Visualizing uncertainty in health care: present needs and future directions

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Objectives

- Identify key uncertainties in health care that need to be communicated to patients
- Describe recent efforts to develop novel representations for visualizing uncertainty in clinical risk prediction
- Outline potential directions for future uncertainty visualization efforts in health care
Communicating uncertainty to patients: a growing need

- Growth of evidence-based medicine (EBM)
  - “The conscientious, explicit, and judicious use of current best evidence in making decisions about individual patients.”
- Increasing visibility of medical controversies
- Rise of shared decision making (SDM) movement
  - Ethical justification: respect for patient autonomy
  - Idea that patients need to understand uncertainty to make well-informed decisions
- Growing need communicate uncertainty not only to physicians but to patients: what do they need to know?
Uncertainty

Main Entry: un·cer·tain·ty
Pronunciation: \\t-an-tē\\
Function: noun
Date: 14th century
  1: the quality or state of being uncertain: doubt
  2: something that is uncertain

synonyms uncertainty, doubt, dubiety, skepticism, suspicion, mistrust mean lack of sureness about someone or something. uncertainty may range from a falling short of certainty to an almost complete lack of conviction or knowledge especially about an outcome or result <assumed the role of manager without hesitation or uncertainty>. doubt suggests both uncertainty and inability to make a decision <plagued by doubts as to what to do>. dubiety stresses a wavering between conclusions <felt some dubiety about its practicality>. skepticism implies unwillingness to believe without conclusive evidence <an economic forecast greeted with skepticism>. suspicion stresses lack of faith in the truth, reality, fairness, or reliability of something or someone <regarded the stranger with suspicion>. mistrust implies a genuine doubt based upon suspicion <had a great mistrust of doctors>.

• A metacognition: the conscious awareness of ignorance...

• Multiple varieties in health care
Uncertainty in health care: domains

- Prevention and early detection
  - Disease risk estimates
  - Risks and benefits of preventive interventions
  - Performance characteristics of screening tests
- Diagnosis
  - Interpretation of symptoms
  - Performance characteristics of screening tests
- Treatment
  - Risks and benefits of therapeutic, palliative interventions
  - Prognostic estimates
Uncertainty in health care: issues

Examples of specific uncertainty issues: cancer treatment

Uncertainty in health care: sources

- Probability: indeterminacy of future outcomes, 1st order, “aleatory”
- Ambiguity: indeterminacy of knowledge, 2nd order, “epistemic” uncertainty
- Complexity: incomprehensibility of information

Probability

- Formal language of uncertainty
- Expression of indeterminacy/randomness
- Alternative interpretations
  - Objective (frequentist) interpretation
  - Subjective (Bayesian) interpretation
Ambiguity

- Decision theory construct (Ellsberg*)
- A specific type of uncertainty: “second order” vs. “1st order risk”, “epistemic” vs. “aleatory”
- Lack of “reliability, credibility, adequacy”
  - Incomplete / missing information
    - Amount or quality of available evidence
  - Questionable precision or accuracy
    - Wide confidence intervals
  - Questionable reliability
    - Inconsistent findings, reproducibility
    - Conflicting expert opinion

Complexity

- Features of information that make it difficult to understand
- Conditional probabilities, multiple risk factors, attributes, outcomes
Sources of uncertainty in health care

20% probability of benefit from treatment (*Indeterminacy of future outcome*)

10-30% probability of benefit from treatment (*Imprecision*)

Expert disagreement about benefits of treatment (*Conflicting opinion/evidence*)

Insufficient scientific evidence of benefit (*Lack of information*)

20% probability of long-term remission from treatment in patients with localized disease and who are HER2/neu-positive, estrogen-receptor positive, pre-menopausal, and have no other comorbidities (*Multiplicity of causal factors and interpretive cues*)

Examples and representations of different sources of uncertainty pertaining to breast cancer treatment outcomes

Challenges in communicating uncertainty to patients

- Topic-related
  - Multiplicity of sources, issues
  - Conceptual complexity
- User-related
  - Innumeracy
  - Cultural barriers
  - Individual preferences, tolerance of uncertainty
  - Potential adverse effects: “ambiguity aversion”
- Method-related
  - Optimal representational methods unknown
  - Unclear outcomes: acceptability, understanding, adverse effects (?)
Can communicating uncertainty be bad?

- “Ambiguity aversion”: propensity to choose against ambiguous options, outcome probabilities being otherwise equal
- Underlying cognitive process: pessimistic bias in the interpretation of ambiguous risk information
- Psychological consequences:
  - Heightened perceptions of risk
  - Diminished expectations of benefit
  - Indecision / inaction
- Greater complexity, potential for confusion

Uncertainty visualization for patients: present needs

- Need for effective representational methods
  - Promote understanding
  - Minimize potential adverse effects
- Promising work on visual approaches
  - Can aid comprehension particularly in low numerate individuals
- Initial work, more research needed
Clinical prediction models (CPMs)

- Statistical models to predict future health outcomes
  “…provide the evidence-based input for shared decision making, by providing estimates of the individual probabilities of risks and benefits…combine a number of characteristics (e.g., related to the patient, the disease, or treatment) to predict a diagnostic or therapeutic outcome.”
- “Individualized” risk estimates used increasingly for clinical decision making
- Numerous uncertainties in risk estimates, but not often communicated to patients

Uncertainty in CPMs: multiple varieties, levels

Figure 1: Five levels of uncertainty. While the first three form a natural hierarchy, Levels 4 and 5 apply to the entire modelling process and may exist even if there is little uncertainty expressed within the modelling framework.

Visualizing uncertainty in risk estimates: past efforts

http://www.yourdiseaserisk.wustl.edu/
Visualizing uncertainty in risk estimates: past efforts

Treatment with statins to reduce the risk of heart attacks and strokes

Figure 1. Control group risk. Next Figure >>
(Click here to save Figure 1)

In the control group 20 people out of 100 had a heart attack, stroke or bypass surgery over 10 years, compared to 15 (95% CI 14 to 17) out of 100 for the active treatment group.

http://www.nntonline.net/visualrx/v3/display.aspx#Figure_1
Visualizing uncertainty in risk estimates: past efforts

- No attention to fundamental uncertainties
  - Aleatory (first-order): indeterminacy/randomness
  - Epistemic (second-order): ambiguity
- Mental visualization, understanding of users is assumed
- Need to better represent these uncertainties
  - Users need to understand, but do have problems
- How should effectiveness be evaluated?
  - Risk perceptions
  - Affective response
  - Decision making
  - Understanding / insight
Visualizing uncertainty in risk estimates: new approaches

Communicating uncertainty in cancer risk estimates: effects

- NCI Colorectal Cancer Risk Assessment Tool (CCRAT) – Freedman et al 2008
- Effort to develop patient-centered communication tool using visual representations of uncertainty:
  - Ambiguity (imprecision): model misspecification, error
  - Randomness: indeterminacy
- Use of new visualization methods: blurring, disarraying
- Mixed-methods study examining effects of different representational formats


Visual representations of uncertainty: imprecision

**Textual, ambiguity absent**
Your chances of developing colon cancer in your lifetime are 9%

**Textual, ambiguity present**
Your chances of developing colon cancer in your lifetime are between 5%-13%

**Visual, ambiguity absent**

**Visual, ambiguity present**
Visual representations of uncertainty: imprecision

Textual only

Your chances of developing colon cancer in your lifetime are most likely between 5%-13%, but they could be higher or lower. Risk estimates are not exact.

Integrated textual + visual: Solid bar

Your chances of developing colon cancer in your lifetime are most likely between 5%-13%, but they could be higher or lower. Risk estimates are not exact.

Integrated textual + visual: Blurred bar

Your chances of developing colon cancer in your lifetime are most likely between 5%-13%, but they could be higher or lower. Risk estimates are not exact.
Effects of visual representations of imprecision: experimental evaluation

**Experiment 1**: 2 x 2 x 2 design testing effects of ambiguity (absent vs. present), representational format (textual vs. visual).

Additional test of comparative risk information (pre- / post-)

Representing imprecision: effects on perceived risk, worry

- **Main effect of ambiguity** (Wilks’ $\lambda = .97$, $F(3, 230)=3.54$, $p=.03$)
  - Primary effect: increased cancer-related worry ($F(1, 231)=5.19$, $p=.02$)
- **Interactions:**
  - Ambiguity x Representational format (visual format $\rightarrow$ ambiguity tolerance)
  - Ambiguity x Dispositional optimism (high optimism $\rightarrow$ ambiguity tolerance)
- **No difference between enhanced text + visual representations**

Interaction of ambiguity and representational format on level of perceived risk

Interaction of ambiguity and dispositional optimism on cancer-related worry
Visual representations of uncertainty: randomness

Text-only, non-random

Your chances of developing colon cancer in your lifetime are 9%.

Text-only, random

Lifetime Risk: 9.0%
Explanation: Based on the information provided, the estimated chance for developing colorectal cancer over the lifetime is 9%.

We can’t predict the future of any one person. Risk estimates only tell us how many people in a population are likely to get colon cancer; they can’t tell us who will get the disease or not.

Visual non-random

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Explanation: Based on the information provided, the estimated chance for developing colorectal cancer over the lifetime is 9%.

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Visual representations of uncertainty: randomness

Visual random static

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Visual random dynamic

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Effects of visual representations of randomness: experimental evaluation

Total participants (N=225)

- Text-only non-random (n=45)
- Text-only random (n=45)
- Visual non-random (n=45)
- Visual random static (n=45)
- Visual random dynamic (n=45)

5-condition design testing effects of alternative representations of randomness

Representing randomness: effects on subjective uncertainty

- **Main effect of representational format** \((F(4, 210)=2.98, p=.02)\)
  - Subjective Uncertainty greatest for Dynamic Random vs. Text-only Random
  - No effects on perceived risk, worry (no “ambiguity aversion” with randomness)
- **Format x Optimism interaction**: \((F(4, 210)=3.51, p=.01)\)
  - Low optimism → greater sensitivity to format effect, in expected direction

<table>
<thead>
<tr>
<th>Representational format</th>
<th>Subjective uncertainty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Text-only non-random</td>
<td>3.4</td>
</tr>
<tr>
<td>Text-only random</td>
<td>3.2</td>
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<tr>
<td>Low Optimism</td>
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<tr>
<td>High Optimism</td>
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Visualizing uncertainty in cancer risk estimates: initial lessons

- Communicating imprecision leads to effects consistent with “ambiguity aversion”
  - Heightened worry
  - Heightened perceptions of risk, but moderated by individual optimism
- Visual representations appear to reduce ambiguity aversion
  - Enhanced textual representations may also be effective
- Communicating randomness increases subjective uncertainty about risk
  - A desired effect, although problematic
  - No effect on risk perceptions (akin to ambiguity aversion)
- Unanswered questions
  - Effects on understanding
  - Mechanisms
  - Right amount of information, for different users
Visualizing uncertainty in risk estimates: new approaches

Visualizing uncertainty in risk estimates: new approaches

http://understandinguncertainty.org/spinning
Visualizing uncertainty in health care: future directions

- Novel representational methods
  - Aleatory uncertainty: dynamic representations, risk over time
  - Epistemic uncertainty: beyond fuzziness
- Novel functionality: interactivity, tailorability
- Evaluation of outcomes
  - Usability
  - Understanding
  - Psychological, behavioral outcomes; clinical care settings
- Other uncertainty issues, domains, users
Thank you!

Questions, ideas:
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