Where next for palliative care? A vision for palliative care research and development

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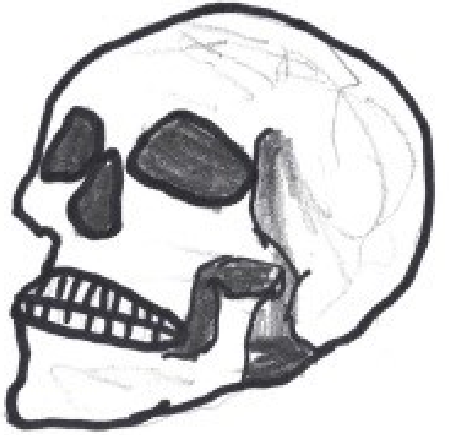
Intuition Without Rigor



Rigor without Intuition

How much palliative care research?

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Bibliometric Analysis of Palliative Care-Related Publication Trends During 2001 to 2016

Chia-Jen Liu, MBA[1,2], Te-Chun Yeh, MPH[3], Su-Hsuan Hsu, MD[4], Chao-Mei Chu, MPH[5], Chih-Kuang Liu, MD, PhD[2,6,7], Mingchih Chen, PhD[2], and Sheng-Jean Huang, MD[1,8]

Abstract

Background: The scientific contributions (publications) and international influence (citations) from authors providing the palliative care (PC)-related literature has a limited number of bibliometric reports. We aimed to analyze PC-related literature using the Institute for Scientific Information Web of Science (WoS) database. **Methods:** WoS database was used to retrieve publications with the following key words with title: "palliative care" OR "End of Life care" OR "terminal care.". The statistical analysis of the documents published during 2001 to 2016 was performed. The quantity and quality of research were assessed by the number of total publications and citation analysis. In addition, we also analyzed whether there were possible correlations between publication and socioeconomic factors. **Results:** The total research output was 6273 articles for PC. There was a 3-fold increase in the number of publications during the period and strong correlation between the year and number of PC-related publications ($R^2 = .96$). The United States took a leading position in PC research (2448, 39.0%). The highest average citations was reported for the Norway (21.8). Australia had gained the highest productive ability in PC research (24.9 of articles per million populations). The annual impact factor rose progressively with time and increased 1.13 to 2.24 from 2003 to 2016. The number of publications correlated with gross domestic product ($r = .74$; $P < .001$). **Conclusion:** The United States and United Kingdom contributed most of the publications, but some East Asian countries also had a great performance. According to the socioeconomic factors, the publication capacity of top 20 countries is correlated with their economic scale.

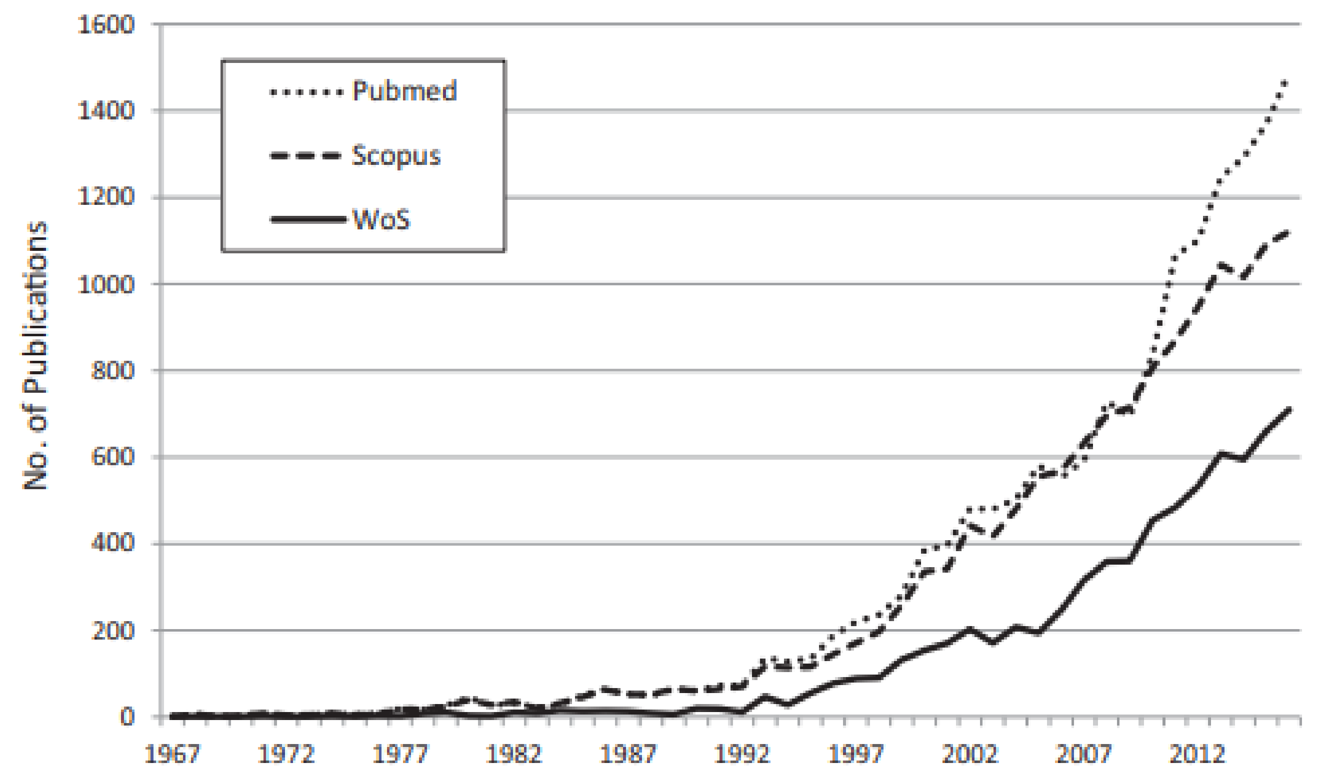


Figure 1. Growth of worldwide publications on PC from PubMed, Scopus, and WoS in the past 5 decades (1967-2016). PC indicates palliative care; WoS, Web of Science.

Table 1. List of Top 20 Productive Countries With Citation Analysis.

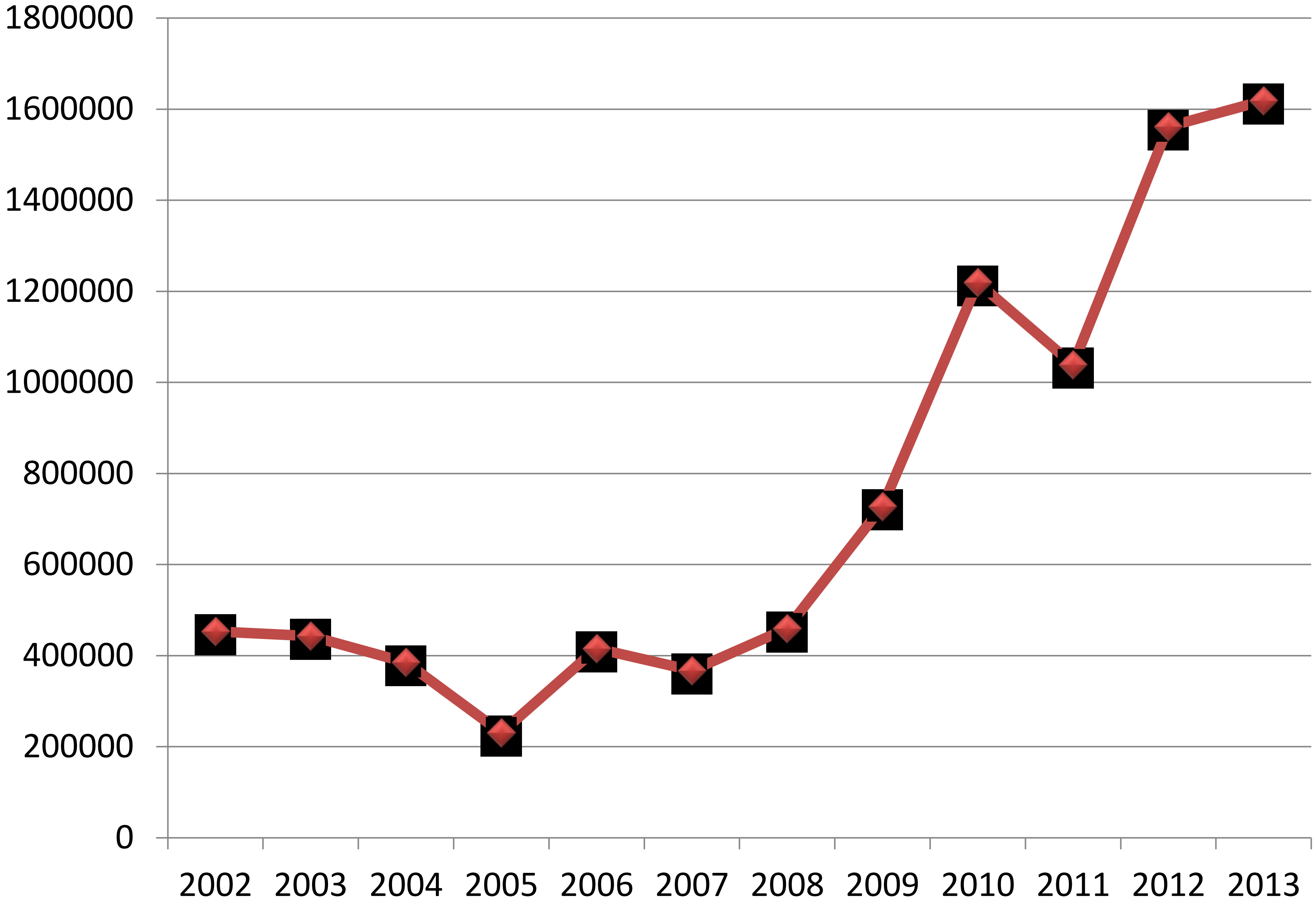
		Number of Articles			
Rank	Countries	2001	2016	2001-2016	Growth Rate
1	United States	79	291	2448	268.4
2	United Kingdom	31	120	1112	287.1
3	Australia	11	65	598	490.9
4	Canada	14	48	594	242.9
5	Germany	7	56	364	700.0
6	Netherlands	3	38	265	1166.7
7	Spain	4	29	222	625.0
8	Japan	0	20	193	–
9	Italy	7	26	165	271.4
10	Belgium	2	19	153	850.0
11	France	2	15	152	650.0
12	Sweden	1	18	131	1700.0
13	Switzerland	6	10	98	66.7
14	Ireland	1	17	96	1600.0
15	Norway	2	8	88	300.0
16	Taiwan	0	12	77	–
17	Brazil	0	9	75	–
18	China	3	16	74	433.3
19	South Korea	0	6	73	–
20	New Zealand	2	9	71	350.0
	Worldwide	170	710	6273	317.6

Abbreviation: cIF, calculated impact factor.

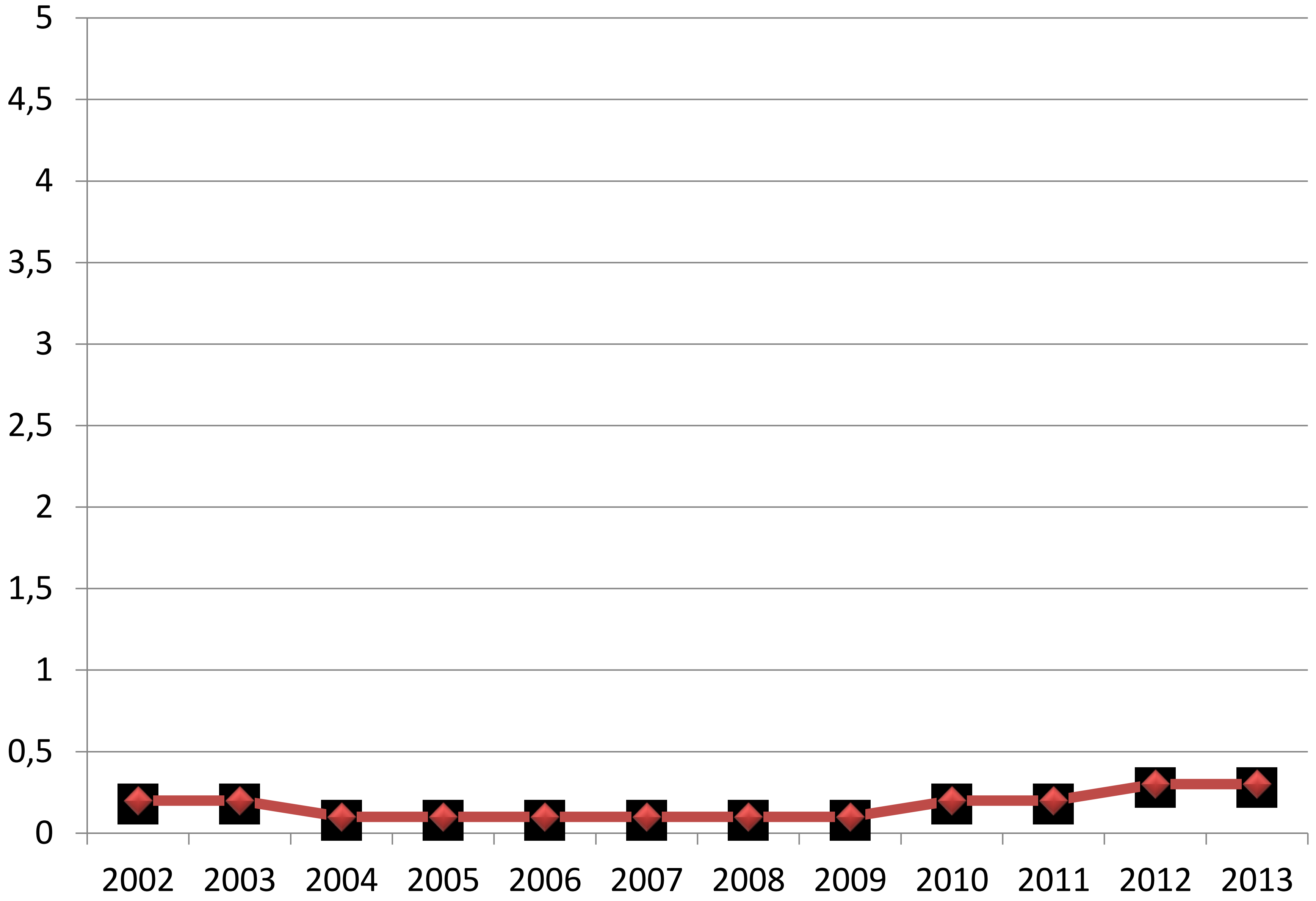
2017 Clarivate Analytics Data for Denmark

BMJ Supportive and Palliative Care 12th
BMC Palliative Care 22nd
Palliative Medicine 24th
Journal of Palliative Medicine 25th
Journal of Pain and Symptom Management 25th

How well funded is research?



NCRI spend on end of life care research (CSO 6.6)
http://www.ncri.org.uk/what-we-do/research-database



NCRI **percentage** spend on end of life care research (CSO 6.6)
http://www.ncri.org.uk/what-we-do/research-database

48%

Original Article

Key Characteristics of Palliative Care Studies Reported in the Specialized Literature

Jane L. Wheeler, MSPH, Aine Greene, RN, FRCNA, Jennifer J. Tieman, BSc, MBA, Amy P. Abernethy, MD, and David C. Currow, BMed, MPH, FRACP

Division of Medical Oncology (J.L.W., A.P.A.), Department of Medicine, Duke University Medical Center, Durham, North Carolina, USA; and Discipline, Palliative and Supportive Services (A.G., J.J.T., A.P.A., D.C.C.), Flinders University, Daw Park, South Australia, Australia

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Abstract

Context. Although research activity in palliative care is rapidly increasing, the composition of published studies—in terms of significant research characteristics—has not yet been well described.

Objectives. To describe the topics of and funding for palliative care studies reported in the three hospice and palliative care journals with the highest impact factors (*Journal of Pain and Symptom Management*, *Palliative Medicine*, and *Journal of Palliative Medicine*).

Methods. This was a substudy of a larger bibliographic study. The targeted journals were searched for 2007 using a previously validated Ovid MEDLINE filter for palliative care. All empirical palliative care studies were included. Articles were classified according to topics (palliative care patient, caregiver/family, health professional, service provision, tool development, healthy volunteer, medication compatibility, community), study type (intervention, nonintervention), country of origin, and funding source (pharmaceutical company, other funder, unfunded).

Results. Of 409 citations identified, the search yielded 189 eligible articles. Most articles were descriptive/observational. Approximately half were unfunded. Caregivers, healthy volunteers, and health service research were the least frequent topics for research. Only five randomized controlled trials were reported.

Conclusion. Although there is a broad range of research undertaken in palliative care, few studies generate high-level evidence, with data showing a relative lack of funding for hospice and palliative care studies. J Pain Symptom Manage 2012;43:987—992.

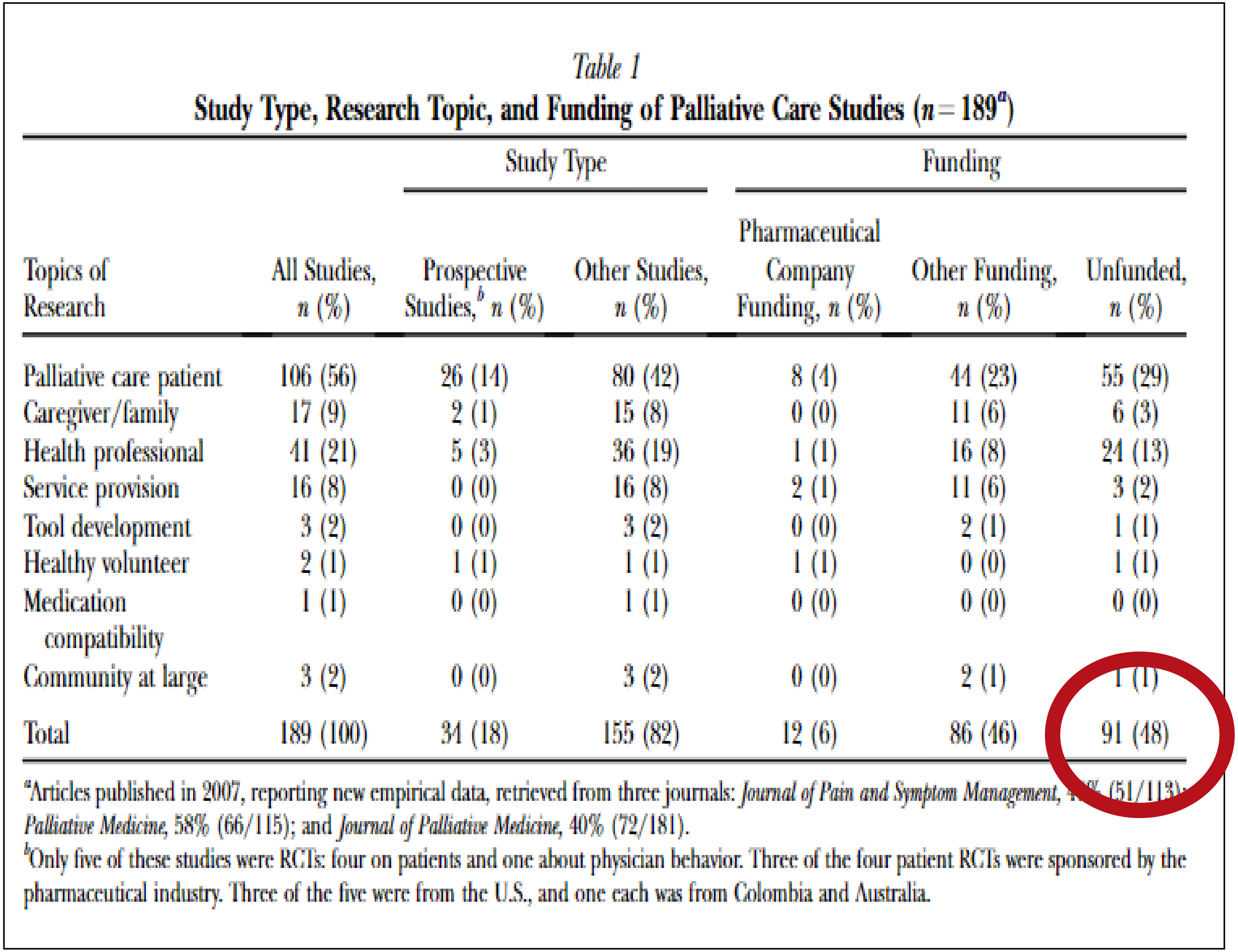

Table 1

Study Type, Research Topic, and Funding of Palliative Care Studies ($n = 189^a$)

Topics of Research	All Studies, *n* (%)	Study Type Prospective Studies,[b] *n* (%)	Study Type Other Studies, *n* (%)	Funding Pharmaceutical Company Funding, *n* (%)	Funding Other Funding, *n* (%)	Funding Unfunded, *n* (%)
Palliative care patient	106 (56)	26 (14)	80 (42)	8 (4)	44 (23)	55 (29)
Caregiver/family	17 (9)	2 (1)	15 (8)	0 (0)	11 (6)	6 (3)
Health professional	41 (21)	5 (3)	36 (19)	1 (1)	16 (8)	24 (13)
Service provision	16 (8)	0 (0)	16 (8)	2 (1)	11 (6)	3 (2)
Tool development	3 (2)	0 (0)	3 (2)	0 (0)	2 (1)	1 (1)
Healthy volunteer	2 (1)	1 (1)	1 (1)	1 (1)	0 (0)	1 (1)
Medication compatibility	1 (1)	0 (0)	1 (1)	0 (0)	0 (0)	0 (0)
Community at large	3 (2)	0 (0)	3 (2)	0 (0)	2 (1)	1 (1)
Total	189 (100)	34 (18)	155 (82)	12 (6)	86 (46)	91 (48)

[a] Articles published in 2007, reporting new empirical data, retrieved from three journals: *Journal of Pain and Symptom Management*, 4[illegible]% (51/113); *Palliative Medicine*, 58% (66/115); and *Journal of Palliative Medicine*, 40% (72/181).

[b] Only five of these studies were RCTs: four on patients and one about physician behavior. Three of the four patient RCTs were sponsored by the pharmaceutical industry. Three of the five were from the U.S., and one each was from Colombia and Australia.

What should we study?

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Original Articles

Developing a Research Agenda for Adult Palliative Care: A Modified Delphi Study

Rebecca Sullivan, BPsych (Hons),[1] Anna Ugalde, PhD, BA (Hons),[2]
Craig Sinclair, PhD, BA, BSc,[3] and Lauren J. Breen, PhD, FT, BSc (Hons)[1]

Abstract

Background: Little is known about research priorities in adult palliative care. Identifying research priorities for adult palliative care will help in increasing research quality and translation.
Objective: The aim was to identify the views of health professionals' research priorities in adult palliative care that lead to development of a palliative care research agenda in Australia.
Design: A modified three-round Delphi survey.
Setting/Subjects: Palliative care researchers and clinicians in Australia were invited to participate.
Results: A total of 25 panelists completed round 1, 14 completed round 2, and 13 completed round 3. Round 1 resulted in 90 research priorities in 13 categories. Round 2 showed consensus agreement on 19/90 research priorities. Round 3 resulted in the top 10 research priorities of the 19 achieving consensus in round 2. Panelists agreed that research is needed on the transition to palliative care; improving communication about prognosis; increasing access to palliative care for indigenous communities, people who wish to remain at home, and people in aged care; addressing family caregivers' needs; promoting patients' and families' decision making; improving cross-cultural aspects of palliative care; determining the effects of assisted dying legislation; and improving bereavement care in rural, remote, and Aboriginal populations.
Conclusions: The expert panelists identified the top 10 research priorities for adult palliative care. These identified research priorities are the most urgent topics requiring attention to increase the quality of life of patients requiring palliative care and their family members.

Keywords: Delphi; palliative care; research agenda; research priorities

TABLE 3. PRIORITIZED RESEARCH AGENDA FOR PALLIATIVE CARE IN AUSTRALIA

Rank	*Research priority*	*Category*	*Round 2 Rating*	*Rated very important/ urgent priority in round 2* N *(%)*	*Ranked in top 10 in round 3* N *(%)*
1	Developing communication between active treatment and palliative care so that the transition to palliative care is less of a surprise to patients and families.	Integration of palliative care	1.71	6 (42.86)	9 (69.2)
2	Improving the communication of accurate information about prognosis upon diagnosis to patients.	Communication between health care professionals and patients/families	1.64	7 (50)	9 (69.2)
3	Improving palliative care for indigenous communities.	Specific populations	1.71	6 (42.86)	7 (53.8)
4	Establishing palliative care packages for those wishing to remain home, but have significant care needs outside of usual available provision of care.	Models of care	1.86	7 (50)	7 (53.8)
5	Determining how to routinely and formally identify and address family caregivers' needs for support during the palliative care trajectory so that they are part of standard care.	Family and caregiver well-being	1.79	6 (42.86)	8 (61.5)
6	Investigating how the aged care sector can identify and provide for the potentially lengthy end-of-life support to the aged who may have multiple comorbidities, but no clear diagnosis for palliative intervention.	Models of care	1.64	7 (50)	7 (53.8)
7	Improving involvement of patients and significant others in decisions regarding care in the last week of life.	Communication between health care professionals and patients/families	1.50	8 (57.14)	11 (84.6)
8	Exploring cross-cultural approaches to terminal illness, death, and dying and how these can inform palliative care.	Community education and capacity building for end-of-life care	1.79	4 (28.57)	9 (69.2)
9	Assessing the impact of assisted dying legislation on family decision-making and bereavement outcomes.	Bereavement care	1.64	7 (50)	9 (69.2)
10	Improving bereavement care in rural, remote, and Aboriginal populations.	Bereavement care	1.71	7 (50)	7 (53.8)

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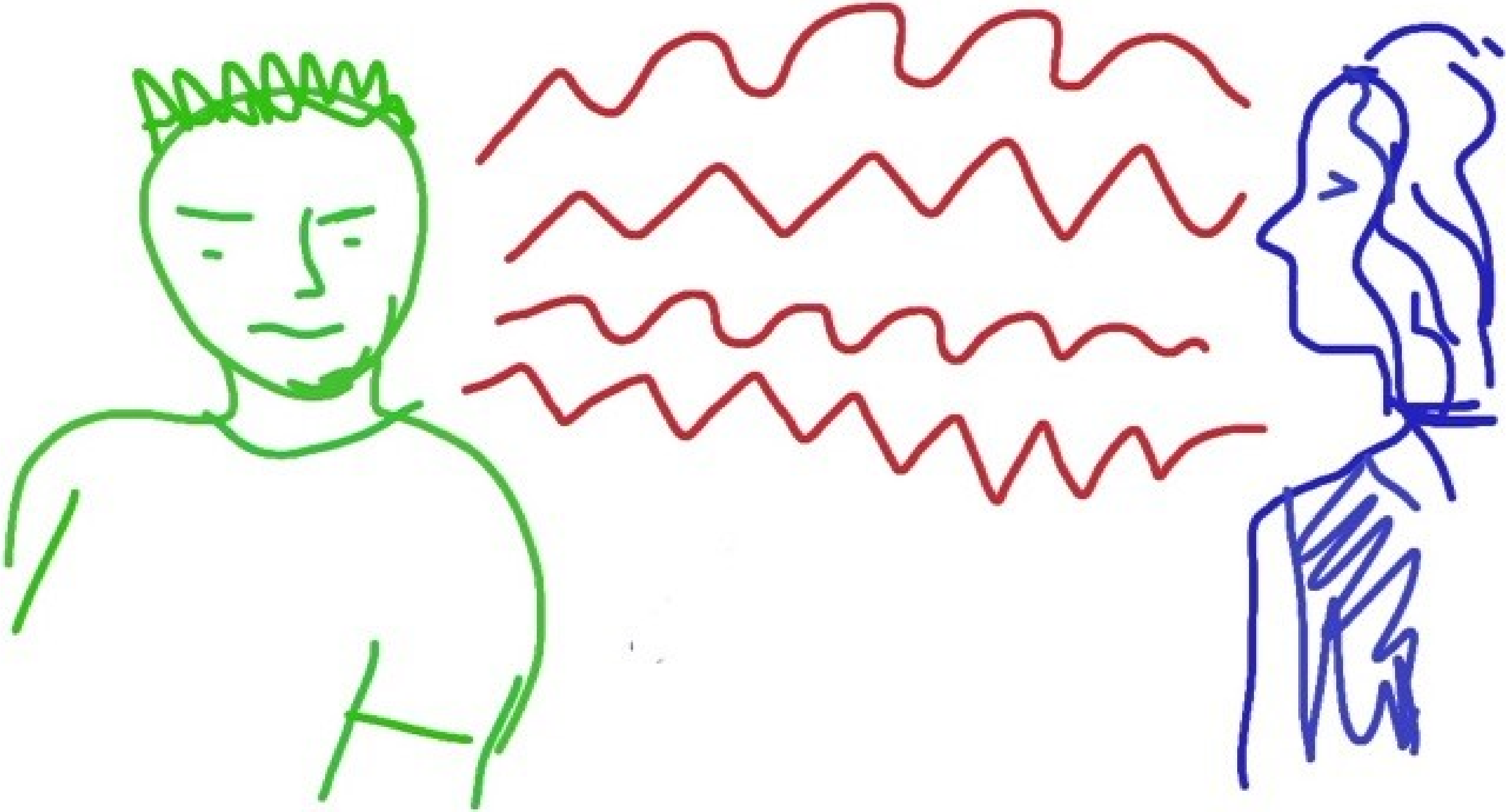
1. Out of hours care	2. Access
3. Advance Care Planning	4. Carer information
5. Staff training	6. Patient needs outside cancer
7. Core services	8. Home care
9. Continuity	10. Pain

What are the needs?



Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study

Karen Barnett, Stewart W Mercer, Michael Norbury, Graham Watt, Sally Wyke, Bruce Guthrie

Summary

Background Long-term disorders are the main challenge facing health-care systems worldwide, but health systems are largely configured for individual diseases rather than multimorbidity. We examined the distribution of multimorbidity, and of comorbidity of physical and mental health disorders, in relation to age and socioeconomic deprivation.

Methods In a cross-sectional study we extracted data on 40 morbidities from a database of 1 751 841 people registered with 314 medical practices in Scotland as of March, 2007. We analysed the data according to the number of morbidities, disorder type (physical or mental), sex, age, and socioeconomic status. We defined multimorbidity as the presence of two or more disorders.

Findings 42·2% (95% CI 42·1–42·3) of all patients had one or more morbidities, and 23·2% (23·08–23·21) were multimorbid. Although the prevalence of multimorbidity increased substantially with age and was present in most people aged 65 years and older, the absolute number of people with multimorbidity was higher in those younger than 65 years (210 500 *vs* 194 996). Onset of multimorbidity occurred 10–15 years earlier in people living in the most deprived areas compared with the most affluent, with socioeconomic deprivation particularly associated with multimorbidity that included mental health disorders (prevalence of both physical and mental health disorder 11·0%, 95% CI 10·9–11·2% in most deprived area *vs* 5·9%, 5·8%–6·0% in least deprived). The presence of a mental health disorder increased as the number of physical morbidities increased (adjusted odds ratio 6·74, 95% CI 6·59–6·90 for five or more disorders *vs* 1·95, 1·93–1·98 for one disorder), and was much greater in more deprived than in less deprived people (2·28, 2·21–2·32 *vs* 1·08, 1·05–1·11).

Interpretation Our findings challenge the single-disease framework by which most health care, medical research, and medical education is configured. A complementary strategy is needed, supporting generalist clinicians to provide personalised, comprehensive continuity of care, especially in socioeconomically deprived areas.

Funding Scottish Government Chief Scientist Office.

Lancet 2012; 380: 37–43

DOI:10.1016/S0140-6736(12)60240-2

See Comment page 7

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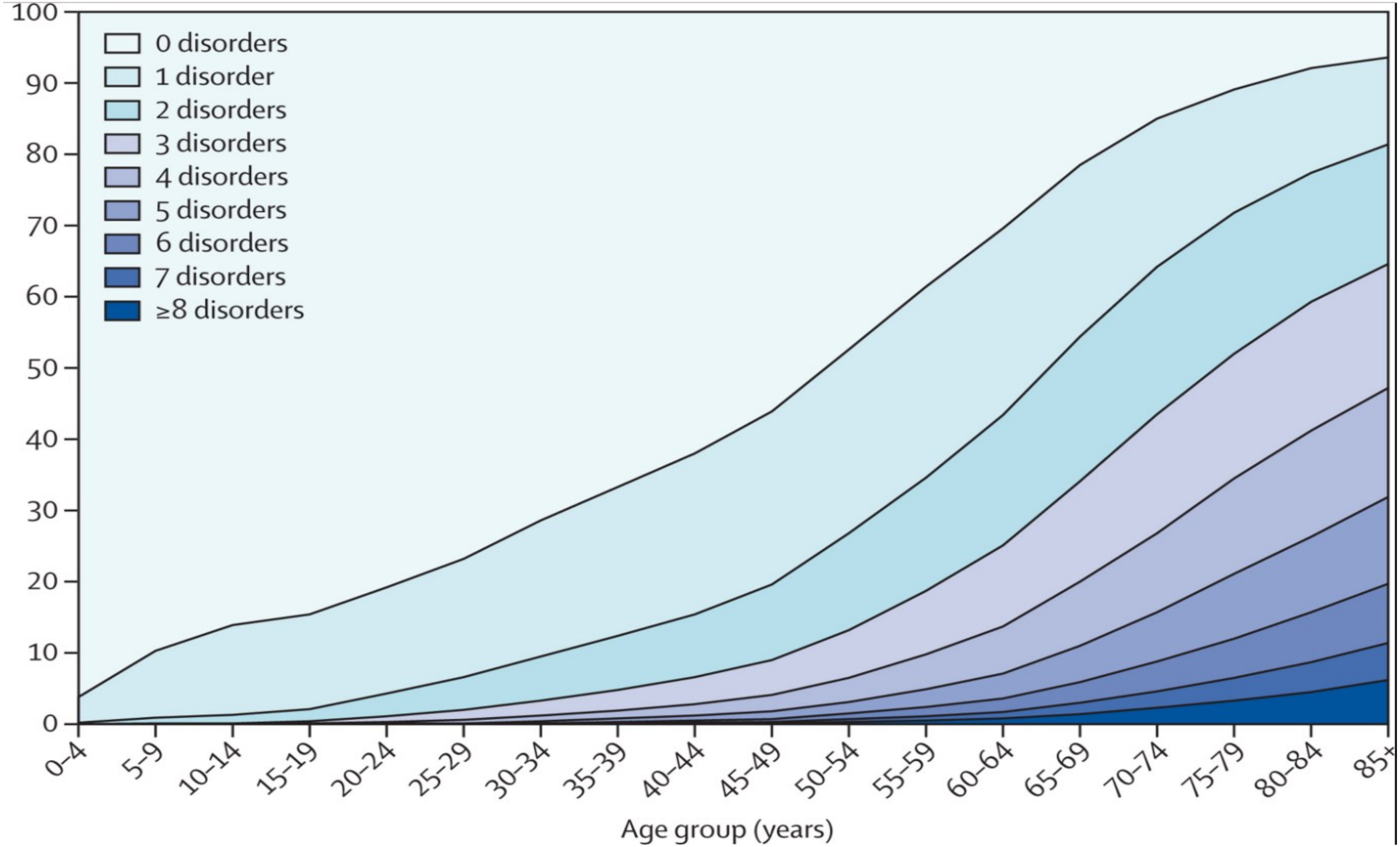
0 disorders
1 disorder
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3 disorders
4 disorders
5 disorders
6 disorders
7 disorders
≥8 disorders
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40–44
45–49
50–54
55–59
60–64
65–69
70–74
75–79
80–84
85+
Age group (years)

PALLIATIVE
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Original Article

Palliative Medicine
2016, Vol. 30(1) 45–53

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The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993–2012

Katherine E Sleeman[1], Joanna M Davies[1], Julia Verne[2], Wei Gao[1] and Irene J Higginson[1]

Abstract

Background: Studies in the United Kingdom and elsewhere have suggested inequality of hospice provision with respect to factors such as age, diagnosis and socio-economic position. How this has changed over time is unknown.
Aim: To describe the factors associated with inpatient hospice death in England and examine how these have changed over time.
Design: Population-based study. Multivariable Poisson regression compared 1998–2002, 2003–2007 and 2008–2012, with 1993–1997. Explanatory variables included individual factors (age, gender, marital status, underlying cause of death) and area-based measures of deprivation.
Setting: Adults aged 25 years and over who died in inpatient hospice units in England between 1993 and 2002 (n = 446,615).
Results: The annual number of hospice deaths increased from 17,440 in 1993 to 26,032 in 2012, accounting for 3.4% of all deaths in 1993 and 6.0% in 2012. A total of 50.6% of hospice decedents were men; the mean age was 69.9 (standard deviation: 12.4) years. The likelihood of hospice decedents being in the oldest age group (>85 years) increased over time (proportion ratio: 1.43, 95% confidence interval: 1.39 to 1.48 for 2008–2012 compared to 1993–1997). Just 5.2% of all hospice decedents had non-cancer diagnoses, though the likelihood of non-cancer conditions increased over time (proportion ratio: 1.41, 95% confidence interval: 1.37 to 1.46 for 2008–2012 compared to 1993–1997). The likelihood of hospice decedents being resident in the least deprived quintile increased over time (proportion ratio: 1.25, 95% confidence interval: 1.22 to 1.29 for 2008–2012 compared to 1993–1997).
Conclusion: The increase in non-cancer conditions among hospice decedents is encouraging although absolute numbers remain very small. Deprivation trends are concerning and require further exploration.

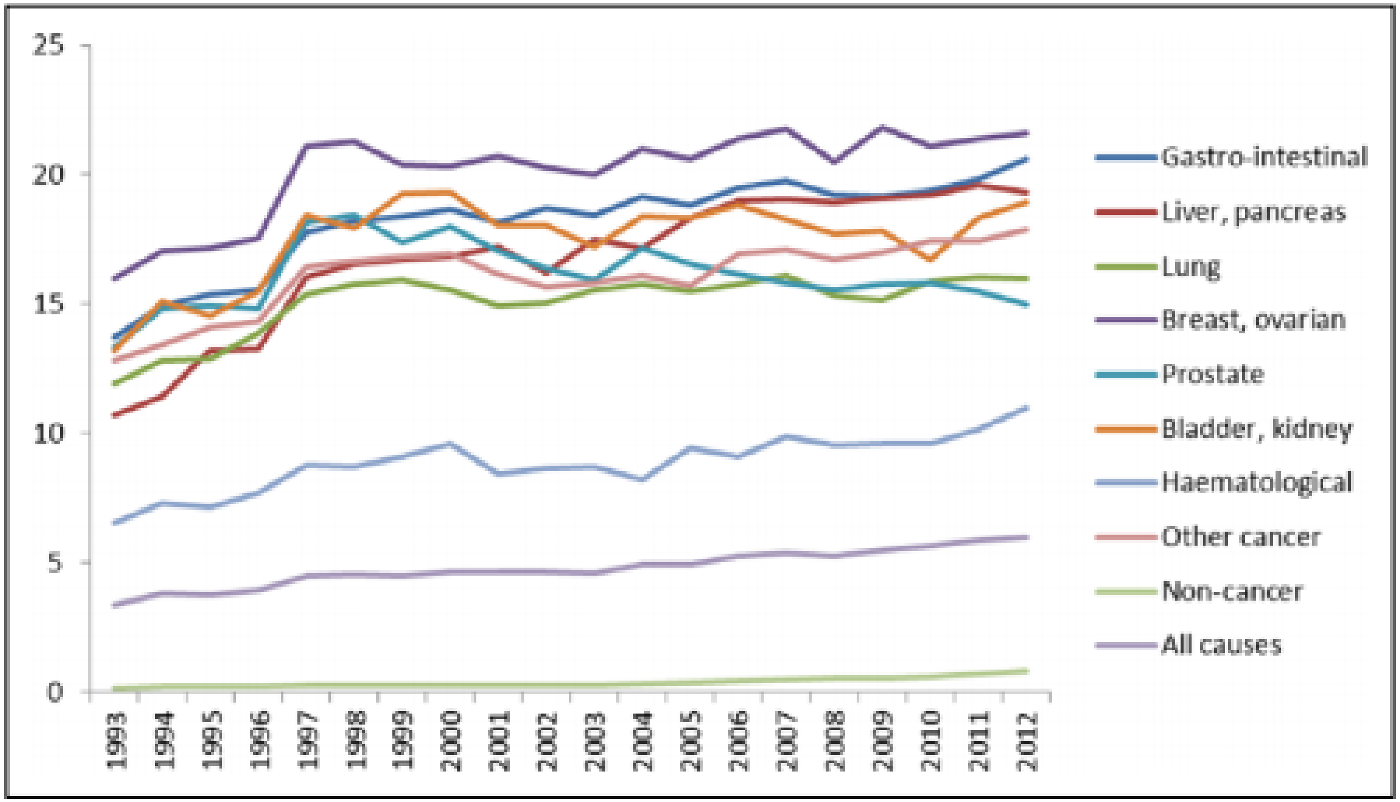


Figure 2. Percentage of deaths in England that occurred in hospice, by underlying cause of death, 1993–2012.
Hospice deaths accounted for 3.6% of all deaths in England in 1993 and rose to 6.0% of all deaths in 2012. The proportion of cancer deaths that occurred in hospice was highest in breast/ovarian cancer (16.0% of deaths in 1993, 21.6% of deaths in 2012) and lowest among people with haematological malignancies (6.5% of deaths in 1993, 11.0% in 2012). Very few people with non-cancer conditions died in hospice (0.2% of deaths in 1993, 0.8% in 2012).

Social care

Care homes could become most common place to die by 2040

Experts estimate that 76% of all deaths in England and Wales will occur in care facilities, hospices and at home by 2040

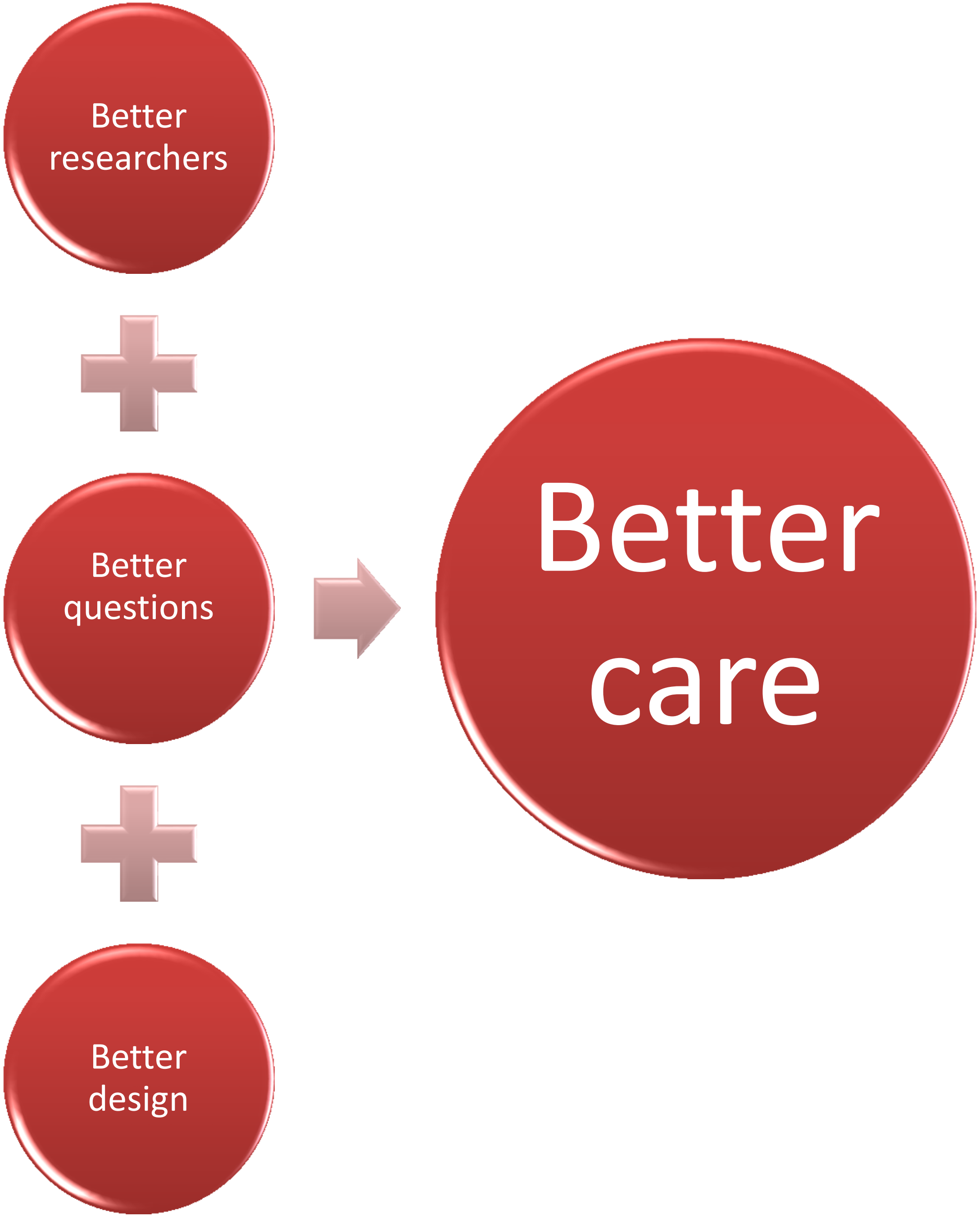
151

Press Association

Wednesday 11 October 2017 00.11 BST

Experts from King's College London found that between 2004 and 2014, deaths at care homes increased from 17% to 21%. Photograph: Alamy

What does this mean for palliative care research?



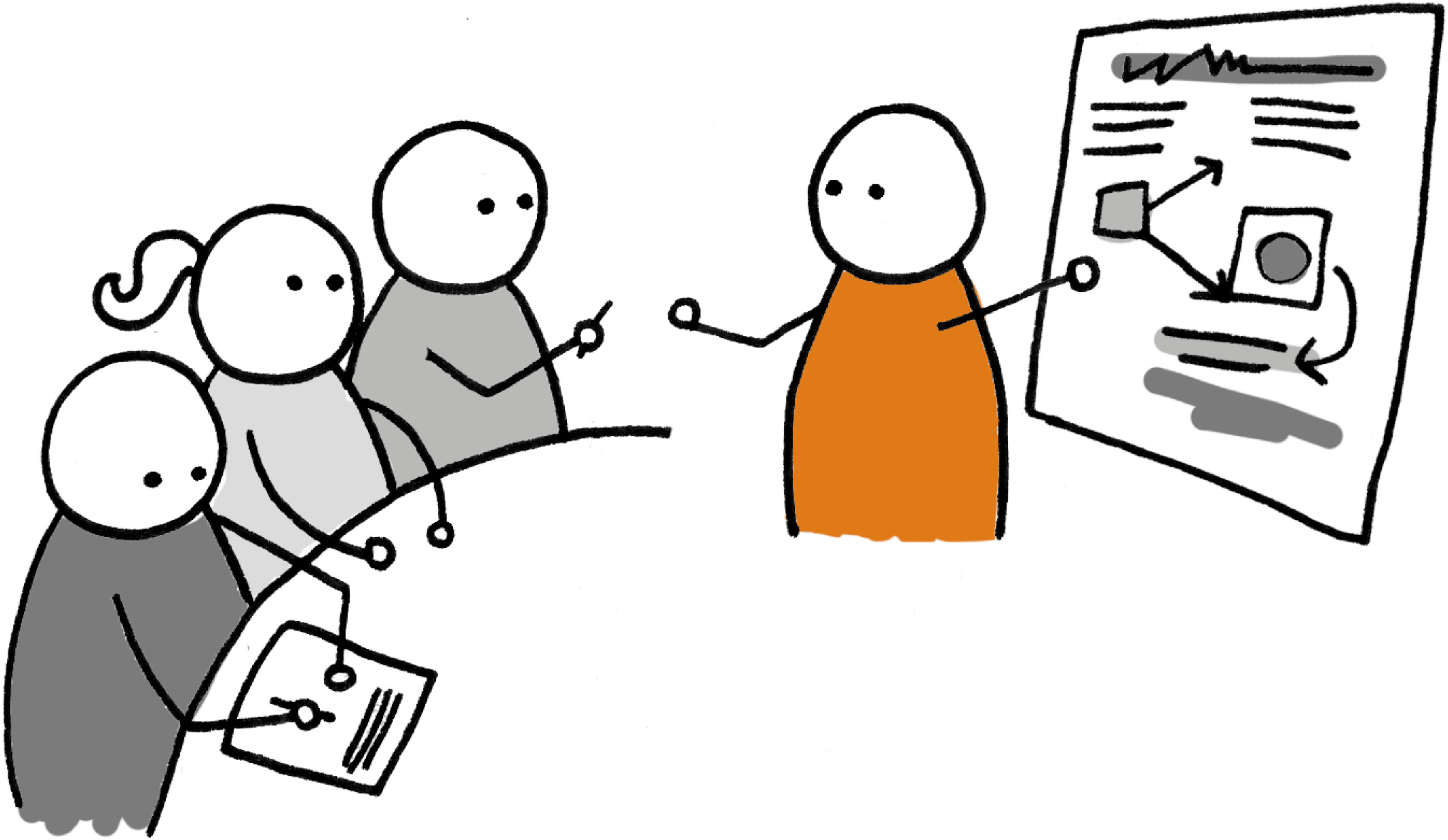
Better researchers

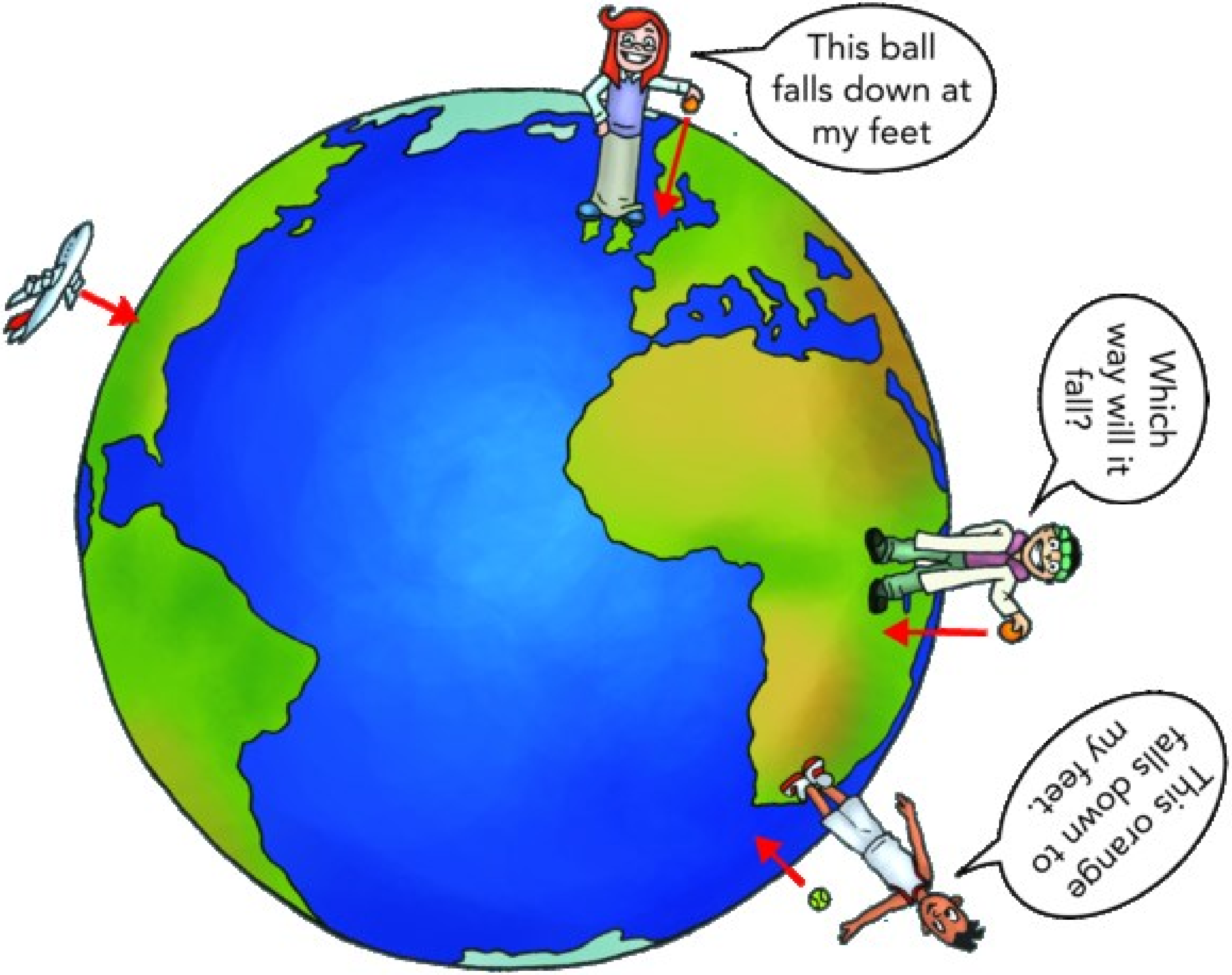
Better questions

Better design

Better care

Better researchers

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Which way will it fall?
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Better design

Palliative Medicine 2008; **22**: 336–342

Research methodologies in palliative care: a bibliometric analysis*

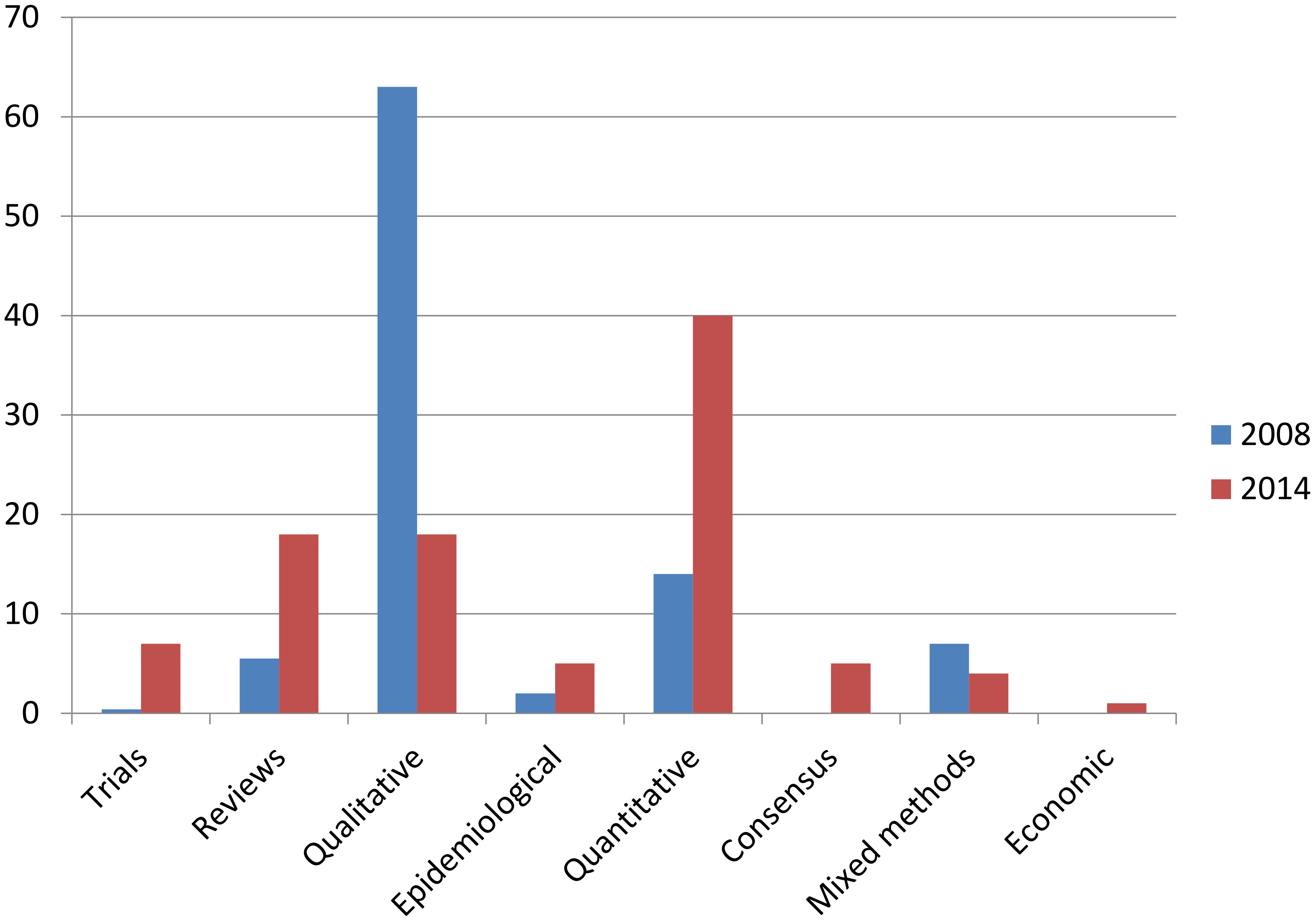
SA Payne and **JM Turner** International Observatory on End of Life Care, Lancaster University, Lancaster

The aspiration to design and conduct high-quality research in palliative care has been an important but elusive goal. The article evaluates the nature of research methodologies presented in published research within the broad remit of palliative care. A systematic search of the Medline database between 1997 and 2006, using the keywords 'palliative care' or 'end-of-life care' and 'research methodology', identified over 318 publications. A bibliometric analysis indicates an incremental increase in published outputs per year, from 27 countries, with articles widely distributed across 108 journals. The heterogeneity of the research methodologies and the journals publishing them, present challenges in defining what constitutes 'high quality'. We argue that although this diversity leads to a lack of coherence for a single disciplinary paradigm for palliative care, there is a greater acknowledgement of the differing epistemological and theoretical frameworks used by researchers. This could be regarded as enriching our understanding of what it means to be dying in contemporary society. *Palliative Medicine* (2008); **22**: 336–342

Table 4 Types of research methodologies

Classification	Number of articles	% of total articles ($n = 215$)
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	

Classification	Number of studies published in PM in 2014	Percentage
Trial	5	7
Review	13	18
Qualitative	13	18
Epidemiological	4	5
Quantitative/cohort	20	28
Survey	9	12
Consensus	4	5
Mixed methods	3	4
Economic	1	1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Qualitative
Epidemiological
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Consensus
Mixed methods
Economic
2008
2014

Bouça-Machado *et al. BMC Palliative Care* (2017) 16:10
DOI 10.1186/s12904-016-0181-9

BMC Palliative Care

RESEARCH ARTICLE Open Access

Clinical trials in palliative care: a systematic review of their methodological characteristics and of the quality of their reporting

Raquel Bouça-Machado[1], Madalena Rosário[1], Joana Alarcão[2], Leonor Correia-Guedes[1], Daisy Abreu[1]
and Joaquim J. Ferreira[1,3*]

Abstract

Background: Over the past decades there has been a significant increase in the number of published clinical trials in palliative care. However, empirical evidence suggests that there are methodological problems in the design and conduct of studies, which raises questions about the validity and generalisability of the results and of the strength of the available evidence. We sought to evaluate the methodological characteristics and assess the quality of reporting of clinical trials in palliative care.

Methods: We performed a systematic review of published clinical trials assessing therapeutic interventions in palliative care. Trials were identified using MEDLINE (from its inception to February 2015). We assessed methodological characteristics and describe the quality of reporting using the Cochrane Risk of Bias tool.

Results: We retrieved 107 studies. The most common medical field studied was oncology, and 43.9% of trials evaluated pharmacological interventions. Symptom [illegible] intervention on pain, breathlessness, nausea) were the palliative care-specific issues most studied. We found under-reporting of key information, in particular on random sequence generation, allocation concealment, and blinding.

Conclusions: While the number of clinical trials in palliative care has increased over time, methodological quality remains suboptimal. This compromises the quality of studies. Therefore, a greater effort is needed to enable the appropriate performance of future studies and increase the robustness of evidence-based medicine in this important field.

Keywords: Palliative care, Methodological quality, Risk of bias, Clinical trials


BIG DATA

Better questions

- Not describing situation
- How to improve care?
- Testing interventions?
- Implementation and KT

Better care


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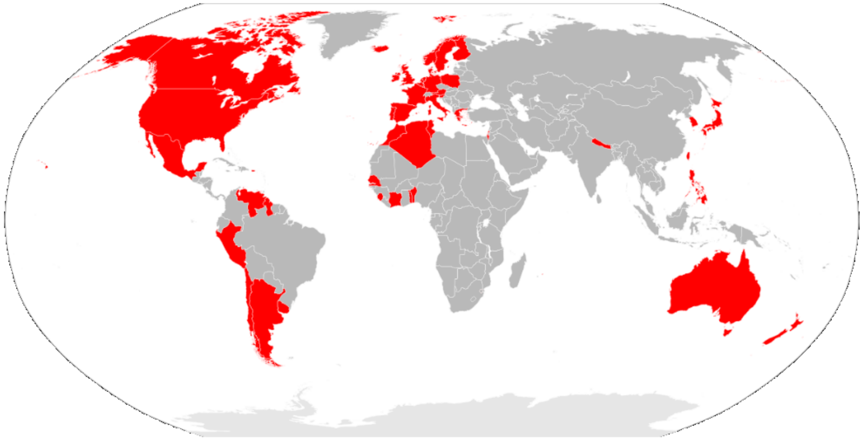
☐ Average
☐ Po

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