The Challenge of Numeracy: 

Who, Why, and How We Should (or Should Not) Use Numbers to Communicate with Patients

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Health Numbers

- Blood test results
  - Bilirubin
  - Hemoglobin A1c
  - CBC
  - Hormone levels
  - ...
- Home test results
  - Blood pressure
  - Glucose
  - ...
- Diabetes
- Cancer
- Heart disease
- Diabets
- ...
- Treatment risk %
  - Success rates
  - Side effects
  - False positives
- ...

Disclosure

I have no financial relationships with commercial entities producing healthcare related products and/or services.

Why Do We Give People Health Data?

- Disease risk %
- Diagnosis
- ...
- Screening
- ...
- Monitoring
- ...

Blood Tests

- Why do clinicians conduct blood tests?
- Why do we want to communicate blood test results to patients?
- “Because!”
- “Because it’s their data”
- “So they know their numbers”
"So that they can use them"

### Blood Tests

Why do we want to communicate blood test results to patients?
- Awareness?
- Concern?
- Classification?
- Gist differences?
- Exact differences?

### Why Does Need / Purpose Matter?

**Numbers need to "speak" to us**

But...we can’t “hear” numbers very well

### Numeracy

- The ability to understand, transform, and derive meaning from quantitative (health) information

### Numeracy Measures

- Which of the following numbers represents the biggest risk of getting a disease?
  - 1 in 100
  - 1 in 1000
  - 1 in 10

### 1 in X Formats

**Age: a major factor**

A research shows that age is a major factor in the risk of developing cancer. Here are the statistics for different age groups:

- Age 20: 1 in 149
- Age 30: 1 in 15
- Age 40: 1 in 20
- Age 50: 1 in 25
- Age 60: 1 in 30
- Age 70: 1 in 35
- Age 80: 1 in 40

### Subjective Numeracy

- How good are you at working with fractions?
- How good are you at figuring out how much a shirt will cost if it is 25% off?
- How often do you find numerical information to be useful?

### Numeracy Is Related To...

- Understanding uncertainty yet predictability of health
  - What is a risk factor?
  - Population rates vs. individual propensity
  - Clinical trials
Numeracy Is Related To...

- Understanding uncertainty yet predictability of health
- Using data
  - Translate between formats
  - Interpret visuals
  - Find relevant data

More Data...

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Hospital A</th>
<th>Hospital B</th>
<th>Hospital C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of data used</td>
<td>2005</td>
<td>2007</td>
<td>2006</td>
</tr>
<tr>
<td>No. of patients per hospital</td>
<td>500</td>
<td>500</td>
<td>500</td>
</tr>
<tr>
<td>No. of hospital stays per patient</td>
<td>3.5</td>
<td>3.5</td>
<td>3.5</td>
</tr>
<tr>
<td>Days in hospital stay per patient</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>No. of lab tests per patient</td>
<td>20</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>No. of medication prescriptions per patient</td>
<td>15</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Days of hospital stay with medications</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

Vs. Less Data

Table 3

<table>
<thead>
<tr>
<th>Measures</th>
<th>Hospital A</th>
<th>Hospital B</th>
<th>Hospital C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year of data used</td>
<td>2005</td>
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</tr>
<tr>
<td>Days of hospital stay with medications</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

Less is More

Numeracy Is Related To...

- Understanding uncertainty yet predictability of health
- Understanding risk information
- Being able to make better health decisions
  - Adjust decisions based on data

Numeracy, Not Literacy, Predicts Reading Nutrition Labels

Numeracy, Not Literacy, Relates To Anticoagulation Control

Numeracy as Deriving Meaning

Numeracy as...
Can Patients Use This?

- Patient Portals
  - Increasing direct access to test results
  - BUT, patients must be able to recognize out-of-range values before they can derive any meaningful use

What Is Out of Range?

Scenario
- Type 2 diabetes scenario
  - Hemoglobin A1c 3 months ago = 6.8%
  - Explicit goal of A1c<7%
  - Being tested in-between appointments

Test Results
- Participants received tables of:
  - CBC counts
  - CBC differential %’s
  - Hemoglobin A1c
  - Renal panel

- Tables included standard range but did not include high/low flags

Participants
- 1817 adults age 40-70
  - Recruited from a demographically diverse Internet panel
  - Measured both health literacy and numeracy

Experimental Design
- A1c level
  - 7.1%
  - 8.4%

- Number of out-of-range values
  - A1c only
  - A1c + viral infection
    - WBC, platelet, MCH, MCHC, neutrophil %, lymphocyte %, monocyte %, ANC, and serum glucose

Effects of Numeracy and Literacy
- Zikmund-Fisher BJ, Exe NL, Witteman HO. Numeracy and literacy independently predict patients' ability to identify out-of-range test results.
  - Journal of Medical Internet Research
    - 2014;16(8):e187.
Estimated Likelihood of Calling a Doctor

“Houston, we have a problem!”

- Tables of test results are NOT the “right tool” for less numerate/literate people.
- Problem: We can know what numbers are without knowing what they mean.

Information

Evaluability

Good or Bad?

Choosing a Fertility Clinic

Preference Reversal in Ratings of Fertility Clinics

Good or Bad?

5-year Breast Cancer Risk: 2.6%

Decision Making

- Hard-to-evaluate data requires reference standards to be meaningful
  - Such data are generally ignored unless comparative data are provided
Information Evaluability

Functional Numeracy

“The Curse of Knowledge”

“Once we know something, we find it hard to imagine what it was like to not know it.”

Good or Bad?

Dioxin Blood Concentration:
33 parts per trillion TEQ

Platelets:
145 x 10^9

What is normal?

What is dangerous?

NOTHING!

Context?

Context!

Ongoing Design Research
Imagine Robert

Your 10-year risk of cardiovascular disease is: 11.22%

Robert’s Tale

"Am I at high risk, or not?"

Problems

- Excess precision
- Do we really think we know Robert’s risk to a hundredth of a percent?
- Integers are more believable and easier to recall than decimals

Problems

- Excess precision
- Number-only formats

Problems

- Excess precision
- Number-only formats
- Unmet information needs

Robert's Risk

Iconarray.com

Created at iconarray.com
Evidence-Based User's Guide. FDA, 2011.

Risk Estimates

- Why do clinicians estimate health risks?
  - Evaluation
  - Decision making
  - Surveillance

- Risk Estimates
  - Why do we want to communicate risk estimates to patients?
  - Inform?
  - Change beliefs?
  - Change behavior?

Question

- Is Robert "informed" about his cardiovascular disease risk?

A Taxonomy of Risk Concepts

<table>
<thead>
<tr>
<th>Concept</th>
<th>Precision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relative/Comparative Probability</td>
<td>Relatively probable or improbable</td>
</tr>
<tr>
<td>Categorical Probability</td>
<td>Categorical probability</td>
</tr>
<tr>
<td>Absolute Probability</td>
<td>Absolute probability</td>
</tr>
</tbody>
</table>

Needs

- What Robert wanted:
  - "I am a person who has a high risk"
- What Robert got:
  - "My risk is this"

Need-Congruent Types of Risk Knowledge

<table>
<thead>
<tr>
<th>Need</th>
<th>Valid Reaction</th>
<th>Comprehensible Reason</th>
<th>Comprehensible Risk Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Central Data Center</td>
<td>Care about this more</td>
<td>Care about this more</td>
<td>Risk Factor</td>
</tr>
<tr>
<td>Website is Not or Not About</td>
<td>Care about this more</td>
<td>Care about this more</td>
<td>Risk Factor</td>
</tr>
<tr>
<td>Make-Me-Informable Textlines</td>
<td>Care about this more</td>
<td>Care about this more</td>
<td>Risk Factor</td>
</tr>
<tr>
<td>Make Collectable</td>
<td>Care about this more</td>
<td>Care about this more</td>
<td>Risk Factor</td>
</tr>
<tr>
<td>Incremental Probabilities</td>
<td>Care about this more</td>
<td>Care about this more</td>
<td>Risk Factor</td>
</tr>
</tbody>
</table>

Context Via Side by Side Icon Arrays

- What does Robert need?
  - Context!
Does Robert need a number?

Questions People Ask

What is my number?

Questions People Ask

What is my number?
What is normal?
What is dangerous?
Am I high?
Is the difference important?

Labels?

- E.g., “above average,” “high levels,” “above threshold”
- BUT: When statistics and evaluative labels are presented together, the label, NOT the number, dictates what people do.

Non-Numerical Risk Displays

Visual Displays That Aid Categorization

Patient Needs

- ALWAYS consider the congruence of data type and format with patients’ immediate and specific needs

“The Right Tool at the Right Time”
Take Away Messages

- We must recognize why we are providing data before we provide numbers.
- Improve functional numeracy via:
  - Context to create evaluability
  - Need-congruent formats

Providing the right number does not guarantee the right message.