Towards a patients’ contribution to more optimal health care?
Implications for EBM

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Outline

• Optimizing health care: the problem

• Health Care analysis for optimal care: some experiences

• Future routes and implications for EBM
OPTIMIZING HEALTH CARE: THE PROBLEM
Optimization of health care

• Generally observed:
  – Health care costs increase
  – Quality does not improve accordingly
  – Accessibility increasingly a problem
Underlying problem 1: Epidemiological transition
Underlying problem 2: Demographic transition
Underlying problem 3: dominant paradigm
HEALTH CARE ANALYSIS FOR OPTIMAL CARE: MEBEVERINME FOR IBS
Mebeverine and the treatment of Irritable Bowel Syndrome

- Mebeverine for Irritable Bowel Syndrome
  - Effectiveness comparable to predecessor and placebo
  - Slight reduction of limited side effects
- 1995: Minister requested ZFR to do the assessment
- In spite of advice, Minister removed mebeverine from reimbursement package
- Minister lost Court Case
- 1997: novel attempt by CVZ
CVZ analysis of mebeverine
Round 1: producing a pre-study

• Initial proposal: focus on effectiveness rather than efficacy
• Committee: methodological difficulties
• Thus:
  – Focus effectiveness > therapeutic value
  – Attention to alternative interventions and influencing of prescription behaviour
  – Design for a follow-up study on basis of adequate standards for therapeutic value
CVZ analysis of mebeverine
Round 2: tendering

• 6/9 groups submitted a research outline
• 3 were asked to elaborate it
• Winning proposal: research question:
  – Appreciation of therapeutic effects of medicines?
  – Is diet standardization possible?
  – What are the opportunities for a controlled follow-up study?
1. Appreciation of therapeutic effects:
   - Literature shows wide variation of outcome measures, no unambiguous evaluation of therapeutic effects
   - In interviews, general practitioners
     • emphasised patient satisfaction as standard for success
     • Appreciated significant placebo effect
     • Appreciate patient satisfaction through drug prescription
   - Patients: feel taken seriously and comfortable through prescription
CVZ analysis of mebeverine
Round 3: findings (cont’d)

2. Diet standardization:
   Difficult, if possible at all, because of variability of responses
   Best advices: fibres; must be administered as drugs because of compliance problems

3. Design for follow-up study
   Not enough knowledge for evidence based guidelines
   Efficacy of fibres compared with mebeverine
CVZ analysis of mebeverine

• Reflection:
  – Problem started due to supply-oriented policy mechanisms
    • > one limite to patient involvement
  – Central problem initially focused on therapeutic value; then shifted back to effectiveness/efficacy
    • In both cases, the reasons were:
      – Diversity in treatment and treatment responses
      – Ambiguity and uncertainty concerning underlying pathology
  – Reinforced by methodological focus on RCT, i.e. on ‘universal’ knowledge
Medical literature on IBS: Theoretical reductionism

- Critical scrutiny: medical literature
  - Strong focus on gut motility and intestinal hyper-sensitivity
  - Much less attention to alternative pathologies:
    - Food habits
    - Brain-gut axis and stress
    - Work done indicates that they have therapeutic value, and that psycho-social actors influence complaints as well as help-seeking behaviour
  - No attempts to relate different hypotheses to individual cases
Medical literature on IBS: another problem

- Methodological: one-sided focus on RCT
  - Difficult to account for diversity
- Reasons:
  - Multiple causes
  - Non-linear causation
Medical practice: a critical scrutiny

- Critical scrutiny: medical practice
  - Interviewed practitioners: often see value of alternative treatments, but lack convincing power vis-a-vis patients
  - protoprofessionalization
Alternative practice: the belly clinic

• UMCL:
  – ‘belly clinic’: Interdisciplinary team: dietary advice, cognitive behavioural therapy, physiotherapeutical advice etc.
  – analyze with patients, in detail, nature of complaints, and the relation to the ways in which they deal with their consequences
  – Experience: much tact is needed; expert knowledge often appears persuasive.
LOW BACK PAIN
Low Back Pain

• In Netherlands:
  – 15% of work absenteeism
  – 12-14% of long term work inaptitude

• In 90-98% of the cases, complaints are ‘non-specific’, i.e. they cannot be attributed to a clear, single bodily defect

• Traditionally:
  – First recourse: diagnose and treat bodily defect
  – If absent: ‘psychogenic’ => rest + pain killers + advice “learn to live with pain”

• More recently:
  – from separation mind – body towards bio-psycho-social model
Bio-psycho-social model

• LBP arises from multiple, potentially interacting factors:
  – Bio: reduced mobility, muscle power or coordination
  – Psycho: mobility anxiety, stress or irreal fears regarding LBP
  – Social: work situation, lack of understanding from others
Bio-psycho-social model
The ‘back school’

• Conceived by Zachrisson (Sweden)
• Multidisciplinary treatment
• Learning objectives:
  – Empower patients towards agency in improving their workplace
  – Increase understanding of LBP > eases, and reduces chances of wrong treatment choices
  – Secondary prevention
Back school & EBM (1)

• Early EBM studies:
  – Diversity in back school curricula => metastudies complicated
  – Internal validity limited: rarely RCT methodology

• Miedema & van Loon (2003)
  – Internal validity has recently increased
  – Metastudy, with pain, absenteeism and workstatus as dependent variables:
    • Effects of mondisciplinary interventions on functioning limited for acute, but significant for chronic complaints
    • Effects of mondisciplinary interventions on pain, but short term
    • Most successful are programmes that comprise active practicing
    • Multidisciplinary interventions difficult to evaluate
    • Second order effects of e.g. Attention for complaints hard to establish
    • Gender differences
• Problems underlying metastudy difficulties: not taken into account as independent variables:
  – Context
  – Responses (psychological, behaviour) to treatment
From RCT-based EBM to realist synthesis

The basic ingredients of realist social explanation and experiment (CMO configuration)

Source: Pawson and Tilley, 1998, Reference 18
CMO and theory building

Figure 1: The Realist Evaluation Cycle

Realist synthesis for LBP

• Pawson (2002) in *Evaluation*

• N.B.: bio-psycho-social model comprises
  – Context
  – mechanisms

• Use bio-psycho-social model to
  – understand CMO outcomes,
  – and vice versa
  – And top integrate different mechanisms into more comprehensive theory
FUTURE ROUTES AND IMPLICATIONS FOR EBM
Lessons (1)

• Crucial in patient-doctor relationship:
  – Trust
  – Role / identity: who can, who must maintain health?
  – Also patients attach significance to formal medical knowledge and ‘scientific’ treatment

• Employ the latter to address the former: evidence-based treatment that include the patient.
Lessons (2)

• There is a need for
  – Novel types of medical understanding and associate practices
  – Associate methodologies for EBM

• Novel practices + Novel methodologies for EBM → developing and testing novel theory
Lessons (2)

• Potential strategy:
  – Take exemplary cases which involve many patients, with high burden for individuals and system
    • E.g. IBS, COPD, cardiovascular afflictions, diabetes, low back pain,, Alzheimer, ..
  – For these cases:
    • Broaden theoretical scope of medical research
    • Employ different methodologies for collecting evidence, incl realist syntheis
    • Use common communication channels for medical novelties to inform the public
  – Learn and use lessons for
    • strategic R&D programming
    • Reconsidering EBM standards
    • Public (re-)education
Examples

• IBS self-help site

• ‘Back schools’ for low back pain

• Returning agency to children with diabetes
Further reading


