

Research Update

Newsletter of the Northern Ireland Hospice & University of Ulster Research Committee

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Welcome to the second edition of the Northern Ireland Hospice and University of Ulster Research Committee's Newsletter. As you are aware, palliative care (PC) concentrates on improving quality of life rather than cure with its emphasis on multi professional medical, nursing, allied health, emotional, social and spiritual care.

However, research has uncovered negative perceptions of palliative care among health and social care professionals and an unwillingness to accept palliative care until the very end of life, when its capacity to make a difference to patients and families is severely restricted.

Our work with people with advanced non-malignant conditions and their carers confirms that many people see palliative care as 'the end.' They may put off or refuse an otherwise appropriate referral to specialist care, until the symptoms have been very advanced, simply because of these negative perceptions which can be a serious barrier to good palliative care, despite the evidence that most patients with chronic neurological disorders, need to be looked after by a multidisciplinary team that includes a general practitioner, a neurologist, a geriatrician, pharmacists, specialist nurses, and physiotherapists (Kale and Menken, 2004, Giles and Miyasaki 2009).

Such negative perceptions about palliative care need to be addressed through a concerted action to educate professionals, patients and the public about the role of palliative care in the more advanced stages of disease.

Until we as researchers, educators, clinicians, carers and people with advanced diseases address these negative perceptions, patients and families will continue to be denied the benefits of advanced symptom control as well as social, emotional, spiritual and other vital aspects of care, which can have a transformational impact not just on the last 48 hours of life but on the whole disease journey.



Projects

Current Projects

Palliative Care Needs of People with Parkinson's Disease, (Prof George Kernohan)

Specialist Palliative Care and Learning Disability Service: promoting collaborative working, (Dorothy McLaughlin)

Involvement in the soon to be established All Ireland Institute of Palliative Care Research and Education, (Dr Max Watson)

Organisation of Palliative Care across boundaries, (Dr Sonja McIlpatrick)
Overview of Interventions for Managing Fatigue & Weight Loss in Adults with Advanced Progressive Illness (Cathy Payne)

Assessment of Patient Centredness in the Clinical, Administrative and Cultural Life of a Hospice In-Patient Unit, (Dr Sonja McIlpatrick & Prof George Kernohan)

NCRI trial development into the use of Melatonin in patients with Lung Cancer, (Dr. Max Watson)

Palliative Care Needs and Services Available in Advanced COPD

Background: Chronic Obstructive Pulmonary Disease (COPD) is an incurable and disabling lung disease; however the concept of palliative care in this area has received little attention.

Aim: To explore the needs of the patient with advanced lung disease, their informal carers and their healthcare professionals' views.

Findings:

- Living with COPD has wide ranging physical and psychological effects; however health and social care services rarely deal effectively with non-acute concerns.
- Patients and carers of wrongly 'accepted' that medically nothing more could be done for them;
- Unmet needs among patients with COPD and their carers includes lack of information and equipment; long waiting lists which affected quality of life;
- Both patients and carers associated palliative care with end-of-life and were unwilling to discuss it with each other and their health and social care professionals;
- Perceived barriers to extending palliative care services included: unpredictable disease trajectory, concerns about service saturation, lack of knowledge and training in what messages should be delivered to the patient and when and how to do so.

Conclusion: Palliative care in COPD provision requires a multi-disciplinary approach within which the patient and carer are at the centre of care.

For further information contact: Barbara Watson Clinical Services Manager, NIH, Email: Barbara.watson@nihospice.org. T: 02890781836

Extending Palliative Care Education to Nursing Home Staff

Background: It is recommended that all staff providing care in the independent sector should have access to education in palliative care. However, research indicates that nursing home residents have limited access to palliative care.

Aim: to develop and enhance the knowledge and delivery of palliative care by care staff in the nursing home setting via their attendance at training programmes.

Findings: Participants identified changes in their personal practice of palliative care following the training programme and a positive change in the form of better teamwork and an overall awareness of how to access external services.

Conclusion: There is a continuing need to provide comprehensive, well-resourced palliative care training in the nursing home environment to develop and sustain an ethos of palliative care, thus impacting positively on the quality of end-of-life care.

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Research News

Northern Ireland Hospice Courses

Commencing Monday 12 October 2009
Northern Ireland Hospice Essential Palliative Care for Allied Health Professionals £350

Commencing Thursday 15 October 2009
Seven Week Training Course in Bereavement Care £160

Monday 19 October 2009
Masterclass: Dealing with Bereavement Following the Death of a Child: a health/educational professional's perspective (1/2 day pm) £60

Wednesday 4 November 2009
Mental Health: Recognising psychiatric syndromes in palliative patients (1/2 day pm) £50

Tuesday 17 November 2009
Managing the Transition from Home to Care Home: Easing the burden (1/2 day pm) £50

Friday 11 December 2009
Managing Bereavement in Schools £90

Tuesday 6 & Wednesday 7 October 2009

All Ireland International Conference

Pushing Boundaries in Palliative and End of Life Care

Pushing the boundaries of understanding to demonstrate the relevance of this high quality care to patients and their families, irrespective of diagnosis or setting.

This conference is organised by Northern Ireland Hospice in collaboration with other stakeholders to promote the continual growth of service improvement and practice development within palliative and end of life care.

It will capture new developments in palliative and end of life care from professional users' perspectives, and hopes to inspire those who shape policy and commission palliative and end of life care services. The sessions will be of great interest to all health care professionals in the primary, acute, independent and voluntary sectors who seek to deliver responsive holistic patient centred care.

Presentations from nationally and internationally renowned speakers will provide a very comprehensive and holistic programme; evidence based in the knowledge and understanding which evolves as we push the boundaries of palliative and end of life care.

Speakers include:

Day 1:

- Baroness Ilora Finlay of Llandaff, Cardiff University Medicine;
- Ms Liz Henderson, NICaN;
- Prof. Phil Larkin, Our Lady's Hospice, Dublin;
- Mr Michael Connolly, University Hospital of South Manchester;
- Ms Emma Murphy, Guy's Hospital;
- Dr Val Stevenson, University College London Hospitals.

Day 2:

- Prof. Henk Schut, Utrecht University;
- Prof. Keri Thomas, National Gold Standard Framework Centre
- Prof. Julian Hughes, Institute for Ageing & Health, Newcastle
- Prof. David Clark, University of Lancaster & Trinity College Dublin & University College Dublin;
- Dr Max Watson, Northern Ireland Hospice & University of Ulster;
- Dr Rob George, Guy's & St Thomas' NHS Foundation Trust.

Further information available on www.nihospiceeducation.org

Research Ideas Form

Have You Any Research Ideas?

Would You Like to Become Involved in Research?

If you have a research idea arising from your work, we can provide you with advice, support and assistance with securing funding. For an electronic copy please email: education@nihospice.org

Title of Proposed Research:

Investigators:

Department:

The Research Question or Hypothesis:

Background:

Signature:

Date:

Simply complete and return to Tracey McTernaghan, Education Department,
Northern Ireland Hospice, Adult Services, 74 Somerton Road, Belfast, BT15 3LH