Defining Health Services Research and Its Role in Cancer Control

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Defining Health Services Research

There is no real consensus to the definition of Health Services research.

The IOM suggests definitions and identifies HSR studies as such if:
- It deals with some features, processes or effects of personal health services
- At least one of its features is related to a conceptual framework other than that of contemporary applied biomedical science
The Science of Health Services Research

- It lacks a widely adopted standard definition or conceptual structure, in part because of its markedly multidisciplinary nature;
- It is conducted in many different settings (e.g., academia, government, clinical health care settings);
- It has diverse purposes (e.g., empirical data collection, development of research instruments and methodologies, policy and operational decision making);
- It focuses on several different geographic levels (e.g., international, national, state, county) and on broad populations as well as specific population subgroups;
- It uses a particularly disparate set of theories, concepts, statistics, and devices derived from various disciplines, and it uses a wide range of time frames for data collection and analysis (e.g., historical, most current, future trends).

(IOM, 1991:6)

Health Services Research

- Measures the financing, organization, delivery, and outcomes of health services
- Community, management, and policy focus
- Multidisciplinary
- Typically cost, quality, and access focus
- May also be more traditional outcomes
Health Services Research:
the impetus....

- Variation in patterns of care have been identified and measured across the country.

These variations can be the result of:
- Variations in disease (i.e., severity or incidence),
- Variation in patient preferences (or a reflection of variation in physician preferences)
- Variation for other reasons
  - Uncertainty about optimal treatment (Prostate cancer)
  - Density of services available—(MRI, CT scans)

The Need for This Research

- How do we know how much of care is absolutely necessary (we should pay for)?
  - Vs. How much is questionable?
  - Vs. How much is unnecessary?
    - Harvard Community Health Plan
Health Services Research

- Measures Structure
  - Accreditation
  - Certification

- Measures Process
  - Technical excellence and availability
  - Access
  - Utilization

- Measures Outcomes
  - Patient satisfaction
  - Mortality
  - Morbidity

HSR & Outcomes Research

- Measures what works in practice (effectiveness) vs. in clinical trials (efficacy)
- Measures outcomes usually other than biomedical
- Studies large populations, regardless of eligibility for trials **
- Uses insurance claims data, etc. when applicable

** Approximately 2% of clinical population eligible for RCTs - efficacy vs. effectiveness.
Definition of Outcomes for Health Services Research

• “. . . A change in a patient’s current and future health status that can be attributed to antecedent health care.”
  – Includes social and psychological function, as well as physical and physiological performance.

“But, while process is the primary object of assessment, the basis for the judgment of quality is what is known about the relationship between the characteristics of the medical care process and their consequences to the health and welfare of individuals and of society, in accordance with the value placed upon health and welfare by the individual and by society.”

Categories of Outcomes in HSR

Generic Health Outcomes

• Patient Satisfaction
• General Health Status
• Functional Status
• General Quality of Life
Categories of Outcomes in Health Services Research

- **Disease Specific Indicators**
  - Laboratory or other diagnostic test results
  - Prevention measures (mammography use, retinal exams for diabetics, immunization rates)
  - Symptoms
  - Severity or stage of disease
  - Progression of Disease
  - Remission of Disease
  - Recurrence of disease or symptoms

- **Utilization (Process)**
  - Hospitalization rates
  - Readmission rates
  - Rates of Hormonal use for breast cancer
  - Rates of Bone Scan among women with breast cancer (node positive versus node negative)

- **Cost (Direct and Indirect)**
  - Total Costs
  - Costs to insurers
  - Costs to consumer

Health Outcome Domains

The Five [Six?] D’s

- **Death**
  Universal - focus on timing of the event

- **Disease**
  Measured as symptoms, signs, and/or laboratory tests

- **Disability**
  Diminishing of independent living and function

- **Discomfort**
  Symptoms affecting living: pain, nausea.

- **Dissatisfaction**
  Emotional discomfort with situation

- **(Destitution)**
  Financial effect resulting from health care payment
Outcomes as measures--Advantages

- When the scientific basis for accepted practice is in doubt, using outcomes discourages dogmatism and maintains more flexible approach to management
- May help develop less costly and yet equally effective management strategies
- May reflect contributions of all practitioners to the care of the patient
  - Inclusive, integrative
- May reflect patients’ contribution to care
  - Potential influence of patient-practitioner relationship
- Client satisfaction as an outcome reflects this relationship

Outcomes as measures--Disadvantages

- Even expert practitioners often unable to specify outcomes of optimal care
  - Magnitude, timing, duration
- How much of observed effect of health status due to health care factors (controllable) vs patient factors (uncontrollable)?
  - How to attribute outcomes to specific aspects of care?
- Timeliness may preclude use as a real time monitor
  - May be unethical to wait for a pattern of adverse outcomes
- Outcomes for outcomes sake without regard for means to outcome
  - May overlook redundant, overly expensive care.
What to measure?

• Depends on the purpose of performing quality assessment
  – Set policy
  – Measure quality and provide feedback to providers
  – Provide measures of accountability to payors (insurers or patients)
  – Assessing cost/cost effectiveness

What to Measure?
Depends on who receives the information.

• Insurers

• Health care providers
  – hospitals, physicians, other health care providers such as group practices
  – specialty care providers- mammography centers, makers of policy, researchers.

• Patients
  – The end receiver of outcomes information will in large part determine which outcomes are measured.
What to Measure?
Depends on Disease/Condition.

- The lag time does not always permit direct measure of outcome:
  - Eg: intervention in diabetics to reduce diabetic retinopathy and blindness
  - Cannot wait the years required to measure the change
    outcome: rate of blindness
  - Therefore assess a process measure that directly impacts on the rate of diabetic retinopathy: dilated eye exam rates.

What to Measure?
Quality is Key.

- The Institute of Medicine suggests that one must always consider outcomes in the context of quality.

“Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” National Academy Press 1990
Defining Quality Standards

- Guidelines
- Benchmarking
- Clinical Consensus
- Expert Opinion
- Intuition

Deciding How to Measure Quality

- Choice is based on the requirements of the situation
- If you need timely info about conduct of care, that pinpoints responsibility for error:
  - use detailed process, procedural end point,
  - and immediate, process-specific, “mini-outcomes”.
Deciding How to Measure Quality

• If you need measures of general program effectiveness, more inclusive health status measures,
  – such as when a group of providers have responsibility for overall health of a defined population over longer periods of time,
  – use outcomes

Deciding How to Measure Quality

• Process as a measure of outcome:
  – If good science (i.e. clinical trials) showing that a given process leads to a desirable outcome, then measuring the process is sufficient
    (mammography utilization and mortality)

  – Measuring the outcome could be misleading because of extraneous influences on the outcome
    (treatment, race, age)
    • Must control for these (adjusting for confounders)
Deciding How to Measure Quality

- Outcome
  - If no science exists showing that a given process leads to a desirable outcome:
    - Evidence-based medicine agrees with measuring neither
    - Donabedian suggests measuring both simultaneously and try to show a valid association between the two, or use outcomes as a screen to measure process

Health Services Research: What do we do?

- Patterns of Care
- Costs of Care
- Cancer Prevention
- Outcomes from Care
- Efficacy vs. Effectiveness
- Dissemination of practices/new therapy
- Monitor Quality of Health Care Provision
- Cancer Surveillance Tools
HSR and Cancer Surveillance: a specific example.

• **Using Claims Data for Cancer Surveillance**
  – Link data from multiple sources to
  – Supplement cancer case identification
  – Supplement reported treatments
  – Reduce Bias in reporting of incidence/treatment
  – Permit better assessment of effectiveness of therapy

HSR and Cancer Surveillance: a specific example

• Claims data validated for reporting cancer treatment (chemotherapy)
• Chemotherapy provided predominantly in MD offices and *NOT* reported to cancer registry
• Therefore incomplete treatment
• Limits utility of cancer data for
  – Patterns of care studies
  – Assessing outcomes among different populations
  – Evaluating the effectiveness of various regimens in the general population
HSR and Cancer Surveillance: a specific example

• Propose to develop a system using prior information (validity of MD office claims for reporting chemo)
• Reporting is mandated by law
• Difficulty enforcing the regulation
  – Therefore we propose to develop a system for capturing treatment (and missed cases) directly from MD office to central cancer registry
  – Based on billing stream
    • so does not require work for MD office,
    • makes them compliant with reporting regs and
    • allows an opportunity for them to receive data back from the central registry on their patients

Categories of Outcomes

• Good Outcomes
  • Increased survival
  • Fewer Adverse events
  • Reduced Costs of care WITHOUT an increase in bad outcomes!

• Bad Outcomes
  • Death
  • Amputation
  • Rehospitalization
  • Reduced Costs of care WITH an increase in bad outcomes
  • Unexplained Increased Costs of care
Categories of outcomes:

Continuous vs Dichotomous Outcome Measures

- **Dichotomous:**
  - Alive versus Dead
  - Sick versus Well
  - Symptom Present versus Symptom Absent

- **Continuous:**
  - General Health Status (SF 36, SF 12) Scales
  - Functional Status: Number of ADLs or IADLs
  - BPH Symptom Index