

Palliative Care Research – an Introduction



Staffan Lundström, MD PhD, Associate Professor, Consultant
Palliativt Care unit and R&D-unit Stockholms Sjukhem,
Dept of Oncology-Pathology Karolinska Institutet

This lecture

- A brief history of palliative care research
- Some examples of important studies
- Is palliative care research special?

What is research?

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History of palliative care research

- Modern hospice movement
- St Christopher's Hospice in London 1967
 - Scientific program
 - Studies in pain control
- Palliative care → mainstream of healthcare → research not prioritized
- But things have evolved...



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Palliative care research is growing

- A rapid increase in published (and indexed) articles relevant to palliative care since the 1980s
- Around 50 journals publish papers on palliative care, focus on cancer
- Growing number of specialist palliative care journals – around 30 relevant journals
- International research networks
- International research congresses

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Pain study at St. Christopher's hospice

- Controlled trial comparing oral diamorphine and morphine given regularly
- 699 patients in the study
- Studied potency ratios, gender differences
- Conclusion: Morphine is a satisfactory substitute for orally administered diamorphine

Twycross R. Choice of strong analgesic in terminal cancer: Diamorphine or morphine?. Pain 1977; 93-104

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The impact of early palliative care

- Patients with newly diagnosed metastatic non–small cell lung cancer.
- Early palliative care integrated with standard oncologic care vs standard oncologic care.
- The first group had a better quality of life (QOL), less depressive symptoms, and longer median survival than did those who were assigned to oncologic care alone.

Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010; 363:733-742.

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Cost-effectiveness of palliative care

- Literature review of available international evidence on the costs and cost-effectiveness of palliative care interventions in any setting (e.g. hospital-based, home-based and hospice care) over the period 2002–2011
- Palliative care is most frequently found to be less costly relative to comparator groups, and in most cases, the difference in cost is statistically significant.

Smith S, Brick A, et al. Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative Medicine* 2014; 28:130-150.

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Is palliative care research special?

Study	Cardiovascular	Palliative care
Population	Homogenous	Heterogeneous
Age	Middle-aged	Elderly
Symptoms	Few	Many
Functional status	Often high	Often poor
Cognitive status	Adequate	Often impaired
Medication	Well defined	Polypharmacy
Survival	Long	Short
Endpoints	Biochemical, survival	Symptoms, QoL
Ethical issues	Minor	Major

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Obstacles to research in palliative care

- Ethical issues:
 - Palliative care patients - a vulnerable group
 - Can their interests be protected?
 - Understand information?
 - Give informed consent?
 - Limited life expectancy – patients hardly benefit from the research
 - Research ethics committees difficult to persuade
- ...but palliative care patients have a positive attitude to research participation!

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Is palliative care research special?

- Palliative care research struggles with:
 - Difficulties in accrual of patients into trials (e.g. prognosis)
 - Attrition (cases are lost from the sample over time)
 - Missing data
- We often have to consider the proximity to death:
 - Constant progression – few things can be kept constant
 - Disease
 - Symptom intensity
 - New symptoms
 - How to assess? E.g. EORTC QLQ C-30 – high reliability, poor validity?
 - How to evaluate if constant progress?

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Is palliative care research special?

- We are often moving around in unknown territory:
 - The most ill... The least knowledge...
 - Descriptive studies are needed
 - How common is a symptom?
 - Symptom clusters?
 - What treatments are used?
 - Qualitative methods are needed
 - When we do not have the answers
 - Focus on “Why?” instead of “How many or how often?”
 - “What is your biggest problem right now?”

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Do not forget...

- Palliative care research, like palliative care itself, needs to be multidisciplinary and multiprofessional.
 - Different research methodologies
 - Researchers from different backgrounds
- Palliative care patients have a positive attitude to research participation!
- Palliative care research is fun and rewarding!

