Nature of Medical Data

6.872/HST950

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Outline

- Recall context of current medical practice
- History of medical record keeping
- Organization of medical records
- Computerized medical records
  - Why
  - Key issues
  - Failures and successes
- Current approaches

Implications of Health Care Organization for Informatics

- Money determines much
  - Medicine spends 1-2% on IT, vs. 6-7% for business overall, vs. 10-12% for banking
  - “Bottom line” rules, therefore emphasis on
    - Billing
    - Cost control
    - Quality control, especially if demonstrable cost savings
    - Retention and satisfaction (maybe)
  - Management by accountants

Why Keep Records?

- Basis for historical record
- Communication among providers
- Anticipate future health problems
- Record standard preventive measures
- Identify deviations from the expected
- Legal record
- Basis for clinical research
**Who Keeps Records?**

- Doctor
- Nurse
- Office staff, admissions
- Administrator
- Physical therapist
- Lab personnel
- Radiologist
- Pharmacist
- Patient

**Forms of Clinical Data**

- Numerical Measurements
  - Lab data
  - Bedside measurements
  - Home instrumentation
- Recorded signals (e.g., ECG, EEG, EMG)
- Images (X-ray, MRI, CAT, Ultrasound, Pathology, …)
- Genes (SNPs, expression arrays, pedigrees, …)
- Coded (?) discrete data
  - Family history
  - Patient’s medical history
  - Current complaint
    - Symptoms (patient)
    - Signs (doc)
  - Physical examination
  - Medications
- Narrative text
  - Doctor’s, nurse’s notes
  - Discharge summaries
  - Referring letters

**Organization of Data**

- Doctor’s journal (traditional)
- Time order of collection, per patient (Mayo)
- Source of data
- Problem-Oriented Medical Record (POMR) (L. Weed, 1969)
  - Notes organized by problems
  - SOAP: subjective, objective, assessment, plans

**POMR**

- Data Base
- Problem List
- Progress Notes (by problem)
  - Diagnostic, therapeutic, patient education
- Plans (by problem)
The Data Base

- Identifying information (name, age, sex, race, religion, insurance info, etc.)
- Patient profile (occupation, education, marital status, children, hobbies, worries, moods, sleep patterns, habits, etc.)
- Medical history
  - Chief complaints
  - History of present illness
  - Past medical history
  - Review of systems
  - Family history
  - Medications
- Physical examination
- Laboratory data and physiologic tests (complete blood count, electrocardiogram, chest x-ray, creatinine, urinalysis, vital capacity, tonometry, etc.)

The Problem List

- “those features in the patient’s psychobiological makeup that require continuing attention”
  - Social history
  - Risk factors
  - Symptoms
  - Physical findings
  - Lab tests
- Causally organized; e.g., GI bleeding caused by duodenal ulcer appears under the ulcer

Example Problem List

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<th>No</th>
<th>Active</th>
<th>Date</th>
<th>Inactive</th>
<th>Date</th>
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<td>1958</td>
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<td></td>
</tr>
</tbody>
</table>

Problem-Related Plans

- Diagnostic: lab tests, radiology studies, consultations, continued observations, …
- Therapeutic: medications, diet, psychotherapy, surgery, …
- Patient education: instruction in self-care, about goals of therapy, prognosis, …
### Plans per problem

1. **Diarrhea**
   - **Dx:**
     - stool for occult blood, culture, ova, and parasites, microscopic fat; and muscle fibers
     - Sigmoidoscopy
     - Barium enema if persistent
   - **Rx:** Avoid foods that exacerbate
   - **Ed:** Informed that more info is needed to make a diagnosis, will aim for symptomatic therapy for now.

2. **Pyuria**
   - **Dx:**
     - BUN
     - Repeat urinalysis
     - Urine culture

3. **Obesity**
   - **Rx:** 1500 kcal diet, Weight Watchers
   - **Ed:** Dangers of obesity cited. *Goal:* 170 lbs.

### Progress Notes

- **Subjective:** interval history, adherence to program
- **Objective:** physical findings, reports of lab, x-ray, other tests
- **Assessment:** Appraisal of progress, interpretation of new findings, etc.
- **Plan:** Dx, Rx, Ed.

### Example SOAP Note

**#3 RHD with mitral stenosis**

- **S:** 2 flight dyspnea, mild fatigue. No orthopnea, hemoptysis, ankle edema. Child has strep throat.
- **O:** BP 120/70, P 78 regular
  - Neck veins normal, lungs clear.
  - Grade iii diastolic rumble, wide opening snap, P₂ slightly ↑
- **A:** Stable. Catheterization still not indicated. Risk of strep throat present.
- **P:** Dx: Cardiac fluoroscopy
  - Rx: Continue chlorothiazide and penicillin V 250mg b.i.d.—2 weeks
  - **Ed:** Reinstructed about antibiotic coverage for tooth extractions, sched. for next month. (Will contact oral surgeon.)
POMR characteristics

- Augment with data flow sheets
- Importance of clinical judgment
- Benefits:
  - Communication among team members, explicitness
  - Education and audit
  - Clinical research

POMR evidence

- Difficult adoption
- Some duplication
- Some doctors liked it
- Paper-based POMR slow, computer-based maybe faster
- Demand-oriented MR: by time, by source, by problem, etc. Dynamic arrangement.

Mayo experience

- Paper records, mostly
- Pneumatic tube delivery, therefore limited size
- Formal procedures for reaping and organizing records at discharge
- Comprehensive index

The Computer-based Patient Record

- Made strong case for CPR
- Recommended CPRI (Institute), but it never caught on
- Today’s standards grow more out of communication standards: HL7 (labs) and DICOM (digital images)
Paper record: Strengths

• Familiar; low training time
• Portable to point of care
• No downtime
• Flexibility; easy to record subjective data
• Browsing and scanning
  – Find information by unanticipated characteristics (e.g., Dr. Jones’ handwriting)

Paper record: Weaknesses

• Content: missing, illegible, inaccurate
  – E.g., one hospital study: 11% of tests were repeats to replace lost information
  – Too thick (1.5 lbs avg.)
  – Fail to capture rationale
  – Incomprehensible to patients and families

Sample paper record defects

• 75% of face sheets had no discharge disposition, 48% no principal Dx
• Agreement between encounter (witnessed) and record: 29% med hx, 66% Rx, 71% info re current illness, 72% tests, 73% impression/Dx, 92% chief complaint
• 20.8% of Medicare discharges coded incorrectly (DRG inflation)

More paper record defects

• Unavailable at up to 30% of patient visits
  – Two clinic visits in a day
  – Docs keep records in their office
  – Failure to deliver
  – Misfiled in file room
• Discontinuity across institutions
  – In/outpatient records separate
Ethnographic Design

- Xerox PARC analysis of office work
  - Sociologists, Anthropologists, Engineers
  - Much of work is
    - communication,
    - assignment of responsibilities,
    - problem solving

Medicine is an Information Industry

- 35-39% of hospital operating costs due to professional and patient communications
- Physicians spend 38%, nurses 50% of their time charting
- Exponential growth of medical knowledge and literature

Individual Users of Patient Records

- Providers
  - Chaplains
  - Dental hygienists
  - Dentists
  - Dietitians
  - Lab technicians
  - Nurses
  - Occupational therapists
  - Optometrists
  - Pharmacists
  - Physical therapists
  - Physicians
  - Physician assistants
  - Podiatrists
  - Psychologists
  - Radiology technologists
  - Respiratory therapists
  - Social workers
- Management
  - Administrators
  - Financial managers and accountants
  - Quality assurance managers
  - Records professionals
  - Risk managers
  - Unit clerks
  - Utilization review managers
- Reimbursement
  - Benefit managers
  - Insurers (Fed, State, private)
- Other
  - Accreditors
  - Gov’t policymakers, legislators
  - Lawyers
  - Health care researchers, clinical investigators
  - Health Sciences journalists and editors
  - Patients, families

Institutional Users of Patient Record

- Healthcare Delivery
  - Alliances, associations, networks, systems of providers
  - Ambulatory surgery centers
  - Donor banks (blood, tissue, organs)
  - HMO’s
  - Home care agencies
  - Hospices
  - Hospitals
  - Nursing homes
  - PPO’s
  - Physician offices, group practices
  - Psychiatric facilities
  - Public Health Departments
  - Substance abuse programs
- Management and Review
  - Medicare peer review organizations
  - Quality assurance companies
  - Risk management companies
- Reimbursement
  - Business Health coalitions
  - Employers
  - Insurers
- Research
  - Disease registries
  - Health data organizations
  - Health care technology developers and manufacturers
  - Research Centers
- Education
  - Allied health professional schools, medical, nursing, public health schools
- Accreditation
  - Accreditation organizations
  - Inst. licensure agencies
  - Prof. Licensure agencies
- Policymaking
  - Fed, State, Local gov’t agencies
Primary Uses of Patient Record

• Patient care delivery (Patient)
  – Document services received
  – Constitute proof of identity
  – Self-manage care
  – Verify billing
• Patient care delivery (Provider)
  – Foster continuity of care
  – Describe diseases and causes
  – Support decision making about Dx and Rx
  – Assess and manage risk
  – Facilitate care via Clin. Practice Guidelines
  – Document patient risk factors
  – Assess and document patient expectations and satisfaction
  – Generate care plans
  – Determine preventive advice
  – Remind clinicians
• Patient care management
  – Document case mix
  – Analyze severity of illness
  – Formulate practice guidelines
  – Manage risk
  – Characterize use of services
  – Basis for utilization review
  – Perform quality assurance
• Patient care support
  – Allocate resources
  – Analyze trends and develop forecasts
  – Assess workload
  – Communicate between departments
• Billing and reimbursement
  – Document services for payment
  – Bill for services
  – Submit insurance claims
  – Adjudicate insurance claims
  – Determine disabilities (workmen’s comp)
  – Manage & report costs
  – Perform actuarial analysis

Secondary Uses of Patient Record

• Education
  – Document health care professional experience
  – Prepare conferences and presentations
  – Teach students
• Regulation
  – Evidence in litigation
  – Foster postmarketing surveillance
  – Assess compliance with standards
  – Accredit professionals and hospitals
  – Compare health care organizations
• Policy
  – Allocate resources
  – Conduct strategic planning
  – Monitor public health
• Research
  – Develop new products
  – Conduct clinical research
  – Assess technology
  – Study patient outcomes
  – Study effectiveness and cost-effectiveness of care
  – Identify populations at risk
  – Develop registries and databases
  – Assess cost-effectiveness of record systems
• Industry
  – Conduct R&D
  – Plan marketing strategy

User Requirements

• Record Content
  – Uniform core data elements
  – Standardized coding systems and formats
  – Common data dictionary
  – Information on outcomes of care and functional status
• Record Format
  – “Front-page” problem list
  – Ability to “flip through” the record
  – Integrated among disciplines and sites of care
• System Performance
  – Rapid retrieval
  – 24/7
  – Available @ convenient places
  – Easy data input
• Linkages
  – To other info systems (e.g., radiology, lab)
  – Transferability of information among specialties and sites
  – With relevant literature
  – Other registries and institutional databases
  – To records of other family members
  – E-billing
• Training and Implementation
  – Minimal training required
  – Graduated implementations
• Intelligences
  – Decision support
  – Clinician reminders
  – “Alarm” systems, customized
• Reporting
  – “Derived documents”, e.g., insurance forms
  – Easily customized output, UI
  – Standard clinical reports, e.g., discharge summary
  – Custom and ad hoc reports
  – Trend reports and graphics
• Control and Access
  – Easy patient access
  – Safeguards of confidentiality
Why is this hard?

- Characterize edema:
  - Where?
  - When?
  - How often?
  - Temporal variation?
  - Severity
  - Symmetry
  - What other characteristics?
- Uncertainties in all of the above

- Thousand diseases, syndromes, clinical states
- Few thousand symptoms, signs, observables
- Few thousand specific lab tests
- Thousands of meds, variations, combinations, routes, dosage schedules, …
- ??? Treatments

Not just database, knowledge representation

- “Sometime before his 5th birthday, Johnny had scarlet fever, which caused changes in his heart sounds.”
- LEG <S> WEAKNESS PROXIMAL ONLY
- (EDEMA with LOCATION = FACIAL or PERI-ORBITAL, PAINFULNESS = not PAINFUL, SYMMETRY = not ASYMMETRICAL, ERYTHEMA = not ERYTHEMATOUS)

What is the “Right” representation?

Inadequate Coding Systems

- Low degree of refinement
  - E.g., ICD-9’s categories for Chronic Bronchitis
    - Simple
    - Mucopurulent
    - Obstructive
    - Other
    - Unspecified
- Poor coverage of symptoms
- Difficulty of automatic coding
  - Gabrieli’s 10M-phrase thesaurus
What Have We Learned?

- Real world is ugly!
  - Poor (inchoate) design
  - Non-adherence to design (+historical debris)
- Standards desperately needed:
  - Terminology & Concepts
  - Structure of relationships
  - Communication
- But, world is quite complex, and different complexity is appropriate for different uses

Current Status of EMR

- Fully computerized in many hospitals
  - billing, labs, pharmacy, medication administration
- Some computerization
  - Physician orders, visit histories, discharge summaries, vaccination records, emergency dept notes, pathology & radiology notes
- Little computerization
  - Anything outside hospitals & large clinics
  - History, physical, plans, rationale, …
Current Ideas

- Improved Coding
- Data Capture
  - Dictation to text, or speech understanding
  - Text to meaningful code extraction
  - Comprehensive instrumentation
  - Capture at point of generation
- Integration to Workflow
  - Direct physician order entry, protocols, expert systems
- “Aware” environments