

## Palliative Care Research – an Introduction



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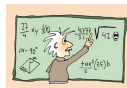
## This lecture

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

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## What is research?

- A systematic search for new knowledge
- Using scientific methods to collect, organize and analyse information, and relate to previous results and theories
- Includes presenting the results and make it available for a wider audience
- Research is based on a problem from which the researcher has created a research question



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## The research process

Identified problem



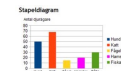
Research question/hypothesis

Method



Collect data  
Analysis

Results



Conclusion



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## Your research question

- Previously studied?
  - Search in medical databases, e.g. Pubmed
- If previously studied
  - To what extent?
  - Which method was used?



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## Choosing the method

- Available resources?
  - Financial resources
  - Coworkers
  - Access to data, other material
- Available time?
- Choose a feasible method – simpler is often better!
- Can you use already collected data/material?



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## The research process – an example

|                              |                                                                   |
|------------------------------|-------------------------------------------------------------------|
| Identified problem           | Which factors affect the place of death?                          |
| Research question/hypothesis | Differences between men and women? Other factors?                 |
| Method                       | Retrospective review of medical records                           |
| Results                      | No gender differences. Key predictive factor: Patient preferences |
| Conclusion                   | Specialised home care can offer equal care                        |

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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!



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