemented the first fully integrated guidelines and documentation for DNAR decisions enabling all healthcare settings to have a consistent approach to this sensitive and potentially distressing issue. These guidelines are in line with the newly revised national guidance on decisions relating to CPR² and they also present the opportunity for patients to have their DNAR forms at home with them to ensure end-of-life care wishes are adhered to even when emergency services are involved.

Methods or theme Implementation of these local guidelines have raised the profile of the need for DNAR discussions and highlighted the fact that many doctors and nurses feel ill-equipped to embark on such discussions. International literature confirms that this is a widespread concern that undergraduate and postgraduate training has so far failed to address as there are still many perceived barriers.³

National guidance promotes respect for patient autonomy and human rights, but the traditional view of patient autonomy may not serve the needs of most patients and their families in end-of life care decision making and this can be confusing for the healthcare professional.⁴ DNAR discussions should be placed within the context of individual patients' end-of life care goals and wishes.

Conclusions Discussions about DNAR decisions must be a core communication skill for every doctor and nurse as an essential part of improving end-of life care for patients in all areas of today's healthcare system. An individualized approach is key, but there are also some general techniques that can be helpful.

References

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Putting it into practice – three illness trajectories

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Abstract

Background Patients with an advanced illness can present with complex clinical problems that require careful, individualised management. We will present three challenging case histories reflecting the cancer, heart failure and stroke illness trajectories to our expert panel and audience for discussion. Symptom control in metastatic cancer and in heart disease will be covered along with ethical issues such as use of implanted defibrillators, deciding when interventional therapies may be of benefit in advanced disease, and feeding for patients with a severe stroke.

Sponsors None.

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