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)

Plans (by problem)
diagnostic, therapeutic, patient education
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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<tr>
<th>No</th>
<th>Active</th>
<th>Date</th>
<th>Inactive</th>
<th>Date</th>
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<td>Recurrent bronchitis</td>
<td>1958</td>
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<td>Penicillin allergy</td>
<td>1958</td>
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<td>Cholecystectomy</td>
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<td>8</td>
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<td>June 1973</td>
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<tr>
<td>9</td>
<td>Unemployment</td>
<td>Nov 1973</td>
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</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.

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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.

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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
  - Support nursing care
  - Document services provided

- 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
### TCH Database

- **Documents**
  - DOC_STORE
  - DOC_ATTRIBUTES
  - DOC_DESCRIPTION
  - CHILD_DOCS
- **Doctors**
  - PERSNL_PUBLIC
  - PPR
- **Patients**
  - PAT_DEMOGRAPH
  - PAT_FIN_ACCT
- ...
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