

Research Networks- Nasjonalt og internasjonalt Fordeler og utfordringer

Stein Kaasa

Research in palliative care

- Do we need PC research?
- How is the situation today?
 - The clinical barrier
- What is a palliative care population?
 - How to classify?
- What do we need to do to improve?

Do we need research?

Some historical considerations

- Ethical considerations
- Organisational/practical considerations
- Medical considerations
 - Diagnosis
 - Treatment
 - Care

Ethical considerations

some statements from ‘the old days’

- “Research is not a part of hospice.....”
- “The population is too frail for clinical research.....”
- “Hospice and palliative care promotes individual treatment, personal care and not research”.

“The Declaration of Helsinki is generally accepted as an ethical code of practice for clinical research and its principles are applicable to palliative medicine”

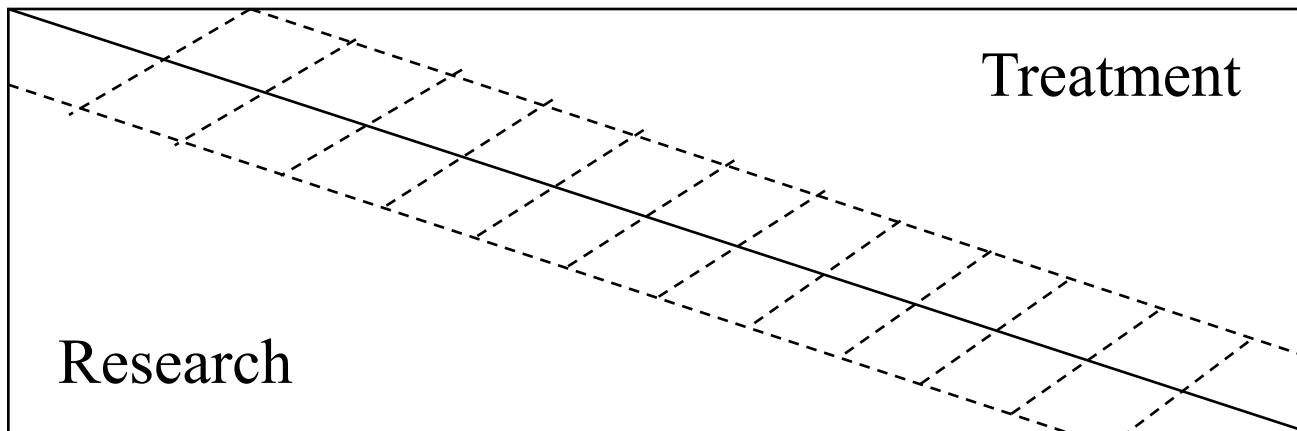
Hanks G, Kaasa S and Robbins M. Research in palliative care: getting started.
Oxford Textbook of Palliative care, 3rd edition

In order to improve the field of palliative medicine as in all branches of clinical medicine, systematic research is necessary to evaluate the effectiveness of interventions.

The clinical barrier

Research and treatment

Common conflicts of interest in the clinic?



'Current' status

Methods

- EAPC pilot survey
- Journal reviews

Kaasa et al Pall Med
2006;20,727-734

Anno 2006

- Few large RCT s
- Many similar small surveys on service delivery
- Major resources are used to conduct small inconclusive studies
-what about collaboration?

Funding

- No “ear marked” funding for palliative care research
- STREP – 6th Framework
-and we hope to see it in the 7th Framework

Comments

- Few full time research chairs in palliative care
 - In palliative medicine most chairs are also involved in service delivery and service development
 - That is positive ...to involve PCR in the clinic
 -but can we compete on the open market?
- Funding – “One need to compete on the open market”
- Too few and too small research groups
- Publications
 - Few randomised studies
 - Dominated by survey/audit/description

How to make high quality research sustainable?

- Research groups of a minimum size and competence
- Necessary infrastructure
- Arenas of collaboration
- Long term funding
- University based activity

Anno 2008

Pain Assessment Tools in Palliative Care; a call for consensus

Marianne Jensen Hjermsstad, Jane Gibbins, Dagny Faksvåg Haugen, Augusto Caraceni, Jon H. Loge, Stein Kaasa

On behalf of the EPCRC, European Palliative Care Research Collaborative

In press Pall.Med.

Aims:

- Identify pain assessment tools for use in PC, published after 2003 or not included in the previous review (Hølen et al JPSM 32; pp 567-580)
- Examine the dimensions and items of these tools
- Examine the rationale for development of these tools
- Examine the instruments' stage of development, according to the European Organisation for Research and Treatment of Cancer (EORTC) standards
- Identify the relevance of dimensions for pain tool assessments in PC by an extended expert panel of PC clinicians and researchers

Results

- Nine new publications were identified
- All tools presented as a part of a clinical study

Results – content assessment tools

- All included pain intensity
- Type of outcome varied (NRS, VRS, VAS, etc.)
- Time frame varied (now, 24 hrs, etc.)

Rationale for the new development

- The Existing tools are
 - Too long
 - Lack of focus
 - New approaches are needed

Assessment and classification of depression

- A systematic literature review
- How is depression assessed and classified?
- 2419 papers identified, 480 potentially relevant and 199 were finally included

Wasteson et al and EPCRC
Submitted Pall Med 2008

Assessment and classification of depression

Results

- Assessment methods identified n=105
- Used only once n=64
- Heterogeneity and diversity is the final impression

Assessment and classification of depression

Results

- Different methods in different continents
- Depression/distress not conceptualized
- Case definitions are rare
- Common adjustment criteria for the somatically ill do not exist

Palliative care research - priorities and the way forward

Stein Kaasa^{a,b,*}, Lukas Radbruch^c

Eur J Cancer. 2008 May;44(8):1175-9.

Table 1 – Research initiatives in the new millennium on national or international levels

Country	Year	Total amount	Type of funding and project
Canada	2004	16.5 million Canadian dollars	Career transition awards Pilot project grants New emerging team grants
USA	2005		National Palliative Care Research Centre A centre to promote palliative care research
Europe	2006	1.8 million Euro	EU sixth framework – combating cancer European Palliative Care Research Collaborative (EPCRC)
Europe	2007	1.3 million Euro	EU PHEA – health information Describing best practices in palliative care in Europe
Europe	2008	1.6 million Euro	Coordination and supportive actions: Reflecting the positive diversity of European priorities for research and measurement in end of life care (PRISMA)
Europe	2008	2.3 million Euro	EU seventh framework – coordination and support actions (coordinating) – optimizing research on end-of-life care in cancer patients: A European collaboration to optimise research and clinical care for cancer patients in the last days of life Optimizing Cancer Patient Care through the Advancement of Research and Education (OPCARE)

Table 2 – Main areas of focus

- National and regional research agenda with specific priorities
- National and international collaboration
- Development/agreement about outcomes
 - Patient centred
 - Independent from setting
- Development/agreement about patient cohort classification
- Type of studies
 - Move from descriptive to (experimental) intervention studies
 - Sufficiently sampled
- Research in team – multidisciplinary and multi professional
 - Long-lasting of sufficient size
 - Translational with input from basic scientists

Palliative Care Research – Time to intensify the international collaboration

‘The EAPC RN aims to play an active role and aims to be an open arena for palliative care research activity within Europe and with close collaborations with researchers in other parts of the world ’

Palliat Med. 2008 Jun;22(4):301-2

EAPCRN strategy plan

- Train a sufficient number of clinician scientists and scientists in palliative care research
- International network of palliative care research
- At the national level -earmarked funding as in the British and Canadian research programs

EAPCRN strategy plan

- Common indicators for the classification and assessment of subjective outcomes
- Development needs to be fertilized in an open structure
- National and international (EU) funding needs to continue and the successful collaboratives need to receive further funding without unnecessary gaps

European Palliative Care Research Centre

The European Centre will bring the palliative care research forward according to the local -, the EAPC RN - and the world wide agenda through coordination and collaboration

The action should primarily focus in the first period on ...

- Coordinate actions between groups and individual researchers linked to the EAPC RN
- Plan and conduct international multicentre studies
- Promote palliative care research in Europe with the aim to improve research funding

The action should primarily focus in the first period on.. (cont)

- Initiate and develop evidence based guidelines and perform update of treatment guidelines when appropriate.
- Establish an international PhD program for teaching young investigators/researchers
 - E- learning in palliative care research

How to bring collaboration into practice?

Clinical and research based seminar

- Fall 2009 in Trondheim
- Proposed content:
 - Cachexia
 - Depression
 - Assessment and classification
 - Other proposals?
- Format?

Invitation



11TH CONGRESS
OF THE EUROPEAN
ASSOCIATION FOR
PALLIATIVE CARE
7th – 10th MAY 2009
VIENNA AUSTRIA

arrivi
nini
coroos

arrivi
nini
coroos



AUSTRIAN
SOCIETY FOR
PALLIATIVE
CARE



EUROPEAN
ASSOCIATION FOR
PALLIATIVE
CARE
EAPC

For further information please visit: www.eapcnet.org/vienna2009

EAPC

www.eapcnet.org/research2008



5th Research Forum of the European Association for Palliative Care

Glasgow UK 10-12th June 2010

