Opportunities and challenges in palliative care research

Fliss Murtagh

Cicely Saunders Institute
Department of Palliative Care, Policy & Rehabilitation
King’s College London

www.kcl.ac.uk/palliative
Is research fit for purpose?

• Rather extraordinarily, up to 85% of the research carried out in health sciences is likely to be wasted; it never has the chance of improving clinical care (Chalmers and Glasziou, Lancet 2009).
  – Because the wrong question is asked
  – Because the wrong methods are used to answer the question
  – Due to excessive bureaucracy for research projects
  – Due to poor/incomplete dissemination
  – Because results are not implemented into practice
Opportunities and challenges

1. What research should we be doing in palliative care?
2. What capacity and what funding is there for palliative care research?
3. How to get research findings into practice?
4. The wider context in which palliative care research occurs
What research to undertake?
Priority Setting Partnership in PEOLC (N=1403): Top 10 research questions

1. Best ways of providing palliative care *out of working hours*?
2. How can *access* to palliative care services be improved for all?
3. *Advance care planning* and other approaches?
4. Information and training for *carers and families*
5. *Staff adequately trained* to deliver palliative care? Impact of funding?
Priority Setting Partnership in PEOlC (N=1403): Top 10 research questions

6. Best ways to determine and meet a person’s palliative care needs, with non-cancer?

7. What are core services - provided no matter what the patients’ diagnoses are?

8. Benefits and best ways of providing care at home? Does good coordination help?

9. Best ways to ensure continuity for patients at the end of life?

10. Best ways to assess and treat pain in people with communication and/or cognitive difficulties?
What matters most to patients?

1. good pain and symptom control
2. family support and reduction in burden on family
3. having priorities and preferences listened to and accorded with
4. achieving a sense of resolution and peace (time and support for preparation)
5. having well-coordinated and well-integrated care, with continuity of provision (not fragmentation of care e.g. avoiding not knowing professionals, having to repeat to different professionals, etc)
What matters most to patients - mapped to PeolcPSP priorities (Jan 2015):

1. good pain and symptom control
   management – esp if cognition or commun impaired
10. pain management – esp if cognition or commun impaired

2. family support and reduction in burden on family
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   4. information and training for family carers

3. having priorities and preferences listened to and accorded with –
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   3. benefits ACP and listening to preferences

4. achieving a sense of resolution and peace (time / support for preparation) –
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   (3. ACP)

5. well-coordinated and well-integrated care, with continuity of provision
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   8. best ways of coordinating care at home, and 9. continuity of care at end of life

In relation to all 5:

1. ‘out of hours’ provision
2. access for all
5. adequately trained staff
6. non-cancer provision
7. what are ‘core’ palliative care services?
Answering the right questions …

• The questions or areas which matter for patients, families and public
• Clinicians have a distinct perspective – sometimes (but not always) the same questions
• Not always what the policy-makers are asking
• How can we influence policy-makers to ask the right questions?
• How can we persuade them to support research into areas which really matter?
Bennett, Davies & Higginson.  
Pall Med 2010
Number of publications tripled from 1997-2010

2/3 publications in cancer

Few in multimorbidity, health economics, education and training
End of Life Care: first topic for the new NIHR Dissemination Centre, 2015

NIHR Dissemination Centre

THEMED REVIEW

Better Endings
Right care, right place, right time
RIGHT CARE?

• How do we identify patients who need palliative care in the community and in hospital? What kind of staff training do we provide?
• Who currently uses our specialist palliative care services – for instance, what proportion have a diagnosis other than cancer?
• What actions are we taking to reduce inequalities in access to these services?
• What services do we have for people with dementia and carers at the end of life? What kind of ongoing support for care homes?
RIGHT PLACE?

• What proportion of our population die in hospital?
• How does this compare with stated preferences, national trends and benchmarking?
• What plans do we have to coordinate and integrate services 24/7 including community nursing, pharmacy, hospital, general practice, hospice, care homes, voluntary and social care? Are we evaluating any of these new approaches?
• What arrangements do we have to share information about what individual patients and carers want across these agencies? Is there a designated lead for end of life care in these partner organisations?
RIGHT TIME?

• Looking back, how many patients who died that we look after were identified as having palliative care needs at the right time?
• What are we doing to support staff in discussing with patients and families plans for their next phase of care?
• How can we ensure that the expressed wishes of patients and families about when they want to stop invasive treatments or not be resuscitated are known and acted on by our local hospitals, ambulances and others?
The capacity and the funds for palliative care research?
How much is spent on PEOlC research?
(Smith, Best, Noble 2015)

0.7%

% of all cancer research spending
Funding for palliative care research

• In the UK, between 0.5 – 0.7% of cancer research funding is allocated to palliative and end of life care research

• In 2010, this was allocated in 48 awards, providing an average of £25,000 per award

• Piecemeal approach = mass of small-scale studies with little impact, while national policies are developed without an adequate evidence base
“Although physicians must pass rigorous exams to practice medicine, they can practice medical research with nearly no training” Ioannidis et al, Lancet 2014

How can we tackle the two common perceptions among clinical staff?
• either that research is easy; anyone can do it …
• or that it is too difficult to participate in or to get involved?

Clinicians without protected research time and dedicated time/resources cannot contribute effectively to research.

What we need most is good principal investigators who have the time, training and energy to contribute to national studies.
Challenges

• How can we build capacity (the people) to undertake the research?
  – there are more oncology professors at one London hospital than palliative care professors across the five nations
  – there are few clinical academic training posts for doctors (12 in total so far), and even fewer for nurses and AHPs

• How can we build better awareness among practitioners of what good looks like (in terms of evidence and research) and better understanding of implications for practice?
How to get research into practice?
• Sometimes we hide behind the need for more evidence, when really we should just get on and make changes, while rigorously evaluating the impact.

Prof Moira Livingston, NHS IQ
**Problems with under-reporting**

- Only half of EU funded studies between 1998 and 2006 led to identifiable reports.
- Studies approved by RECs are often not reported (50%, 95% CI 40-50%).
- Only 40% of abstracts presented at conferences are subsequently published in full.

Chan et al, Lancet 2014
What about palliative care research?

Hanchanale & Jordan, Pall Med 2014
Knowledge mobilisation: confusing terms

- Knowledge transfer
- Knowledge exchange
- Knowledge translation
- Research into practice
- Knowledge management
- Knowledge mobilisation
Growing understanding of need to mutually generate knowledge and implement into practice

- Mutually identify and articulate a problem (James Lind PSP in PEoLC)
- Understand the context (NIHR Better Endings report)
- Select and develop knowledge together (research evidence, clinical experience, business intelligence, etc)
- Knowledge exchange and mobilisation activity
- Use in practice (and evaluating this) (Ward, Social Science and Medicine, 2012)
Examples of OACC and C-CHANGE

• OACC is about knowledge mobilisation and implementation
  – Identifying a common set of person-centred outcome measures which reflect what matters most to patients and families
  – Implementing these into practice
  – Learning together about what does and doesn’t work well, as we progress
  – Ensuring we all use the same measures
  – Taking policy-makers with us (influencing the national teams on Currency and a new clinical dataset to adopt the same measures)
Examples of OACC and C-CHANGE

- C-CHANGE is about asking and answering key research questions:
  - Ensuring we have valid and reliable outcome measures to use in OACC
  - Defining what makes a patient more or less complex in terms of their palliative care needs
  - Understanding and classifying case-mix classes
  - Describing different models of palliative care consistently and with uniform criteria
  - Costing palliative care services in a transparent and reproducible way
  - Testing different models of palliative care to determine their effectiveness and cost-effectiveness
What is successful in OACC and C-CHANGE?

• Working collaboratively – much more achieved together

• In OACC, developing knowledge together (not a linear model of ‘research evidence going into clinical practice’, but mutual work around a shared purpose to measure the difference

• In C-CHANGE, all sites want their own data and more (answering business, management and quality improvement questions)
The wider context in which palliative care research occurs?
The funding crisis in the NHS

• In England, total annual spend on the NHS is £115 billion, with 20% of Government spend on NHS, about 8.5% of GDP (not unique to UK)

• Population of England is 53,012,456 (2011 census) - so current NHS funding is £2,170 per person per year

• Greatest spend on the sickest people:
  – 27% of NHS spend is in last year of life
  – (approx. £40-50,000 per person in last year of life)

• NICE: interventions < £20,000 per QALY gained are cost effective. Those £20,000 - £30,000 per QALY gained possibly cost effective
The context of end of life care:

- ~27% of NHS spend is in last year of life
- Hospital costs are **by far** the largest cost elements of end of life care. In last 3 months of life, average cost per person who died are:
  - £4,600 for hospital costs (mostly emergency admissions)
  - *About* £280 for DN costs (*although wide variance*)
  - *About* £150 for GP visits (*average 4.6 visits but cancer*)
  - £1,000 for LA-funded social care costs
  - *Approximate – but ? £550 for hospice inpatient costs*
Changing delivery of health and social care:

- Primary care
- Community services
- Hospitals
- Social care

Networks of care

- Out of hospital care
- In hospital care
Urgent need to tackle financial pressures:

- Organisations working in the same area to come together and bid for funding above their ‘base allocations’
- NHS England ‘top slicing’ the NHS budget for 2016/17 in order to galvanise providers and commissioners to agree local transformation plans
- *Depending on the detail of how this works*, it could represent a major change of direction for how resources are allocated within the NHS
- The principal barrier to progress is
  - achieving *transformative collaborations*
  - how to square these ambitions with the legacy of the Health and Social Care Act 2012; avoid falling foul of stakeholders who see moves to stimulate collaboration between NHS providers as a way of frustrating competition and the entry of new care providers
Examples of solutions:

• Care homes: Airedale
  – Linked to hospital by secure video, accessible specialist consultations
  – Reduction in ED admissions by 35%, ED attendance by 53%

• Nottingham City CCG - 342,000, 60 GP practices:
  – structured and pro-active approach to care, with mobile working for primary care; access to SystemOne for care homes; remote video consultations for care home residents and GP; ‘pull’ approach to acute discharges with social services involved very early in hospital admissions.
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Questions to ask ourselves

• Is the research that is funded asking the right questions?
• Do we have a strategy to increase research funding for palliative and end of life care?
• Do we have sufficient skilled research workforce in palliative care (professors, senior lecturers, clinical academics) to deliver high quality palliative care research?
• How can we best maximise the benefit and mobilise research evidence and related knowledge into palliative care practice?
• What opportunities might arise through the urgent need to change patterns of health and social care delivery?
Thank you

fliss.murtagh@kcl.ac.uk