

Scurvy

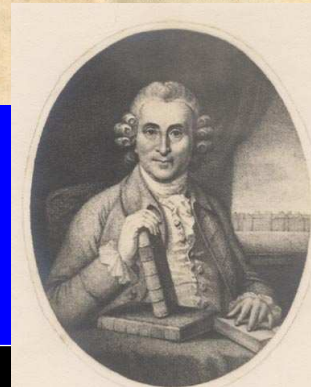
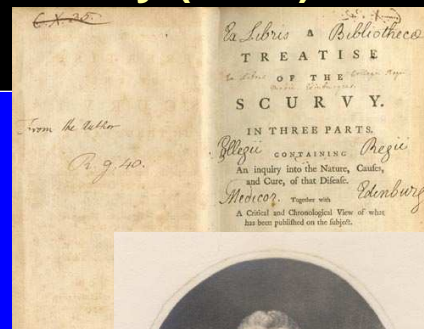


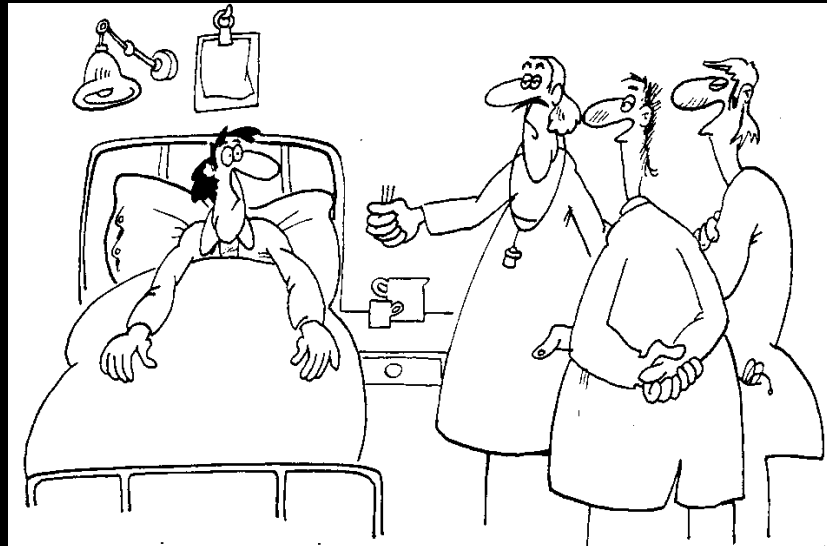
James Lind: Treatise on Scurvy (1753)

12 patients with Scurvy
same symptoms
same nutrition

6 treatments:

- 1 liter Cider per day**
- 25 drops Vitriol 3/d**
- 2 spoons vinegar 3/d with food**
- 0,5 liter sea water oer day**
- 2 oranges, 1 citron per day**
- electuary with garlic, mustardseed**





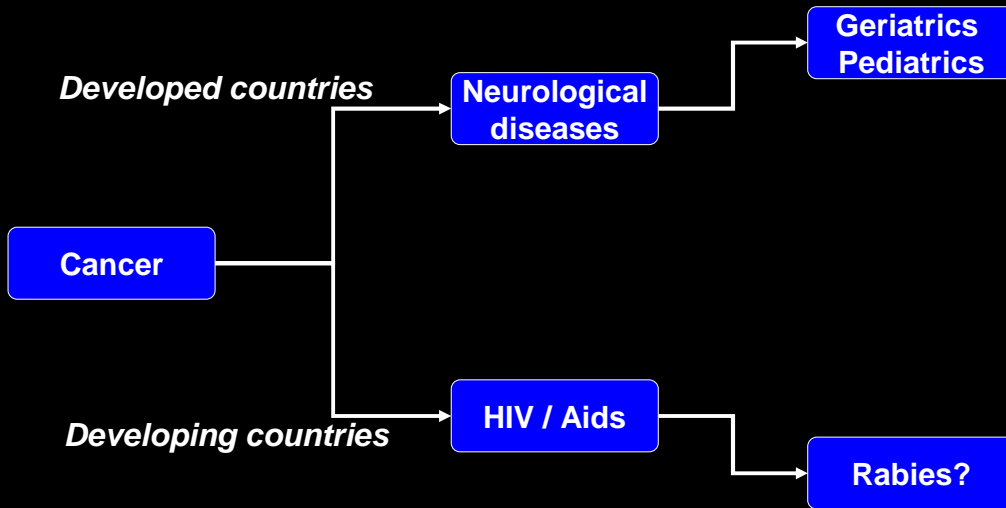
*We have to agree on a therapy.
Draw a match.*

Research in palliative care

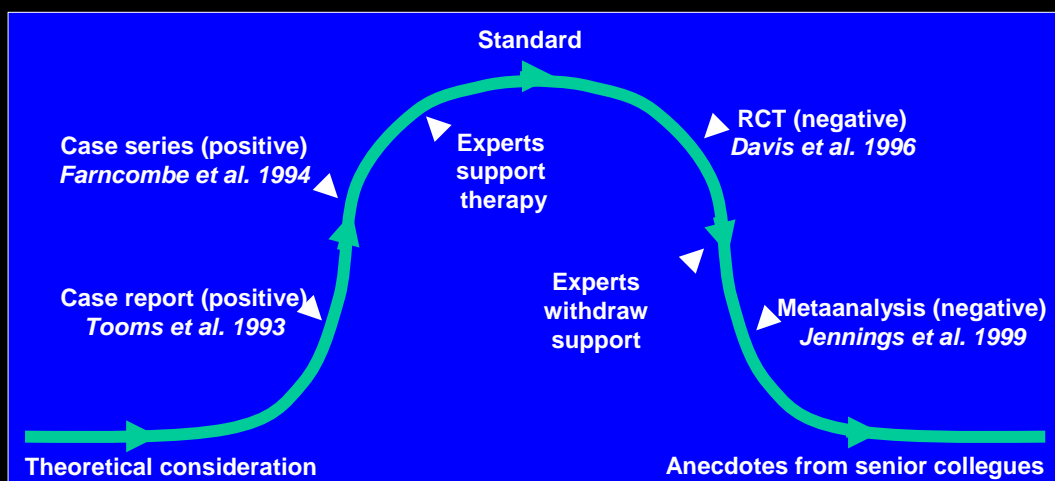
Areas

- Pain management
- Control of other symptoms (dyspnea, fatigue....)
- Quality of life
- Attitudes and emotions (coping, bereavement....)
- Organisation of care
- Others....

Research in palliative care Priorities



Scott's Parabola Rise and fall of a new method



Methodology

Controlled trials

open	patient and physician know treatment arm
single blinded	patient does not know physician knows
(observer blinded)	patient does not know physician knows observer does not know
triple blind	patient does not know what he gets nurse does not know what she gives physician does not know what he does

Journal of Irreproducible Results, New York 1983, p. 96

Research in palliative care

Problems

Low patient numbers, high attrition rates
Trial sizes low

Cognitive and physical function impaired
Tolerance for burden low

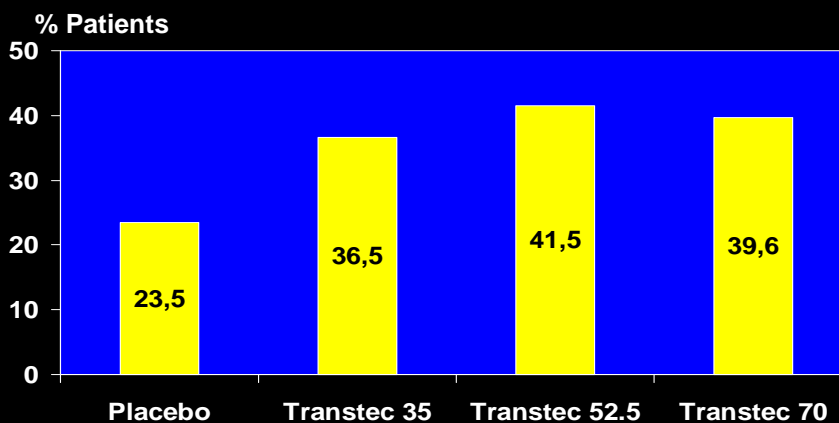
Multimorbid patients, advanced disease
Informed consent often not possible

Outcome criteria Number needed to treat (NNT)

$$\text{NNT} = \frac{1}{(\text{Responder}_{\text{Verum}} - \text{Responder}_{\text{Placebo}})}$$

Moore et al. www.ebandolier.com

Outcome criteria Responder (n=249)



Responder= ≤ 1 tablet s.l. per day
and \geq satisfactory pain relief

Outcome criteria

Cluster randomised study

Palliative care unit Trondheim
6 communities: 3x palliative vs. 3x conventional care

	<i>palliative</i>	<i>conventional</i>
patients	235	199
terminal care at home	26%	14%
terminal care in nursing home	9%	22%

Jordhoy et al. J Clin Oncol 19 (2001) 3884-94

Outcome criteria

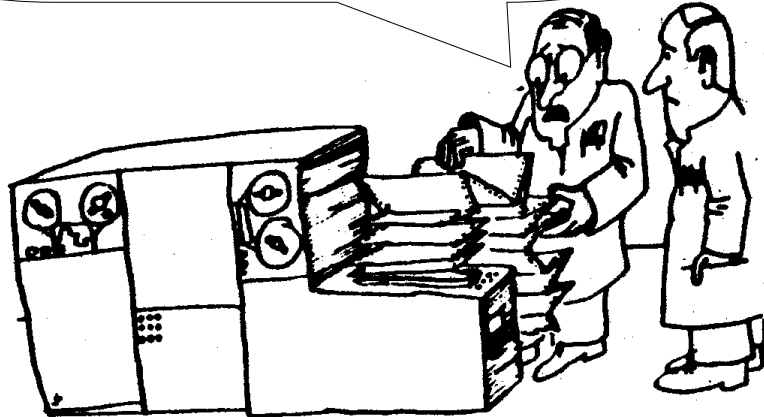
Cluster randomised study

Palliative care unit Trondheim
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	<i>palliative</i>	<i>conventional</i>
patients	235	199
terminal care at home	26%	14%
terminal care in nursing home	9%	22%
satisfaction of relatives	71,7	63,1

Ringdal et al. J Pain Sympt Manage 24 (2002) 53-63

The evaluation shows that the ambition of the researcher is the only significant factor....



Outcome

Bias: systemic errors

from patients	treatment is good placebo effect
from investigators	new treatment is better inadequate randomisation
from evaluation	statistical vs. clinical selection of positive results extended conclusions
from publishers	positive results are better medline vs. grey literature

Barriers

„You on the upper floor, we down here....“



- Patients are too sick for research
- Who is writing at the desk, does not care for patients
- Research engine University hospital
- There is too much paper produced.....

Ethical barriers

Questionnaire on euthanasia

Ethics comitee Medical Board North-Rhine:

...There should be a comprehensive informed consent, allowing the patient to discontinue further reading of the questionnaire or the information sheet at any time.....

Research in palliative care Advantages

patients' rights for the best available treatment
participation in the „scientific business“

patients feel esteemed
patients can „give back“

research experience
quality assurance

Developing research EAPC Research Forum, May 2006

DECLARATION OF VENICE

Adoption of a Declaration to Develop a Global Palliative Care Research Initiative

The European Association for Palliative Care (EAPC) and the International Association for Palliative Care (IAHPC) worked on a strategy to develop and promote a global palliative care research initiative, with a special focus on non-industrialised countries.

In May 2006 during the 4th Research Forum of the EAPC in Venice, the EAPC and IAHPC convened a meeting and joined forces with other regional and academic organisations to initiate this global initiative.

The following organisations were represented at the meeting:



Breaking down barriers

Integration

Achieving transparency

Information board, information talks

Responsible staff member for each trial

Extending the circle

Involve staff members in research

Breaking down barriers

Networking

EAPC Research Network

Cross-sectional survey

Expert workgroups

European Palliative Care Research Collaborative

EPCRC workpackages

Pain, depression, cachexia

UK Collaboratives

Designing the end of life

DFG workpackages



Palliative Medicine
University of Aachen

Methodology

N of 1 study

Small patient numbers,
evaluation of each individual patient

Cross-over, multiple cross-over

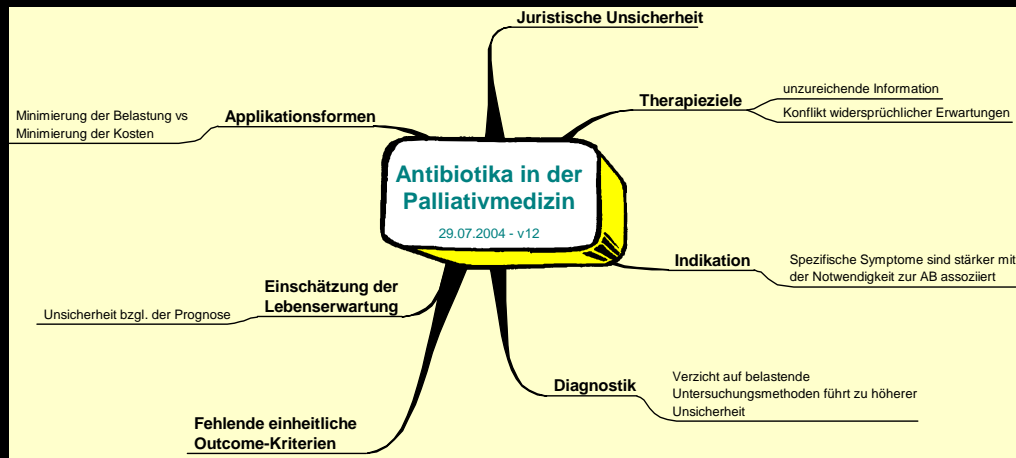
Prerequisites: therapy rapidly effective
 stable conditions



Palliative Medicine
University of Aachen

Qualitative Studien

Fokusgruppe

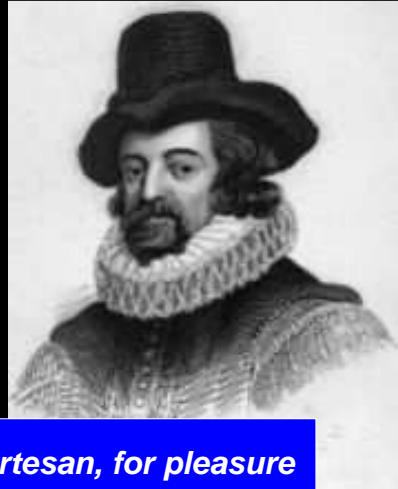


Research in palliative care

How to study

<i>What is the question ?</i>	Define problem !
<i>How do you know ?</i>	Choose study method !
<i>Can you do it ?</i>	Define significant result ! Estimate study size !
<i>Does it work ?</i>	Do the study well !
<i>Is it true ?</i>	Be critical ! Think about bias !
<i>Is it worth it ?</i>	Publish results !

Francis Bacon
(1561-1621)



....Knowledge may not be used as a curtesan, for pleasure and vanity only, but as a spouse, for generation, and fruit, and comfort.

Francis Bacon, *The Advancement of Learning*