Nature of Medical Data

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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
- Plans (by problem)
- Progress Notes (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

<table>
<thead>
<tr>
<th>No</th>
<th>Active</th>
<th>Date</th>
<th>Inactive</th>
<th>Date</th>
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<tbody>
<tr>
<td>1</td>
<td>Hypertension</td>
<td>1953</td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>Recurrent bronchitis</td>
<td>1958</td>
<td></td>
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<tr>
<td>3</td>
<td>Penicillin allergy</td>
<td>1958</td>
<td></td>
<td></td>
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<td>4</td>
<td>S/P pyelonephritis</td>
<td>1960</td>
<td></td>
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<td>5</td>
<td>Gallstones</td>
<td>Oct 1972</td>
<td>Cholecystectomy</td>
<td>Mar</td>
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<td>6</td>
<td>Arthritis</td>
<td>Mar 1973</td>
<td>#9</td>
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<td>7</td>
<td>Pleurisy</td>
<td>Mar 1973</td>
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</tr>
<tr>
<td>8</td>
<td>Proteinuria</td>
<td>Apr 1973</td>
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<td></td>
</tr>
<tr>
<td>9</td>
<td>SLE</td>
<td>June</td>
<td></td>
<td>1973</td>
</tr>
<tr>
<td>10</td>
<td>Unemployment</td>
<td>May</td>
<td></td>
<td>1973</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

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 ↑
P: Dx: Cardiac fluoroscopy
   Rx: Continue chlorothiazide and penicillin V 250mg b.i.d.—2 weeks
   Ed: Reinstrengthened 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 investigations
  – 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
  – Hospitals
  – Nursing homes
  – PPO’s
  – Physicians, offices, group practices
  – Psychiatric facilities
  – Public Health Departments
  – Substance abuse programs
• Management and Review
  – Medicare peer review organizations
  – Quality assurance companies
  – Risk management companies
  – Utilization review/management comp.
• Reimbursement
  – Business Health coalitions
  – Employers
  – Insurers
• Research
  – Disease registries
  – Health data organizations
  – Health care technology developers and manufacturers
  – Research Centers
• Education
  – Accredited health professional schools, medical, nursing, public health schools
  – Accreditation organizations
  – Inst. licensure agencies
  – Prof. Licensure agencies
• Policy
  – Fed, State, Local gov’t agencies
  – Insurers
  – Research agencies
• Industry
  – Design and develop products
  – Environment and market
  – Conduction
  – Plan marketing strategy

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

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
  – Accreditation agencies 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

User Requirements (cont.)

• 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

• Intelligence
  – 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)

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 is the “Right” representation?
TCH Database

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

Database Demo

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
  - Labs, pharmacy, billing
- Some computerization
  - 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