EMERGING INFORMATICS DISCIPLINE:
A PROFESSIONAL PATH TO DEFINING THE FUTURE

2006 November 6
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IOM and the IT Revolution

Delaney 2006
Genetic Counseling

Screening, prognostic, & diagnostic tests

Gene mapping

Gene identification

Gene characterization

Health Phenomena with a Genetic Component

Identification of primary biologic defect

Multidisciplinary management of pharmacotherapy.

Multidisciplinary management of gene therapy.

• Nursing interventions to support clients seeking, managing, or coping with genetic information.
• Gene-driven or targeted nursing interventions.

(Modified from Collins, 1997)
“Health information technology promises huge benefits, and we need to move quickly across many fronts to capture these benefits... The benefits are enormous, but the task is also enormously complex.”
“Harnessing advanced technologies to serve human needs”
• Outcomes measurement and clinical decision support using core nursing and healthcare essential (minimum) data sets

• Informatics framework
  • Data, information, knowledge, wisdom
  • Knowledge – representation, integration, building

* Overview

• Background
Emerging specialty - Informatics
Data – Information – Knowledge
Managing - Processing
Dance between knowledge representation (data, information, & knowledge) and research questions
Inter-relationship of vocabulary, information systems, & research questions
Nursing Information Reference Model

Layer 1: Facts:
- Demographical data
- Observations: signs & symptoms
- Aetiology: facts causal relations / data other disciplines etc.

Layer 2: Registration of:
- Nursing diagnoses
- Nursing interventions
- Results of nursing care

Layer 3: Use of Nursing Minimal Data Set on Institutional level

Layer 4: VMDSN: national & international purposes

Unified nursing terminology for comparable data

Structure characteristics: service items etc.

Policy decisions
Management decisions
Clinical decisions

Goossen, Epping & Dassen, 1997
Outcomes measurement and clinical decision support using core nursing and healthcare essential (minimum) data sets

Knowledge – representation, integration, building

Overview

• Background
Dr. Judith Graves, RN, PhD, the first nurse to complete a National Library of Medicine postdoctoral fellowship in Medical Informatics (Graves et al., 1995).
Nursing standardization efforts
Minimum Data Sets
Standardized vocabulary initiatives
Priority: computerization
McCormick Taxonomy of Research NMDS (1986)
Unique facility/agency number
Unique health record number of client
**Unique number of RN provider**
Episode admission/encounter date
Discharge/termination date
Disposition of client
Expected payer
NMDS

Nursing Care Elements

Pt/Client Demographics

Service Elements

Other Databases

UHDDS
NINR NI Priorities (1993)

Using data, information, and knowledge to deliver and manage patient care,
Defining and describing data and information for patient care,
Acquiring and delivering knowledge from and for patient care,
Investigating new technologies to create tools for patient care,
Applying patient care ergonomics to the patient-nurse-machine interaction,
Integrating systems for better patient care, and
Evaluating the effectiveness of nursing informatics approaches.
Outcomes measurement and clinical decision support using core nursing and healthcare essential (minimum) data sets

Knowledge – representation, integration, building

Overview

• Background

• Studies - examples
NMDS

Nursing Care Elements

Pt/Client Demographics

Service Elements

UB-82
UB-92

Retrieval

Costs

Multi-state

Care needs of elderly at discharge
MULTI-SITE STUDY

Baltimore, MD
Chicago, IL
Cincinnati, OH
Cleveland, OH
Davenport, IA
Denver, CO
Detroit, MI
Iowa City, IA
Milwaukee, WI

DRG
• 112
• 127
• 209
• 410

Delaney 2006
Retrospective, descriptive study
Computerized discharge healthcare record, NMDS
1 calendar year, 1 inpatient healthcare center
Total discharge records N=6219
Inclusion criteria: disposition of self-care at home, nursing home, home with home care [N=4874]
Care needs of elderly at discharge -
Summary of findings

4 most frequent nursing diagnoses = 50.53-63.9% of all diagnoses
4 most frequent nursing diagnoses same regardless of deposition
69 different diagnoses
Significant (p<.0001) differences in acuity among 3 groups
Nursing home care disposition significantly associated with female and married
NMDS

Nursing Care Elements

Pt/Client Demographics

Service Elements

UB-82
UB-92
NMDS

Nursing Care Elements

Pt/Client Demographics

Service Elements

CONTEXT
Purpose: Develop a set of data elements that reflect the context of care process; complement NMDS to support effectiveness research

Research Team: Delaney & Huber

Methods

• Focus group
• State Survey
• National Delphi
Collaborative Project - AONE

- Invitational Working Conference

Dissemination

- 1996 AONE NMMDS Monograph

Clinical Testing

- National convenience sample, 7 sites

ANA recognition – 1998

Registered with HL7
Advances in Knowledge Representation
Availability of Large Data Sets
Advanced Technologies Knowledge Building

Data Warehouse – 1996 - present
Patient Records
  • ~1,000,000 patient records
NMDS variables
  • NANDA/NDEC, S/S, RF
  • NIC
  • Goals/NOC
    Other variables: medical diagnoses, marital status, religion, acuity...
Management variables
Sites/Settings
NMDS/NMMDS Data Points
5886 / 1550
Date/time stamp
Outcomes measurement and clinical decision support using core nursing and healthcare minimum data sets.

- Background
- Studies – examples
  - Profiling practice
  - Knowledge Discovery – 2 methods
  - Decision support
Define the changing trends of DRGs in comparison with the national data.

* Define the changing trends of nursing diagnoses and nursing interventions for top 5 DRGs during the 3 years.

* Define the relationships between nursing diagnoses and nursing interventions for top 5 DRGs during the 3 years.
Rehabilitation (N=1488)
Other Perm DM/PTCA w stent (N=1100)
Major joint & Reattach (N=626)
COPD (N=465)
Simple Pneumonia & Pleur age>17 (N=29)
Fig. 1: 97 Most Frequent Nursing Diagnoses for aggregated 5 most frequent DRGs

- Health maintenance, altered
- Knowledge deficit re: specify
- Infection, potential for
- Pain
- Mobility, impaired physical
- Skin integrity, impaired
- Anxiety
- Injury, potential for
- Self-care deficit, bathing/Hygiene
- Self-care deficit, toileting
- Others
Most Frequent Nursing Diagnoses for aggregated 5 most frequent DRGs

- Health maintenance, altered
- Knowledge deficit re:specify
- Infection, potential for
- Mobility, impaired physical
- Pain
- Injury, potential for
- Anxiety
- Self-care deficit, bathing/hygiene
- Self-care deficit, toileting
- Skin integrity, potential impaired
- Others
<Fig 5> Changing Trends of Nursing Diagnoses 'Health Maintenance Altered' for most frequent DRGs.

- COPD
- Major jt & Reattach px.LE
- Oth Perm DM/PTCA w stent
- Rehabilitation

%
<Fig 7> Changing Trends of Most Frequent Nursing Diagnoses for DRG 'Rehabilitation'

- Self Care Deficit
- Health Maintenance altered
- Injury, Potential
- Knowledge deficit
- Mobility impaired

% 1999 1998 1997
<table>
<thead>
<tr>
<th>Patient care treatments</th>
<th>Rehabilitation (N=1494) – HCFA/CMS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge planning (health</td>
<td></td>
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<tr>
<td>maintenance, altered)</td>
<td></td>
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<tr>
<td>Fall prevention (mobility,</td>
<td></td>
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<tr>
<td>impaired physical)</td>
<td></td>
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<tr>
<td>Support system enhancement</td>
<td></td>
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<tr>
<td>(health maintenance, altered)</td>
<td></td>
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<tr>
<td>Teaching: prescribed</td>
<td></td>
</tr>
<tr>
<td>activity/exercise (knowledge</td>
<td></td>
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<tr>
<td>deficit)</td>
<td></td>
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<tr>
<td>Teaching: prescribed medication</td>
<td></td>
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<tr>
<td>(knowledge deficit)</td>
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<td>Patient care treatments</td>
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<tr>
<td>Rehabilitation (N=1488) – HCFA/CMS</td>
<td></td>
</tr>
</tbody>
</table>

* Surveillance, safety (injury, potential for)

* Exercise therapy: ambulation (mobility, impaired physical)

* Environmental management (injury, potential for)

* Exercise therapy: joint mobility (mobility, impaired physical)

Teaching: prescribed medication (knowledge deficit)
Outcomes measurement and clinical decision support using core nursing and healthcare minimum data sets.

- Background
- Studies – examples
  - Profiling practice
  - Knowledge Discovery in Databases (KDD) – 2 methods
  - Decision support
KDD Process
(FAYYAD, 1996)
Warehouse $[n=476,332 \text{ records}]$
NMDS, Discharge Data Set, +
n$=7860$, transactions $n=37,327$
20 Classes
Nursing diagnoses
Examples
Age: 65-75 [46%]
Gender: M [69.1%]
Marital: married [90.2%]
Zipcode: 52722, 52804, 52807
LOS: 3-7 days [92.8%]
Dates: 12/29-30, 1/7-9
Religion: Lutheran/Catholic/Protestant [87.2%]
NDx:

- Ineffective Airway Clearance
- Pain
- Altered Health Maintenance
- Potential for Infection
- Self-care Deficit, Bathing/Hygiene
Algorithm:

- produces two outputs:
  
  1) a decision, or
  
  2) no decision for a small number (possibly zero) of patients due to insufficient information; another algorithm (confirmation algorithm) identifies the information necessary to arrive at a correct decision
Examples

Decision rule 123. IF
(NOC15 = 0) AND
(NOC1 = 1) AND
(NOC14 = 0) AND
(NC4 = 1) AND
(NOC3 = 0) AND
(CCS3a = 11.70)
THEN (LOS=3);

[3.23% of patients]
[3 patients, Patient Number 43,52,574]

This decision rule describes 3 patients who experienced normal deliveries, with nursing intervention “infection protection” and goal of remain free of infection, and yet had length of stay of 3 days.
Decision rule 14. IF (NC3 = 0) AND (INFECT = 1) AND (NOX10 = 0) AND (NC1 = 1) AND (CCS1a = 11.50) AND (RACE = A) THEN (LOS=1); [4.92% of patients] [6 patients, Patient Number 83,119,247,281,354,382]

This decision rule accurately describes 6 patients in the training set who experienced complicated deliveries, had a nursing diagnosis of infection and had a length of stay of 1 day.
KDD Challenges

Larger databases
High dimensionality
Over-fitting
Assessing statistical significance
Changing data & knowledge
Missing & noisy data
KDD Challenges
continued 2

Complex relationships between/among fields
Understandability of patterns
User interaction & prior knowledge
Integration with other systems, e.g. DBMS, spreadsheets, visualization tools, accommodating real-time sensor readings
Outcomes measurement and clinical decision support using core nursing and healthcare minimum data sets.

• Background

• Studies – examples

  – Profiling practice

  – Knowledge Discovery – 2 methods

  – Decision Support – effectiveness
Medical Center

Acute Care Inpatient Unit

Population

DRG₁, DRG₂

ND₁, NOC₁, NOC₂, ND₂

NIC₁, NIC₂, NIC₃, NIC₄, NIC₅ & NIC₆

Aggregated Unit-Specific Adjusted Patient Outcomes Profiles

Aggregated Unit-Specific Adjusted Patient Outcomes Profiles

Aggregated Unit-Specific Adjusted Patient Outcomes Profiles

Aggregated Unit-Specific Adjusted Patient Outcomes Profiles
Management Interventions

Aggregated Unit-Specific Adjusted Patient Outcomes Profiles

Aggregated Unit-Specific Adjusted Patient Outcomes Profiles

Aggregated Unit-Specific Adjusted Patient Outcomes Profiles

Aggregated Unit-Specific Adjusted Patient Outcomes Profiles
Delaney 2006
**Guidelines - Referential & Executable Knowledge**

**B - Observe behavior when the patient is engaged in activity**


**C - Elders with dementia may not exhibit pain behaviors**


**B - Try to elicit from the family the patient's usual pain behaviors**


**E - In summary, determine pain intensity by assessing the following in order of importance:**


**B - Behavioral: Facial expressions**


**C - Behavioral: change from usual**


## Pain Assessment (Primary Site)

### Primary Pain Location
- Abdomen
- Ankle
- Bladder
- Buttock
- Chest
- Ear
- Elbow
- Epigastrium
- Eye
- Flank
- Foot
- Frontal
- Generalized
- Head
- Hip
- Knee
- Lower arm
- Lower leg
- Mouth
- Neck
- Nose
- Occipital
- Pelvis
- Plantar
- Shoulder
- Supraorbital
- Temporal
- Temporomandibular
- Tongue
- Ulna
- Upper arm
- Upper back
- Upper leg
- Wrist
- Other:

### Laterality
- Bilateral
- Right
- Left

### Intensity (0-10 Scale)

### Acceptable Intensity

### Abdomen Quadrant
- All quadrants
- Left upper quadrant
- Right upper quadrant
- Left lower quadrant
- Right lower quadrant

### Time Pattern

- Acute
- Chronic
- Constant
- Intermittent
- Other:

### Onset
- Gradual
- Sudden

### Pain Duration

### Quality
- Aching
- Burning
- Camplng
- Dull
- Heavy
- Pressure
- Radiating
- Sharp
- Tightness
- Unable to describe
- Other:

### Pain Radiates
- No
- Yes

### Radiation Location/Characteristics

### Interventions Implemented
- Cold
- Heat
- Medications
- Repositioning
- Other:

### Aggravating Factors
- None
- Breathing
- Movement
- Palpation
- Other:

### Alleviating Factors
- None
- Assistive devices
- Repositioning
- Cold therapy
- Deep breathing
- Exercise
- Immobilization
- Massage
- Other:

### Associated Symptoms
- None
- Nausea
- Palpitations
- Shortness of breath
- Sweating
- Vomiting
- Other:

### Pain Negatively Impacts
- Appetite
- Concentration
- Daily life
- Emotions
- Relationships
- School performance
- Sleep

### Additional Pain
- Yes
Overview of Acute Pain Management

Clinical practice guidelines provide recommendations for a particular practice area such as management of acute pain. Studies have shown that evidence-based clinical practice guidelines are effectively implemented, patient outcomes improve and resource use declines (Atkins et al., 1998; Aucott et al., 1996; Feldstein et al., 1995; Kirshbain, 1996; Lubarsky et al., 1997; McCormick et al., 1997; O'Connor et al., 1996; Schneider & Eisenberg, 1998; Tiler et al., 1994).

Development, dissemination and use of evidence-based guidelines promotes application in practice of the current "best evidence". Use of guidelines, however, requires critical thinking and data-based decision making by health care providers. Patient care continues to require individualization based on patient needs, circumstances, and consumer requests.

Approximately 60-80% of the elderly population report some degree of pain that interferes with life activities (B. R. Ferrel & Ferrell, 1996). Research in healthcare, the elderly are frequent recipients of medical and surgical treatments that result in acute pain and are at risk for inadequate pain management during hospitalization (Bowman, 1997; Caccia, 1994; Feldt et al., 1996; Horner et al., 1997; Lamb, 1975). This is particularly troublesome in light of research that demonstrates better patient outcomes, reduced length of stay, and reduced resource use as a result of effective pain management and mobility (Carlile & Haliday, 1997; Hoenig et al., 1997; Keil, 1981; S. S. Liu et al., 1995a; Pati et al., 1994).

This guideline, Acute Pain Management in the Elderly, was developed from a synthesis of current evidence on acute pain management in adults and the elderly. Research, clinical practice guidelines, and other empirical information on acute pain management were critiqued, analyzed, and used as supportive evidence for the practice recommendations.

References:

National & International collaboration

- Unified Nursing Language System (UNLS)
- Unified Medical Language System (UMLS)
- International Classification of Nursing Practice (ICNP)
- Snomed CT Reference terminology model
- HL7 – Reference Information Model
i-NMDS

International Council of Nurses (ICN)
International Medical Informatics Association (IMIA)
Collaboration

U-MN
School of Nursing
New Pathways to Discovery

- Building blocks, biological pathways, networks
- Molecular libraries & imaging
- Structural biology
- Bioinformatics & computation biology

Research Teams

- High-risk research
- Interdisciplinary research
- Public-Private partnerships

Re-engineering
Clinical Enterprise

- Re-engineering clinical care
Informatics Research in Nursing/Health Services Administration
“The information infrastructure is becoming the new architecture for health care. The system will build its future around construction of the information system and the infrastructure necessary to sustain it and the work of health care.”
Theme

- Information systems
- Quality Assurance
- Personnel
- Communication Networks
- Budgeting/payroll
- Census
- Regulation

Theme

- Claims processing, reimbursement
- Risk
- Costing of nursing care
- Case mix management
- Consumer
Theme
• Nursing intensity
• Patient classification
• Acuity
• Staffing
• Scheduling
• Inventory
• Patient billing

Theme
• Adverse events
• Unit reports
• Utilization review
• Shift summary reports
• Decision support
• Data Sets
Administrative data dependent on clinical data
Standardization of management and administrative data
Integrated systems/EHR
Repositories/warehouses
Complex adaptive systems/processes
Data/Information/Knowledge/Wisdom
Democratization of data and information
Mankind suffers not because it has failed to advance but because it has advanced too fast. I attribute the present manifestations of disintegration to the fact that the growth of industry and machinery has sharpened the battle of existence to a point where it impairs the free development of the individual - the world has not adjusted itself to these changes.

• Einstein
Scope

Persuasiveness

Complexity
Ethical Dilemmas

Short time span

Underdeveloped organizational capacity

Computer usage outside profession
Sacred, gentle gifts of nursing

Embracing the technology
Valuing data and information
Commitment to values
Collaboration
Nursing care data are missing from most information systems.

Incentives do not exist to develop data repositories that answer workforce questions, e.g., the relationship between fall rates and decreases in nurse staffing.

Nurses are regularly not at decision-making tables when systems are chosen.

Nurses focus on implementing and using new systems that benefit their institutions, but little attention is focused on systems to benefit nursing practice.

The majority of nurses, particularly those who are the current leaders, lack needed IT skills.

Most systems are not designed to reflect workflow.
Nursing faculty do not have the skills to integrate IT into their courses. There is no systematic implementation of IT core competencies by level of nursing education.
Policies limit multi-site collaboration
Research training must prepare nurses for creating and evaluating health informatics applications
Increases access
Removes geographic and time boundaries
Encourages interactive and problem-based learning
Provides alternative methods of clinical instruction, e.g., simulations, “virtual reality”
Facilitates course-sharing across institutions

Courses can link learning to a world of real-time resources, e.g., government websites and legislative committees

The modules that are part of web-based courses can be made available for continuing education (CE) without much additional development
EMERGING INFORMATICS DISCIPLINE:
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Integrative Nursing Informatics: 
A Unique Focus

Knowledge representation
Knowledge discovery
Knowledge translation
Health care transformation

Clinical provider

Consumer

Public health

The University of Minnesota School of Nursing is unique in incorporating the perspectives of consumer, clinical provider and public health in its informatics program. The program focuses on knowledge enabled health care systems, local to global.
Integrative Nursing Informatics: A Unique Focus

Implications for all areas of excellence in the SoN
Funding

National Kidney Foundation
Nordic Academy for Advanced Studies
Hewlett Packard
National Library of Medicine (NLM)
Department of Health & Human Services
National Institute of Nursing Research
The University of Iowa

National Health Registry – Iceland
American Organization of Nurse Executives
Sigma Theta Tau International
American Nurses Foundation
Agency for Healthcare Research & Quality
American Association of Critical Care Nurses
NANDA
Cerner
Publications (selected)

Books/Monographs


Publications (selected)


Publications (selected)


