



Research in end-of-life care – Clinical Findings and Methodological Challenges

Sheila Payne,
Help the Hospices Chair in Hospice Studies,
Co-director of the UK Cancer Experiences Collaborative,

International Observatory on End of Life Care,
Institute for Health Research,
Lancaster University,
United Kingdom



International Observatory on End of Life Care



International Observatory on End of Life Care





Overview

- Palliative care research – a brief history
- Methods and methodology
- A bibliometric analysis of research methodologies
- The search for a single disciplinary paradigm – diversity or consensus?



Palliative care research – a brief history

Clinical medical research - predominantly on pain management in advanced cancer

- Symptom control
- Pharmacology eg. slow release morphine
- Medical technologies eg. WHO Pain Ladder, syringe driver



Typical methods

- Descriptive studies
- Observational studies – clinical case descriptions
- Experimental studies – quasi-experimental designs
- Clinical trial designs
- Epidemiological analysis of population data
- Comparative analysis of service provision



Palliative care research – a brief history

Psychosocial research:

- ‘Awareness contexts’ – open disclosure
- Communication skills
- Bereavement support theories and services – from psychology (attachment), sociology (narrative), anthropology (cultural meanings of loss).
- Psychological support and counselling
- Sociological theories of ‘the Self’ and death and dying in society
- Organisational theories and the management of change in service development



Typical methods

- Survey methods
- Ethnography
- Qualitative methods including the collection of patient and carer accounts.
- Evaluation methods
- Psychometrics – development of ‘tools’
- Social policy and sociological systems analysis
- Action research and participatory approaches



Research on end of life care ethics

- Empirical enquiry in ethics
- Collaborations between ethicists, social scientists and philosophers.
- *Example:* ten Have, Clark – the Pallium Project in collaboration with the EAPC
- This work is well developed in the Netherlands, Belgium, USA.



Ethical choices

- **What gets researched?**

What funding bodies are interested in. What are the current political issues.

- **What gets funded?**

Not much!

- **How is research designed?**

Dilemmas for researchers working within medical paradigms because of the assumed dominance of the RCT methodology.

- **What gets neglected?**

Lots – research involving: allied health professionals, families, spiritual care, bereavement support, management, volunteers, etc.



Research funding in Palliative Care

- NCRI Strategic Analysis (2002) indicates a research spend on supportive and palliative care of £11m per annum, which represents 4.3% of NCRI Partners spend on cancer.
(Supportive and Palliative Care Research in the UK (2004) NCRI)
- UK spends only 0.18% of its total government and charitable funding for cancer research on end-of-life and palliative care.
- USA spends only 0.9% of its cancer research budget on palliative care.

(Davies and Higginson (2004) WHO)

International Observatory on End of Life Care





Methods and methodology - definitions

- **Methods** – applies to ‘specific research techniques’ which are used to describe the procedures undertaken in an actual research study such as collecting data, selecting a sample and analysing and interpreting data.
- **Methodology** - defined as ‘a general approach to studying research topics (p1)’ which includes analysis of the principles of methods, rules and postulates employed by specific disciplines.

(Silverman D. (1993) *Interpreting Qualitative Data*. London: Sage)



A bibliometric analysis of research methodologies - aims

- to describe and discuss the status and current evidence about developments in the science of methodology in palliative care research.
- to compare with the data presented by Corner (1996) a decade ago.
- to revisit the question she raised: '*Is there a research paradigm for palliative care?*'.

Corner J. (1996) Is there a research paradigm for palliative care?

Palliative Medicine 10: 201-208



Methods of bibliometric analysis

- Medline search
- Key words: 'palliative care', end of life care', research methodology'
- Inclusion criteria: English language, published 1997-2006
- Independent classification of 134 (62%) abstracts, with 94.7% agreement.

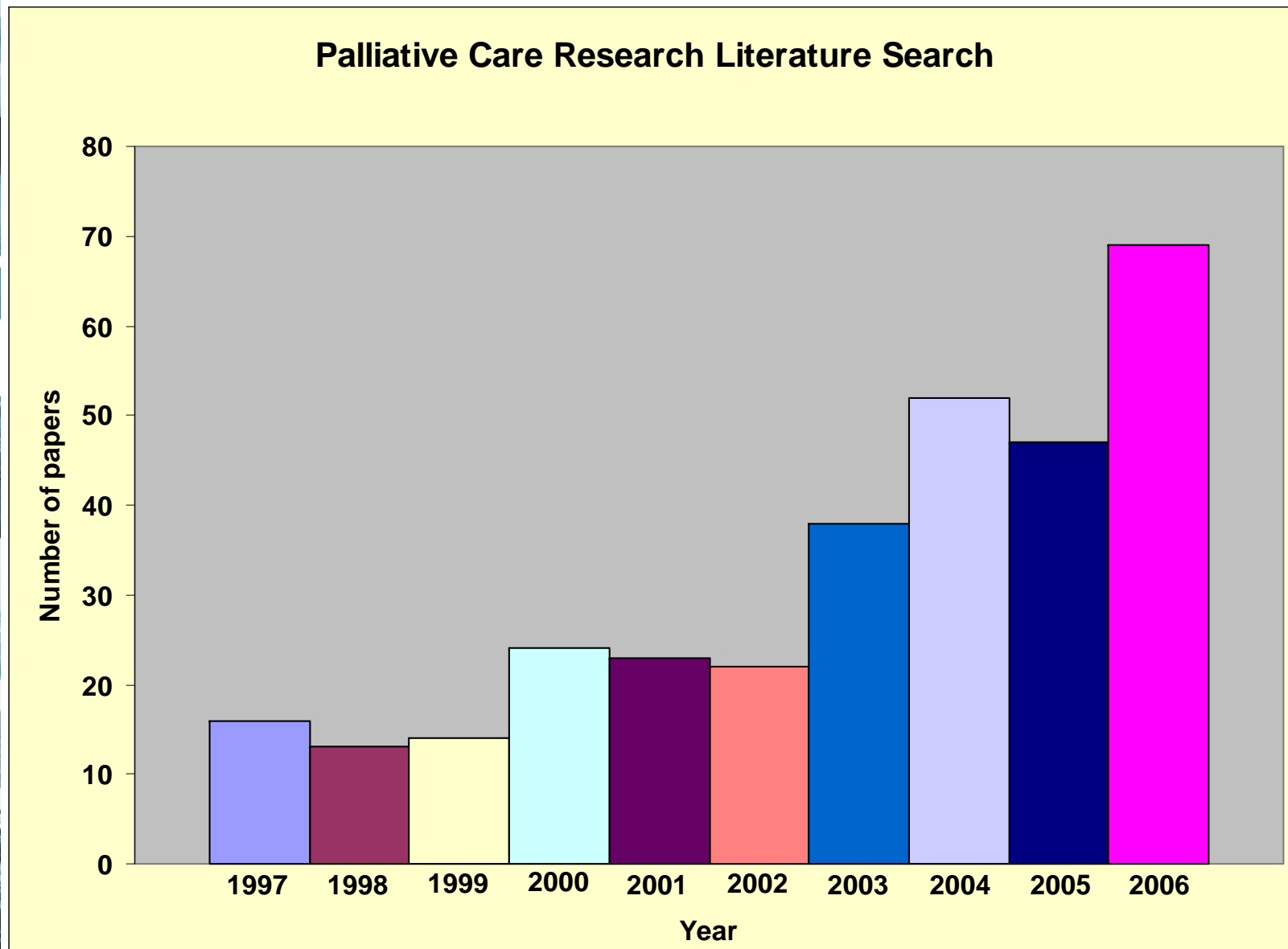


Type of paper

Type of paper	Number
Case study	2
Conference report	2
Discussion/other	48
Editorial	3
Interview	2
Letter	1
News item	2
Paediatric papers	15
Research reports	215
Not about End of Life Care	28
Total	318



Number of publications per year





Top 11 journals where papers were published

Name of Journal	Number of papers	% of total journals (n=318)
International Journal of Palliative Nursing	67	21%
Journal of Palliative Care	21	7%
Journal of Clinical Nursing	15	5%
American Journal of Hospice and Palliative Care	13	4%
Journal of Advanced Nursing	13	4%
Nursing Ethics	13	4%
Palliative Medicine	10	3%
Cancer Nursing	9	2.8%
Contemporary Nurse: A Journal for the Australian Nursing Profession	7	2%
European Journal of Oncology Nursing	6	1.8%
International Journal of Nursing Studies	6	1.8%



Types of research methodologies

Classification	Number of papers	% of total papers (n=215)
Qualitative / descriptive studies	136	63%
Quantitative methods	31	14%
Mixed methods	16	7%
Measurement / methodology	12	5.5%
Systematic reviews	12	5.5%
Secondary analysis	5	2%
Unclassifiable	2	1%
Randomised controlled trials	1	0.4%
Total	215	



Country where the research was conducted



- Total 27 countries
- Five countries (Australia, Canada, Sweden, UK, US) accounted for 179 (83%) of all the publications.
- 14 publications were from three major continents including: 11 from Asia, 2 from Africa and 1 from South America.



Key issues identified

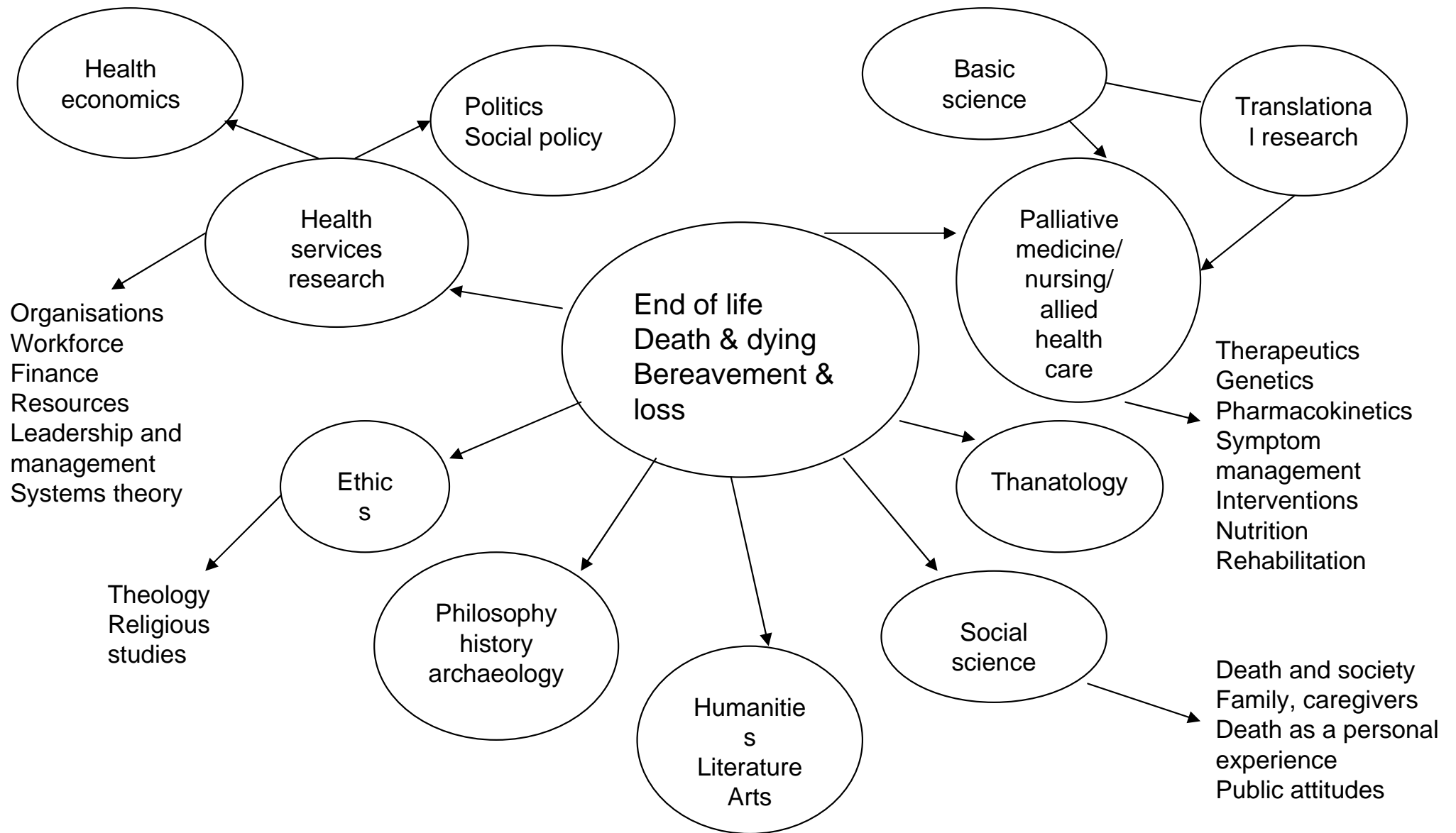
- Increased numbers of papers where ‘research methodology’ has been identified.
- Greater proportion of nursing journals.
- Dominance of certain countries.
- Increase in qualitative methodologies.
- Methodological pluralism.



The search for a single disciplinary paradigm – diversity or consensus?

‘Is there a research paradigm for palliative care?’.

Mapping fields of research and scholarship concerned with death and dying





Conclusions

- Increasing volume of published paper recognising 'research methodology'.
- Heterogeneity of research methodologies.
- Raising questions about research quality.
- No clearly dominant paradigm for palliative care research.

Thank you for listening.

