Primary palliative care research: Developing and sustaining a research agenda

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International Primary Palliative Care Research Group

http://www.som.uq.edu.au/research/phcred/international.htm

Primary Palliative care research

- Single researchers scattered widely
- Priority funding for PC in some places, not others
- Infrastructure support variable
Palliative care research interest group development - New Zealand

Rod MacLeod
University of Auckland

Dunedin School of Medicine

- Developed 2005 – Masters and PhD students (initially with RDM as South Link Health Professor in Palliative Care)
- Housed in the Department of General Practice at DSM
- No on-going academic unit/support for palliative care
Dunedin School of Medicine

- Masters
  - Experiencing palliative care
  - Does current nursing philosophy attend to the needs of people who are dying?
- PhD
  - Spirituality in NZ end-of-life care
  - Ethics based approach to suffering in palliative care
  - Music therapy for the relief of intractable distress
  - Palliative care for people not enrolled in hospice programs
  - Spirituality in general practice

- Preventive and social medicine
- Medical anthropology
- Medical oncology
- Psychological medicine
- Palliative medicine
- Palliative care nursing
- Bioethics/philosophy

- Links to
  - Australia and NZ psycho-oncology research group
  - International observatory on end of life care
  - Flinders University
  - University of Auckland
University of Auckland

- Palliative medicine
  - Admissions to in-patient palliative care (Masters)
- Psychology/education
  - Care at the end of life
- Nursing
  - Philosophy of hope in people who are dying (PhD)

University of Auckland

- Current interests
  - Community awareness of palliative care
  - Patient/family perceptions of medical care near the end of life
  - Preparedness of medical students and doctors to care
  - Palliative care nursing education needs
  - Education needs of lay carers who undertake nursing tasks
The future

- Increase collaboration /cooperation (Massey, AUT, Canterbury universities etc)
- Increase funding for palliative care research in NZ
- Attract/recruit more post-graduates for Masters and PhD study
- Build capability

With special thanks to Roz McKechnie and the DSM PCRIG and colleagues at University of Auckland

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Primary Palliative Care Research Group.

Strategic overview

Professor Scott A Murray

www.chs.ed.ac.uk/gp/research/ppcrg.php
Aim of the Primary Palliative Care Research Group

To understand the experiences of patients with life-limiting illnesses and their carers, and to develop and test best models of care.

MRC Framework for evaluation of complex interventions

Vision for Palliative Care:
3 trajectories of decline, 4 dimensions of need, and in 4 settings
Lung cancer - physical and social trajectories interrelated, while psychological and spiritual distress tends to increase at four specific transitions.

Figure 1: Physical, social, psychological and spiritual wellbeing in the last year of life.
Proposed activities

**Research: intervention studies**
- Advanced care planning at practice level: a cluster RCT.
- Improving services for people with advanced heart failure


**Teaching**
- Undergraduate:
- Postgraduate: research training, PhDs, MSc modules

**Impact on service development**
- More and better care in the community by generalists

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**Development of Palliative Care Research – United States**

**Amy Abernethy**
Duke Cancer Care Research Program
Duke University Medical Center

August 2007
My Story

- Internal Medicine and Oncology training
- Research methods a part of the training
- Applied research methods to palliative care
- NCI-funded fellowship
- Doris Duke Career Development Award
- Australia

Barriers to EBP in Palliative Care

Barriers to high quality symptom management and palliative care

1. Research Block
   - **Palliative care**
     - Historically a low priority research area
     - Eligibility difficulties
     - Recruitment problems
     - Attrition
     - Patient burden
     - Poor outcome measures
     - Ethical concerns
     - Information from disciplines outside of palliative care
   - **General**
     - Need basic biomedical research
     - Career disincentives
     - High research costs
     - Regulatory burden
     - Incompatible databases
     - Lack of qualified investigators

2. Translational Block
   - **Palliative care**
     - Focus on cure rather than care
     - Poor recognition of suffering
     - Inadequate training
     - Inadequate assessment
     - Medication concerns
     - Patient and caregiver fears
     - Funding constraints
     - Access for vulnerable populations
   - **General**
     - Applicability difficulties
     - Limited time and resources
     - Need new skills
     - Need evidence for evidence-based practice
     - Poor secondary research methods

Opinion and anecdote

Research-derived evidence

Improved care
Barriers to EBP in Palliative Care

Impact of Funding

- Ability to be productive is tightly linked to funding
- Research infrastructure based upon grants and overhead
  - Academics must fund research portion of salary through grants
  - Most of the costs of doing research are funded through direct $ from grants
  - Research very difficult to do without $, because even the IRB (Ethics) costs $
Impact of Philanthropy: PDIA

- Project on Death in America
  - Open Society Institute, 1994-2003
  - Goal: to understand and transform the culture and experience of dying and bereavement
  - Funding initiatives in professional and public education, the arts, research, clinical care, and public policy
  - $45 million distributed
  - 78+ PDIA Scholars
  - Stimulate federal funding

Impact of Philanthropy: RWJ+

- Robert Wood Johnson Foundation
  - Center to Advance Palliative Care
    - $4.5 mil in 2003
    - Number of hospital-based palliative care programs increased from <25 in mid 1990s to >1200 in 2006
    - Almost 90% of medical schools now include palliative care in the curriculum
    - 2006 – palliative medicine = medical subspecialty (starting 2008)
  - Other projects
Impact of the NIH

- Growing interest in palliative care research ("symptom control", "caregivers")
  - NCI
    - Cancer specific
  - NINR
    - Majority of funds for palliative care research but still small
    - e.g., pediatric pall care up to $2.5mil; P01 program project grants up to $700K
  - NIA
    - Older persons and caregivers

Impact of Other Disciplines

- Professional societies
  - e.g., American Society of Clinical Oncology, American Thoracic Society
- Training
  - e.g., Masters in Clinical Research
- Multidisciplinary approaches to research
  - Nursing, social work, psychology...
  - Qualitative, outcomes, health economics, basic sciences...
Barriers to EBP in Palliative Care

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     - Funding constraints
     - Worse for vulnerable populations

Can now focus on developing the science

Duke Cancer Care Research Program

Vision

Cancer care that...
- treats the patient as a whole person, in mind, body, and spirit;
- helps the patient travel the full journey of cancer (diagnosis through survivorship or end of life);
- incorporates the best of medical care into a comprehensive, longitudinal, personalized care plan; and
- optimizes the patient's well-being, quality of life, and outcomes.
The cancer patient experience: physical, emotional, social and existential

Spectrum of DCCRP Activities

DCCRP Structure

- Focuses on the cancer patient experience
- Clinical Trials
- Outcomes Research
- Systematic Reviews / Health Policy
Duke Cancer Care Research Program

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<thead>
<tr>
<th>Trials</th>
<th>Outcomes</th>
<th>Policy</th>
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<tr>
<td>Theme 1: Dyspnea</td>
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<td>Theme 2: Cancer Pain</td>
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DCCRP Deliverables

4 Key Deliverables...

- Clinical trials to improve the cancer patient experience;
- Central data system – an ongoing, longitudinal, system that captures and tracks symptoms, QOL, and other patient-centric measures
- Models of care that incorporate this information
- Integration – mechanisms to efficiently integrate assessment and improvement of the patient experience in therapeutic clinical trials and routine clinical care
My Story

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- Research methods a part of the training
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- Australia
- Back to the US

Palliative care research
Bringing the strands together

Geoff Mitchell
University of Queensland
Personal background

- General practice
- Skill maintenance and improvement in general practice
- Palliative care the template (one of several)

National developments

Commonwealth Palliative Care program

Eight years of funding
- Scoping
- Implementation

Themes of work:

1. Support for patients, families and carers in the community
2. Increased access to palliative care medicines in the community
3. Education, training and support for the workforce
4. Research and quality improvement for palliative care services
Merging the personal to the national

3. Education, training and support for the workforce

- National scoping study into education and support needs of GPs
- Precursor to Therapeutic Guidelines

Merging the personal to the national

Research and quality improvement for palliative care services

- Queensland Case Conferences Trial
- Discharge planning in palliative care
- Single patient trials
Collaborations

Centre for Palliative Care Research and Education

- Clinical research into nausea
- National undergraduate education
- Single patient trials

QUT

- Dementia management
Flinders University:

Case conference parallel trials

Literature review of integrated, coordinated and multidisciplinary care

Implementation of case conferences into clinical palliative care practice

Newcastle/ECU

Needs-based palliative care

Caregiver support
International

- Primary Palliative care research group.
- Individuals

Advisory/ support roles – representing general practice

- Palliative Medicines
- Caresearch
- End of life communication
  Systematic review
Teaching

- Palliative care at UQ

- Graduate Health Studies Program:
  - Chronic and palliative care

- Mentoring

My research journey

Initial interest in an area.

Opportunistic uptake of research

Great collaborators – generous ++++
Challenges

- Broad spread of interests
- Developing a research team
- Bringing palliative care interests at UQ together.

Decisions to make

- What is the focus of the research programme?
  - What are the research priorities nationally?
- Finding patients
- Palliative care primarily or grafted on to other specialties?
  - Eg primary care, cancer, aged care
Questions:

- Focussed research or diffuse objectives?
  - How do you choose?

- How many collaborative relationships?

Policy drives research

Research informs policy

?