Communicating and tailoring risks and benefit information

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Overview of talk

- Decision aids vs. health promotion materials
- How to present risk information in an understandable manner
- Tailoring risk communication
Decision aids vs. health promotion materials

- **Decision aids** are designed to educate patients about preference sensitive decisions.
  - Examples: What type of treatment to undergo for breast or prostate cancer
Decision aids vs. health promotion materials

- **Decision aids** are designed to educate patients about preference sensitive decisions.
  - Examples: What type of treatment to undergo for breast or prostate cancer
- **Health promotion materials** are designed to persuade people to engage in a certain type of behavior.
  - Examples: quit smoking, undergo colorectal cancer screening
Decision aids vs. health promotion materials

- Primary difference between the two types of materials is whether you are trying to educate individuals or persuade individuals.
- Methods, particularly risk communication methods, can vary dramatically based on type and goal of materials.
How to present risk information in an understandable manner

- People with low numeracy skills may have difficulty understanding complex statistical information.
  - e.g., risks and benefits of treatment
How to present risk information in an understandable manner

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  - e.g., risks and benefits of treatment
- Even people with good numeracy (and good literacy) skills, can have trouble understanding information in a stressful situation.
How to present risk information in an understandable manner

- People with low numeracy skills may have difficulty understanding complex statistical information.
  - e.g., risks and benefits of treatment
- Even people with good numeracy (and good literacy) skills, can have trouble understanding information in a stressful situation.
- Thus, the goal of educational materials (whether decision aid or health promotion) is to present information in a simple, easily understandable manner.
International standards for presenting numerical information

- International Patient Decision Aids Standards Collaboration (IPDAS)
  - Made numerous recommendations for how to present numerical information to patients.
  - This information is relevant to decision aids and health promotion materials.
Presenting statistical information graphically

- What type of graph to use?
  - Bar graph
  - Pie graph
  - Pictographs (100 image matrices/pictures)
  - Modified pie graph (“clock” graphs)
  - Modified pictographs (“sparkplugs”)
Study Context

- Study with approximately 2400 Internet users
  - 52% female
  - 82% Caucasian
  - 18% high school education, 38% college +

- Scenario
  - Clogged arteries. Will need bypass surgery if continues
  - 2 drugs can reduce need for bypass surgery
  - However, drug has 2 side effects
Bar graphs

Decreased risk of needing bypass surgery caused by taking pills
- **Pill A:**
- **Pill B:**

^ Each graph represents 100 people
- Orange bar: Need bypass surgery

Increased risk of headaches and nausea caused by taking pills
- **Pill A:**
- **Pill B:**

^ Each graph represents 100 people
- Blue bar: Get mild headaches
- Black bar: Get severe nausea
Pie graphs

**Decreased risk of needing bypass surgery caused by taking pills**

**Pill A:**

**Pill B:**

* Each graph represents 100 people

**Need bypass surgery**

**Increased risk of headaches and nausea caused by taking pills**

**Pill A:**

**Pill B:**

* Each graph represents 100 people

**Get mild headaches**

**Get severe nausea**
**Pictographs**

*Decreased risk of needing bypass surgery caused by taking pills*

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<thead>
<tr>
<th></th>
<th>No pill</th>
<th>Pill A</th>
<th>Pill B</th>
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*Each graph represents 100 people*

*Need bypass surgery*

*Increased risk of headaches and nausea caused by taking pills*

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</table>

*Each graph represents 100 people*

*Get mild headaches*

*Get severe nausea*
Clock graphs (modified pie)

**Decreased risk of needing bypass surgery caused by taking pills**

**Pill A:**
- 90~100: 0
- 80~90: 10
- 70~80: 20
- 60~70: 30
- 50~60: 40
- 40~50: 1

**Pill B:**
- 90~100: 0
- 80~90: 10
- 70~80: 20
- 60~70: 30
- 50~60: 40
- 40~50: 1

*Each graph represents 100 people

- Need bypass surgery

**Increased risk of headaches and nausea caused by taking pills**

**Pill A:**
- 90~100: 0
- 80~90: 10
- 70~80: 20
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- 50~60: 40
- 40~50: 1

**Pill B:**
- 90~100: 0
- 80~90: 10
- 70~80: 20
- 60~70: 30
- 50~60: 40
- 40~50: 1

*Each graph represents 100 people

- Get mild headaches
- Get severe nausea
Sparkplug graphs
(Modified pictograph)

Decreased risk of needing bypass surgery caused by taking pills

Pill A:
- Each graph represents 100 people
- Need bypass surgery

Pill B:

Increased risk of headaches and nausea caused by taking pills

Pill A:
- Each graph represents 100 people
- Get mild headaches
- Get severe nausea

Pill B:
Methods: Knowledge questions

- 6 knowledge questions
  - 2 “gist knowledge” questions asked which treatment yielded the best (or worst) outcome (e.g., more likely to experience nausea with Pill A or Pill B?).
  - 4 “verbatim knowledge” questions asked the number of patients affected by a treatment and to calculate numerical differences between treatments.
### Accuracy of responses: Gist knowledge

<table>
<thead>
<tr>
<th></th>
<th>Pie M (SD)</th>
<th>Pictograph M (SD)</th>
<th>Clock M (SD)</th>
<th>Sparkplug M (SD)</th>
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<td>1.56 (.64)</td>
<td>1.55 (.66)</td>
<td>1.50 (.69)</td>
<td>1.45 (.77)</td>
</tr>
</tbody>
</table>

Means = number of correct responses out of 2 questions.

Accuracy was greatest for pie graphs and pictographs (F = 4.09, p = .001).
# Accuracy of verbatim responses: Interpreting numerical information

<table>
<thead>
<tr>
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<th>Pie M (SD)</th>
<th>Pictograph M (SD)</th>
<th>Clock M (SD)</th>
<th>Sparkplug M (SD)</th>
<th>Bar M (SD)</th>
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<tr>
<td>Mean</td>
<td>.12 (.40)</td>
<td>2.17 (1.51)</td>
<td>.74 (.92)</td>
<td>1.03 (1.12)</td>
<td>.90 (1.01)</td>
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<td>5</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
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</table>

Means = number of correct responses out of 4 questions.

Accuracy was greatest for Pictographs (F = 321.03, p < .001)
Accuracy of verbatim responses: Calculate difference between treatments

<table>
<thead>
<tr>
<th></th>
<th>Pie</th>
<th>Pictograph</th>
<th>Clock</th>
<th>Sparkplug</th>
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<td>.04 (.19)</td>
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<td>.26 (.51)</td>
<td>.43 (.66)</td>
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<td>1</td>
<td>4</td>
<td>2</td>
<td>3</td>
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</tbody>
</table>

Means = number of correct responses out of 2 questions.

Accuracy was greatest for Pictographs (F = 83.15, p < .001)
Methods: Graph preferences

- Subjects shown all 5 graph formats
- Participants then rank ordered formats
  - “they would prefer if they were trying to understand the risks and benefits of a treatment.”
If you had to pick one graph…

1. Bar (40%)
2. Pictograph (18%)
3. Clock (17%)
4. Sparkplug (14%)
5. Pie (12%)
If you had to pick one graph...

1. Bar (40%)
2. Pictograph (18%)
3. Clock (17%)
4. Sparkplug (14%)
5. Pie (12%)

- Note the disconnect between which graph people prefer (bar graph) and which graph resulted in highest levels of knowledge (pictograph).
Summary

- Pictographs the best way to present information to increase patients/consumers’ gist and verbatim knowledge.
Risk presentation factors discussed next are some we have recently tested.

Study design
- Tested web-based decision aid regarding use of tamoxifen to prevent first diagnosis of breast cancer.
- Women were at high risk of breast cancer (N = 632)
- Tested impact of 5 risk communication factors on knowledge, risk perceptions, and behavior.
Total vs. incremental risk presentation

- Need for patients to understand baseline risk and the additional risks/benefits they experience due to undergoing treatment.
Baseline risk
Total risk presentation
(risk due to drug)
Baseline risk

Cataracts

Cataracts make one or both eyes cloudy, and make it hard to see.

Among 100 women your age who did NOT take tamoxifen...

- The risk of cataracts in 5 years:
  2.5 women out of 100 (2.5%) would get cataracts.

You may also return to any previous section using the menu at left.
Incremental presentation

Cataracts

*Cataracts* make one or both eyes cloudy, and make it hard to see.

Among 100 women your age who **did take tamoxifen**...

- The additional risk caused by taking tamoxifen:
  - 0.4 *more* women out of 100 (0.4%) would now get cataracts.

You may also return to any previous section using the menu at left.
Impact of incremental vs. total risk presentation

- Using incremental risk format decreased women’s perceptions of:
  - How worried they would be about getting a side effect of Tamoxifen
  - How common side effects are for women who take Tamoxifen
  - How likely they would be to experience a side effect

- No impact on knowledge or behavior
Order of risks and benefits

- The order you choose to describe the risks and benefits of treatment can affect risk perceptions and behavior.
- Psychological research has long shown that information presented last is better remembered.
Order of risks & benefits

- Receiving risks last resulted in:
  - Increased worry about getting side effects
  - Increased perception of how common side effects are
  - Increased knowledge
  - Decreased likelihood of taking Tamoxifen in the next year
2nd web-based study of women who are at high risk for a first diagnosis breast cancer (N = 1035).

Women read about 2 drugs: tamoxifen and raloxifene.

After reading risks/benefits of treatment, given summary table of risks/benefits.
<table>
<thead>
<tr>
<th>Summary Table</th>
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<tbody>
<tr>
<td>Immediately after viewing decision aid, participants who received the summary table were more likely to indicate they would:</td>
</tr>
<tr>
<td>- look for more information about chemoprevention</td>
</tr>
<tr>
<td>- talk with their physician about chemoprevention</td>
</tr>
<tr>
<td>- take tamoxifen or raloxifene</td>
</tr>
</tbody>
</table>
Other risk communication factors

- Denominator
  - 100 vs. 1000
  - Mixed evidence
Other risk communication factors

- **Absolute vs. relative risk presentation**
  - Absolute risk: Taking tamoxifen will reduce your risk of breast cancer from 6% to 3%.
  - Relative risk: Taking tamoxifen will reduce your risk of breast cancer by 50%.
  - Evidence is overwhelming that you should always present at least absolute risk information.
  - Should never just present relative risk information.
Other risk communication factors

- Frequency vs. percentages
  - Frequency: 5 out of 100 patients will experience a side effect of tamoxifen.
  - Percentage: 5% of patients will experience a side effect of tamoxifen.
  - Evidence is consistent that presenting information in frequency format improves knowledge and decision making.
Conclusions

- Design decisions can have a substantial impact on the decision making process.
- When developing tools (either DAs or health promotion materials), you must think carefully about how these risk communication factors can influence patients’ knowledge, risk perceptions, and behavior.
Tailoring and risk communication

- Two types of tailoring that is possible
  - Tailoring risk numbers patients get
  - Tailoring how risk information is presented
Tailoring risk numbers

- Presenting risk information based on patient’s medical history.
- Requires asking participants their medical history.
- Requires being able to tailor risk/benefit information.
Tailoring how risk information is presented

- Conveying that the numbers presented are tailored.
  - Often people do not realize that the numbers are “their numbers” (i.e., that the numbers are tailored).
An example of how to convey tailored information

MAKING AN INFORMED DECISION
ABOUT TAMOXIFEN AND RALOXIFENE

BREAST CANCER: Our best estimate of your 5-year risk

We used information you gave us at the beginning of this program to estimate your risk of breast cancer in the next 5 years.

You told us that you have the following characteristics:
- Are 70
- Are White
- Started your period before age 12
- Have had no live births
- Have 2 relatives with breast cancer
- Have had 1 biopsy

Based on these traits, our estimate of your personal risk of getting breast cancer in the next 5 years is: 10.3%

Among 100 women, who, like you, are 70 years old and White:
- 103.3 women (10.3%) would be diagnosed with breast cancer in the next 5 years.

Please keep in mind this number is our “best guess” about your chance based on what we know today and the facts you gave us. We got this number using a formula created by scientists at the National Cancer Institute who studied thousands of women. This is our best guess, but no one knows for sure who will get breast cancer and who will not.
Impact of highlighting the tailored nature of the risk/benefit information

- Tested the previous method in tamoxifen/raloxifene study (with 1035 women).
Impact of highlighting the tailored nature of the risk/benefit information

- Tested the previous method in tamoxifen/raloxifene study (with 1035 women).
- Results indicate that it increased women’s perceptions that these were “their numbers” and that the information was designed for them.
Impact of highlighting the tailored nature of the risk/benefit information

- Tested the previous method in tamoxifen/raloxifene study (with 1035 women).
- Results indicate that it increased women’s perceptions that these were “their numbers” and that the information was designed for them.
- Had no impact on risk perceptions, knowledge, or behavior.
Other potential ways to tailor the presentation of risk information

- What type of graph to use
  - Give them what we deem is the best method (e.g., pictograph).
  - Give them what they want.
  - Test them and then give them what graph they perform best on.
Other potential ways to tailor the presentation of risk information

- What type of graph to use
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- Numeracy
Final Thoughts

- Designing decision aids/health promotion materials is about more than just providing the basic information about a health condition.
- It is critical to understand how various design decisions influence people’s risk perceptions, knowledge, and behavior.
- When designing tools you really need to consider whether your design decisions affect people’s perceptions, knowledge, and behavior.
Even more concluding thoughts

- How you use risk communication devices will differ based on whether you are designing decision aids or health promotion materials.

Examples:
- Absolute vs. relative risk
- Order of risks and benefits
- Incremental vs. total risk
- Pictographs vs. no pictographs
Contact Information

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