Abstracting the Evidence to Design Informatics Tools that Support Evidence- and Patient Preference- based Practice

Patient-focused Informatics Applications

Specifically:
- Information systems that support patients and/or providers in making health care decisions that are based on clinical evidence and integrate patient preferences
- Decision support systems for shared decision making (SDM) between patients and health care providers

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Types of SDM Tools

- Decision Aids (DAs) for treatment / screening decisions
- Decision support systems (DSS) for preference and evidence-based illness management

Outline

- SDM tools:
  - Rationale
  - Purpose
  - Types of decisions and situations where such tools are appropriate
  - Methods
  - Examples of applications
  - Evidence of effectiveness
- Developing DSS for SDM
  - Abstracting the evidence
  - Important developmental aspects
Acknowledgements

Colleagues from the Shared Decision Making forum, Oxford, Spring 2000, In particular: Hilary Llewellyn-Thomas, PhD Annette O’Connor, PhD Margaret Holmes-Rovner, PhD

Rationale

- Increased focus on SDM and evidence-based practice (EBP)
- Patient autonomy, patient as consumer
- Clinical guidelines movement
- Realization that an important piece of evidence is missing without including the patient’s perspective
- Applying the best clinical evidence combined with patient preferences is crucial for high quality patient care

Important Concepts

- Patient Preferences
- Evidence-based Practice
- Shared Decision Making

Patient Preferences

The appraisal by an individual regarding the desirability of entities, such as treatments, outcomes of treatments, health states, or aspects of health care.
Evidence-based practice / health care decision making

"The conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett et al., 1996)

Shared decision making

- The process of interaction with patients who wish to be involved with their health care providers in making health care decisions
- Involvement of patients with their providers in making health care decisions that are informed by the best available evidence about treatment / screening / management options, potential benefits, and harms, and that consider patient preferences.

Purpose of SDM Tools

- To help patients participate in decisions about their health care
- To help providers in making health care decisions consistent with clinical evidence and patient preferences
  - Diagnosis/screening
  - Treatment
  - Illness management for serious or complex, chronic/long-term illness

Why Important?

- There is no single right answer for everyone
- Health problems have different meanings to different patients
  - Interventions have different benefits/risks that patients value differently
**Requirements for SDM**

- Understanding of the clinical situation
- Information important to the decision problem available in an easily comprehensible format
- Patients are in a position to make choices that will be respected

Hope, 2000

**Situations where DSS-SDM are appropriate**

- Clinical evidence re. effectiveness of screening / testing / treatment indicates no one “best” action
- Decision involves tradeoffs between benefits and harms
- Outcomes are uncertain, much is at stake
- Associated with wide range of strong personal values...
- Illness affects multiple, value-sensitive health dimensions

**Eddy’s Criteria**

<table>
<thead>
<tr>
<th></th>
<th>Standard</th>
<th>Guideline</th>
<th>Option</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcomes</td>
<td>Known</td>
<td>Known</td>
<td>Known / unknown</td>
</tr>
<tr>
<td>Agreement in patient values</td>
<td>High agreement</td>
<td>Majority agreement</td>
<td>Diverse Unknown</td>
</tr>
<tr>
<td>Recomm. treatment</td>
<td>Yes</td>
<td>Variable</td>
<td>Not clear</td>
</tr>
</tbody>
</table>

Eddy, 1992

**Components of SDM Tools**

- Evidence component, a knowledge base that contains the salient aspects of health/decision problem and/or available intervention options
- Assessment/elicitation component, to obtain patient preferences for aspects of their health and/or interventions
- Algorithms to arrive and display the choices / options consistent with patient preferences
- Interaction component: The shared decision making process between patient and provider
How can DSS Help?

- Consider and comprehend relevant clinical information
- Help patients clarify and communicate personal values and preferences to clinicians.
- Patients can engage with their clinicians in arriving at a decision/plan of care that is consistent with these personal values and preferences.

Shared Decision Making Programs for Patients or Patient Decision Aids

Cochrane Definition

- Adjuncts to counseling
- For specific deliberate treatment/screening choices
- Describe options and outcomes tailored to the patients’ health status

Optional Elements

- Information on condition or disease
- Probabilities of outcomes tailored to the patient
- Values clarification exercise
- Guidance in the steps of decision making and communication
- Usually disease specific
Preference Elicitation Methods

- **UTILITY-BASED**
  - e.g. Formal decision analysis, Standard Gamble (SG), Time Trade-off (TTO)

- **NON-UTILITY-BASED**
  - e.g. Analytic hierarchy process J. Dolan
  - Balance technique with “leaning towards scale” A.O.
  - Probability / Threshold tradeoff tech. H.L.T

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**ELEMENTS**

1. **INFORMATION**
   - **Disorder / Disease**
     - **Option A**
     - **Option B**
   - **Process/Protocol**
   - **Side/Toxic Effects**
     - Chances & timing of each
   - **Beneficial Outcomes**
     - Chances & timing of each
   - **Norms**
     - Variations in Pt./MD choices;
     - Guidelines; RCT/DA results

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**Hormones after Menopause**

- **Positives**
  - symptom relief
  - bones
  - ?heart
  - ? brain
  - ? colon

- **Negatives**
  - endometrium
  - ?breast
  - thromoboembolism
  - side effects
  - natural?
  - scientific uncertainty

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**Elements**

**VALUE CLARIFICATION**

Engage patient in considering personal importance of the pros & cons of each option.

Does this in way that reveals …
- attitudes to the attributes of each option;
- overall relative strength of preference for each option.
Other Examples

Screening/Testing - Prostate & colon cancer screening, Amniocentesis
Prevention - Hormones
Treatment - Cancer (breast, lung, lymphoma, leukemia), Heart disease, Low back pain, Atrial fibrillation, Benign prostate enlargement, Circumcision
Advance directives End-stage C.O.P.D.

Media

- PAPER & PENCIL (multiple sites)
- VIDEODISKS (Dartmouth)
- WEB –BASED (Health Dialog)
- DECISION BOARDS (McMaster)
- AUDIOTAPES / WORKBOOKS (Ottawa; U. of Toronto)
- INTERACTIVE PC-BASED (Dartmouth; U. of Ottawa; U. of T.; other N. American; U. of Leiden; U. of Amsterdam, London SHTM)

What are Effects of DAs?

**Summary of Reviews** (O’Connor, Molenaar)

- Help those uncertain at baseline
- Increase participation in decision making without increasing anxiety
- Improve knowledge, more realistic expectations, clearer personal preferences
- Reduce some aspects of decisional conflict
- Uncertain impact on adherence to Tx plans
- Uncertain impact on quality of life
- Little impact on patient satisfaction

Show demo

Health Dialog
Gaps

- DAs have been confined to the relatively narrow segment of decisions about single episodes of screening/treatment choice.
- Little attention on support for preference- and evidence based illness management.

Chronic, or long-term serious illness

- Large patient groups
- Illness management is complex and multidimensional

Program of Research:

- The development, evaluation and implementation of DSS to assist clinicians in combining clinical evidence with patient preferences in management of chronic/long-term serious illness

DSS for preference- and evidence based illness management

1. Support clinicians with the best available evidence about disease/condition specific health problems/intervention options.
2. Assist them in eliciting patient preferences.
3. Support SDM and provide mechanisms whereby patients’ preferences are integrated into interdisciplinary care.
4. Include methods for outcome evaluation from the patients’ perspective as part of clinical practice.
CHOICE
Creating better Health Outcomes by Improving Communication about Patients’ Experiences

A palm-top based support system to assist nurses in clinical practice in eliciting patient preferences for functional performance at the bedside and integrate this information into nursing care planning.

CHOICE
Integrates three essential features:
1. It contains 14 dimensions necessary for a comprehensive assessment of patients’ functional performance dimensions and their importance
2. It displays structured information of dimensions important to patients that helps nurses select care priorities consistent with these preferences.
3. It provides a benchmark for evaluating the degree of congruence between patients’ preferred and achieved functional performance as outcomes of care.

### PATIENT'S PREFERENCES

<table>
<thead>
<tr>
<th>Functional Performance Dimension</th>
<th>Importance</th>
<th>Specifications</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain/PPAD</td>
<td>4</td>
<td>Pain during activity • Pain-relieving activities, pain medications</td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>4</td>
<td>Transfers, balance, walking stairs, • Must walk with help, needs physiotherapy, • Transfer training, physiotherapy</td>
<td></td>
</tr>
<tr>
<td>Safety Risk for Falling</td>
<td>4</td>
<td>Unsteady, dizziness, •南北numbness to go to bed alone, • Need bed assistance</td>
<td></td>
</tr>
<tr>
<td>Lifestyle Adjustments</td>
<td>3</td>
<td>Safety threats, • Patient location, • Lives at 3rd floor, with elevator</td>
<td></td>
</tr>
<tr>
<td>Strong/Motor Functioning</td>
<td>3</td>
<td>Avoiding the bathroom, in time, • Walking, • Training to walk at home</td>
<td></td>
</tr>
<tr>
<td>Dressing</td>
<td>2</td>
<td>Dressing, norms, • Must dress in bed alone, •</td>
<td></td>
</tr>
<tr>
<td>Rest/Activity</td>
<td>1</td>
<td>Resting job, all day, •</td>
<td></td>
</tr>
<tr>
<td>Ability to Care for Own Health</td>
<td>1</td>
<td>Information about diet actions at BP medication, •</td>
<td></td>
</tr>
</tbody>
</table>
Sample

- Hospitalized patients > 62 years, not cognitively impaired
- Admitted to acute care unit for the elderly or rehabilitation unit for at least 3 days

- **Study 1 (USA)**
  - 151 patients (3 groups)
  - Mean age 75 years (SD: 7.7)

- **Study 2 (Norway)**
  - 155 patients (3 groups)
  - Mean age 80.8 years (SD: 5.9)

Study results

- Intervention groups in both studies:
  - Significantly greater congruence between patient preferences and nursing care documented in the care plan.

- Better patient outcomes of:
  - Improved preference achievement
  - In the first study also better physical functioning and
  - Indirectly, patient satisfaction.

Beginning Evidence

- Palm-top based support for preference-based care planning:
- Applicable in clinical practice
- A feasible strategy to include patient preferences in nursing care
- Can improve selected patient outcomes

Ongoing Research

- Interdisciplinary
- QI based conceptual model, applicable to a range of chronic illnesses
- DSS elements: Assessment, evidence-based interventions, outcome evaluation
- Integration in patient record
- Applicability: settings, providers, patients
Abstracting the Evidence:  
1. Identify dimensions of illness condition

- Critical search of literature
- Focus groups with expert clinicians
- Validation with patients (focus groups to supplement with additional information, dependent on the clinical area)

Development Guidelines

- DSS are linked to practice guideline groups when possible
- All options are presented in such a way as to ensure that patients are aware that they have choices
- Benefits and harms are presented for each option in a balanced format
- User evaluation is solicited during pre-testing, applying acceptability tests
- Ensure competent developers

Identifying intervention options: Guidelines

- Statements are linked to evidence sources from peer reviewed journals, with preference for systematic review data
- Level of evidence are provided (ranking system)

Levels of Evidence

Evidence obtained from:

I  at least one properly randomized trial
II--1 from well-designed controlled trials without randomization
II-2 From well-designed cohort or case control studies, preferably from more than one center or research group
II-3 From comparisons between times and places with and without the intervention
III Opinions of respected authorities, based on clinical experience, descriptive studies and expert committees
Summarizing the evidence: Search strategies

- Search Medline, Cinahl etc., using both keywords and free text words, using subject terms and search filters (e.g. Systematic reviews)
- Search online databases and resources, e.g.: Clinical evidence, Cochrane Library, National Guideline Clearinghouse, Trip database, Search cited references
- Ask experts

Summarizing the Evidence: Selection of Studies for Inclusion

- Different levels of evidence are appropriate for different questions
- E.g. Systematic reviews, RCTs, Cohort studies
- Effectiveness of different types of interventions (surgical, medical, WW)
- Appraisal of search results (relevance, quality etc)
- More in-depth appraisal of remaining studies, to ensure that only studies that meet quality indicators are included

Systematic review selection criteria

- Clearly defined research question
- Statement of criteria for exclusion / inclusion of studies
- Systematic and comprehensive search for literature (databases and resources searched, search start and end date, sites and languages included, restrictions made
- Assessment of quality of study included (reasons for studies excluded
- Summary of studies and their results (quantitative if appropriate) including assessment of measurement of heterogeneity between studies
- Discussion and conclusion from studies, answering research question

RCT selection criteria

- Randomized allocation to study groups (details of method)
- Blinding / masking of study group to at least outcome assessor and double blinding when appropriate
- At least 10 patients in each study group, or study is under-powered
- More than 80% available for follow up
- Clinically relevant outcomes measured, not surrogate outcome
Cohort study selection criteria

- Prospective, not retrospective
- Balanced baseline characteristics between comparison groups
- Unbiased assessment of outcomes
- Appropriate statistical evidence with adjustments made for confounding factors
- Study large enough to detect differences
- More than 80% available for follow up
- Clinically relevant outcomes measured, no surrogate outcomes

Summarizing the evidence: Presentation of Evidence

- Data base record for each paper reviewed, essential information on type of study, no. of patients, interventions, outcomes, whether included summary, which questions addressed etc.
- Evidence summary, facts and figures addressing issues and questions with relevant references.

Some web sites

- Trip data base
  http://www.tripdatabase.com/
- Liberian Index to the Internet
  http://lli.org/search/file/health
- National guideline clearinghouse
  http://www.guidelines.gov/
- Virtual hospital
  http://www.vh.org/
- Cochrane library
  http://www.cochranelibrary.com/

Web sites

Cochrane library
http://www.cochranelibrary.com/
The Evidence-based Medicine Resource Center
http://www.ebmny.org/
Clinical evidence (free for Palm users)
http://www.clinicalevidenceonline.org
University of York Center for Reviews and dissemination
http://www.york.ac.uk/inst/erdl/