A systematic review of palliative care research in Ireland

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Background

• Changing demographics combined with rising health care costs - implications for palliative care services.

• Need for clinically-relevant, collaborative, multidisciplinary, and strategic approaches to palliative care research (Bennett et al. 2010; Daveson et al, 2011; Higginson, 2005; Kaasa et al., 2005; Murray et al. 2008; Sigurdardottir et al., 2010).

• Improving service delivery and optimising quality of life requires outcomes-focused & cost effectiveness research (Higginson, 2005; Kaasa, 2008).

• To what extent are health-related outcomes as prioritised by researchers considered priorities by patients, families or clinicians? (Chalmers et al. 2009).
Delivering research in end-of-life care: problems, pitfalls and future priorities

Michael I Bennett  School of Health and Medicine, Lancaster University, Lancaster, UK
Elizabeth A Davies  King’s College London, London, UK
Irene J Higginson  King’s College London, London, UK

“Currently it seems there is too little emphasis on the need to implement and generate knowledge that will ensure evidence based decisions by clinicians who manage patients (& their carers) at the end of life. In particular, research is needed into therapeutic approaches into a range of challenging symptom”
Palliative Care in Ireland: interesting facts

• Ireland is second to the UK in terms of making palliative medicine a specialty / subspecialty: 1995.

• 42 consultants in Palliative Medicine on the Island of Ireland (Northern Ireland - 12 and Republic of Ireland – 30).

• In Northern Ireland, hospices received £5.58 million (approx. €6.6 million) from the DHSSPS in the last financial year. This equates to approx. 0.12% of Health Budget.

• All other operating costs must be raised through fundraising campaigns.

• In Ireland, the total budget from the HSE €78 million ) (a reduction of €3 million on 2011) (approx. £66.1 million). This equates to approx. 0.6% of HSE budget.

• All other costs are met through fundraising campaigns.

– Scores for Palliative Care Provision
  • Euro-barometer rankings; UK (2nd)/Ireland (5th) (Centeno, et al 2007);
  • Quality of Death Index: UK(1)/Ireland (4th) (Economist Intelligence Unit, 2010)
AllHPC Consortium Members

Our Lady’s Hospice, Dublin
St Francis Hospice, Dublin
Milford Care Centre, Limerick
St. James’s Hospital, Dublin
Northern Ireland Hospice, Belfast
Marie Curie Centre, Belfast

University College Dublin
Trinity College Dublin
University of Limerick
DAMC, Dublin
University of Ulster, Belfast
Queens University Belfast
Aim & Objectives

**Aim:** To explore the nature of palliative care research undertaken on the island of Ireland in order to examine its relevance and overall contribution to the area of palliative and end of life care.

**Objectives**

1) Source literature published between January 2002 and May 2012;
2) Provide a thematic analysis of peer-reviewed journal articles published over the last five years;
3) Examine study characteristics in terms of setting, sample, research methodology, and key outcomes;
4) Contextualise palliative care research on the island of Ireland internationally.
Methodology

Search Strategy

- Standard bibliographic databases including CINAHL, MEDLINE, PUBMED & Cochrane
- Irish Health Repository ‘LENUS’/ grey literature / key hospice and palliative care websites

- **Inclusion criteria:**
  - Research output published between January 2002 and May 2012;
  - Research conducted on the island of Ireland;
  - Research relevant to palliative care.
Selection & Review Process

Initial search
Electronic literature searches identified 412 potential documents.

Inclusion criteria applied
186 documents removed

Second Review (2002-2012)
An additional 51 articles do not meet the inclusion criteria

Number of documents remaining after duplicates removed (T=388)

Number of peer-reviewed articles remaining and their abstracts screened (T=202)

Number of peer-reviewed articles remaining (T=151)

Emergence of eight thematic headings and subheadings
Findings

• **151 papers** met the inclusion criteria
  o 2002-2005 = 23
  o 2006-May 2012 = 128

• 72% of papers were published within the previous four years

• Papers were published in a total of 86 journals
Number of Studies Published between Jan 2002 – May 2012
• Study design (T=128):
  - Quantitative (41%)
  - Qualitative (38%)
  - Mixed methods (12%)
  - Retrospective case note reviews (5%)
  - Systematic reviews (3%)

• Twenty-five (20%) studies used a wide range of clinical and/or research-developed standardised measures.

• Majority of studies based on samples sizes of < 100.

• Acute hospitals, the community/home, generalist and specialist services (e.g. intellectual disability, cancer, palliative care), hospices, and nursing homes.
Eight Core Themes

- CAM: 1%
- Spirituality: 2%
- Communication & Education: 3%
- Death & Dying: 4%
- Bereavement Care: 8%
- Services & Settings: 21%
- Symptoms: 21%
- Specific groups: 40%
Discussion

• Increase in palliative care research in Ireland
  • Reasons: Funding & clinical developments
• Diversity of research activity.
• Focus on specific groups and populations – beyond cancer
• 2\textsuperscript{nd} largest area: Symptom Management
• Health services research
• Methodological limitations
Conclusions

• **Limitation of this study:** key words used to select publications may not have captured other studies in the area of palliative care which used different terminology. This may have excluded relevant peer-reviewed papers due to them not mentioning a keyword in their title, abstract or subject terms.

• Provides baseline measure and ‘picture’ of palliative care research undertaken in Ireland

• Areas of significant strength:
  – specific groups;
  – beyond cancer
  – symptom management

• Areas of weakness: methodological rigour

• Useful in considering future research priorities and strategic planning
Thank you!

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References

• Murray S BS, Bennett MI, Kendall M, Amir Z, Lloyd-Williams M. Palliative care research in the community: it is time to progress this emerging field. Palliat Med. 2008;22(5):609-11.