Communicating CER so Patients Can Share in Decisions

Localized Prostate Cancer

- Patient with small cancer in prostate
  - Meeting with urologist
  - Part of decision making study
    - Including audiotape of post-biopsy interaction
- Receives info on diagnosis:

Here's what the Urologist said

- "So we took twelve cores out of your prostate. Out of those there were three cores that had cancer in them, and the percentage of the cores that was cancer was fairly low, it was under 30%.
- So out of those three cores, . . . a third of them had a little bit of cancer in them. So those three cores out of twelve says that there's probably not an extensive amount of prostate cancer in your prostate.
- But we should talk about different treatment options."

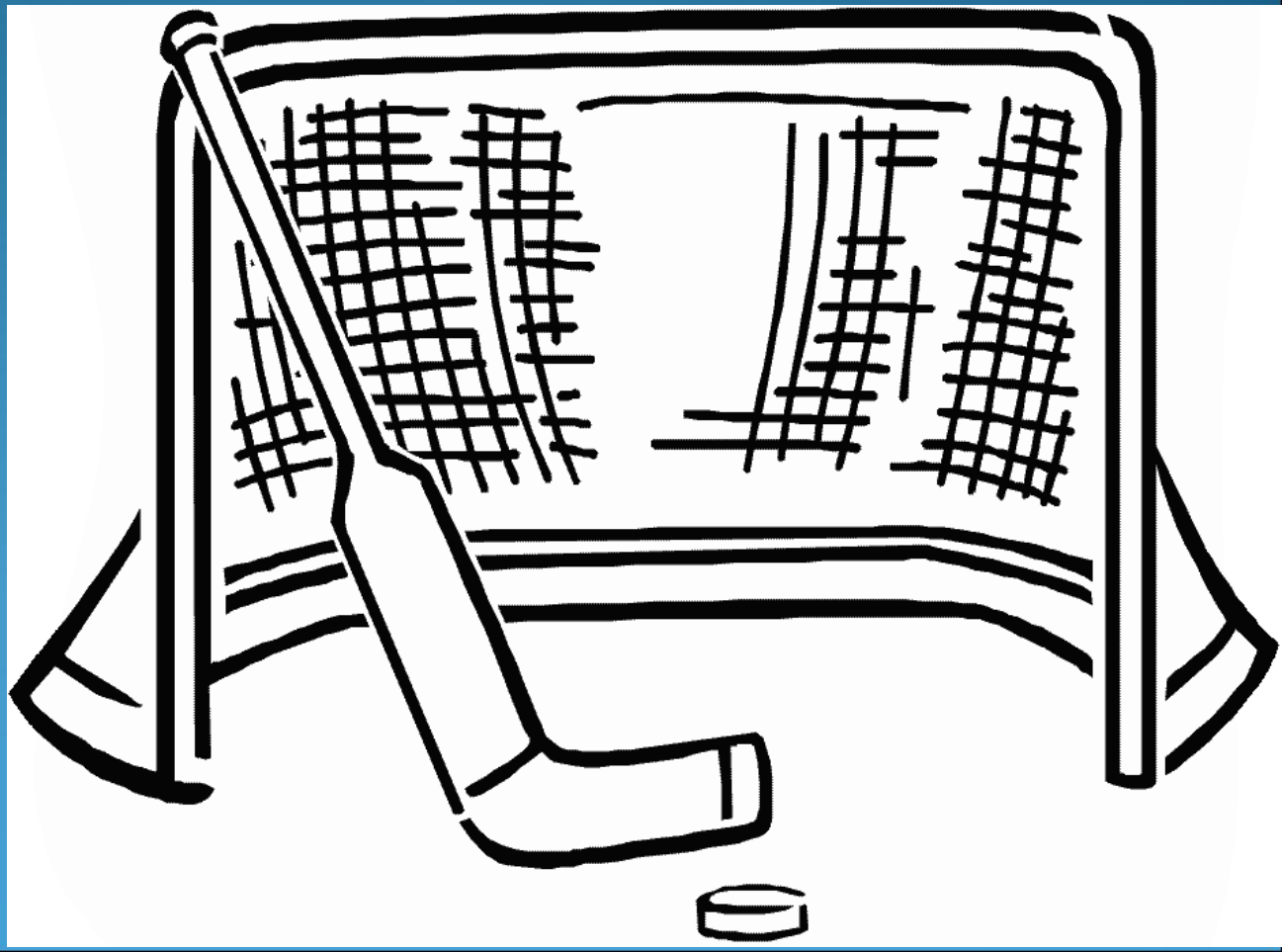
"There cannot be many physicians who also do serious psychological research and explore ethical dilemmas of their profession. It is unlikely that there is anyone besides Ubel who can do all these things extremely well."
—DANIEL KAHNEMAN, author of *Thinking, Fast and Slow*

CRITICAL DECISIONS

How You and Your Doctor Can Make the Right Medical Choices Together

PETER A. UBEL, M.D.

GOALS



Goals of Today's Discussion

- Discuss challenge of involving patients
  - In medical decisions
- Discuss psychological barriers to
  - Optimal decision making
- Explore relevance of these challenges and barriers
  - To making good use of CER info

Time for Emotions

Problem #1: Illustrated by this case

- Time to Deal With Emotions
  - In most of the encounters I have listened to
  - Bad news about cancer diagnosis
    - Almost never followed by time to deal with emotions
    - Or even acknowledgment of emotions
- Consider how my collaborator responded
- Why does this matter?

CER Shows Us that Medical Decisions: Loaded with Tradeoffs

- Quality vs. Quantity
- Quantity vs. Quantity
  - Bypass surgery maximizes long-term survival
  - But short run: chance of surgical mortality
- Quality vs. Quality
  - Pill reduces anxiety
  - But increases lethargy
- This means: “Right choice” often depends on
  - Patient preferences!

More on the Problem of Emotional Obliviousness

- Senior oncologists audiotaped
  - Talking to patients with advanced cancer
- Researchers identified examples of patients
  - Explicitly acknowledging negative emotions
    - "I'm scared"
    - "This pain is hard to live with"
- Oncologists responded appropriately to these emotions
  - 1 in 5 times!!!

Jargon

Next paragraph of same encounter

- “We also grade prostate cancer on how it looks under the microscope. We give it a score between 6 and 10.”
- “6 is what we consider the most low-grade, least aggressive looking, but it’s just abnormal enough for us to call it cancer.
- If it were any less than that, if there were less atypical looking cells, we couldn’t call it cancer.
- So it’s just enough to get a grade of cancer and then that goes all the way up to a score of 10 which is very abnormal looking and is more aggressive.”

Same Encounter: Things get even more complicated

- “Low risk is Gleason 6, intermediate is usually 7’s, either 3+4 or 4+3, depending on how it looks under the microscope, and then 8, 9 and 10 are all high risk.
- So yours was an intermediate risk.
- So it’s in the middle.
- It was 3+3 and 3+4, so just enough of the atypical cells of the grade 4 to make it 3+4, which means you’re intermediate risk.”

Problem #2

- If we want patients to be
  - More active decision makers
  - Perhaps even more savvy health care consumers
- We have to make sure
  - They understand their decisions!!!

The Feel of Risk

Imagine you have Colon Cancer

Surgery A

- 80% cure without complications
- 16% die of disease
- 1% colostomy
- 1% intermittent bowel obstruction
- 1% wound infection
- 1% diarrhea

- **Surgery B**
  - 80% cure without complications
  - 20% die
- **Which surgery would you choose?**

Give me colostomy or give me death!

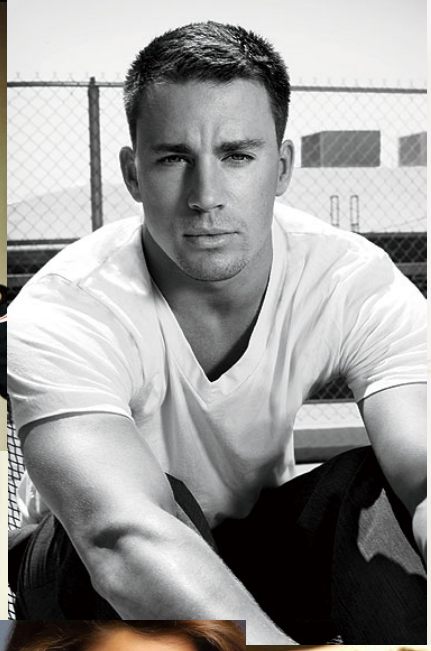
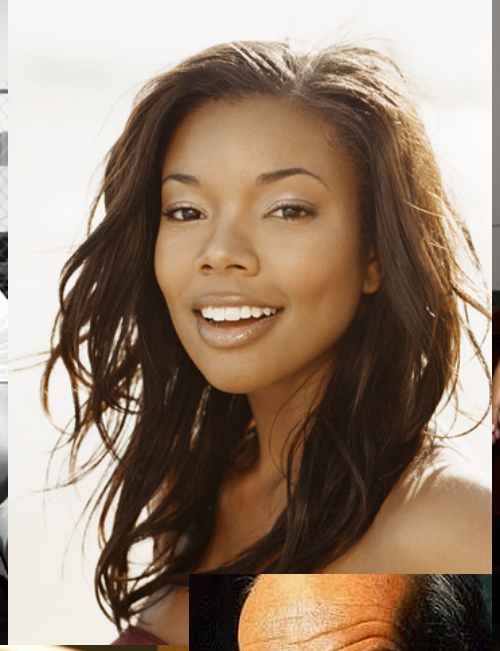
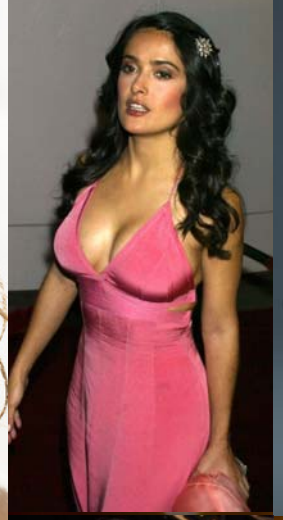
- >90% of people prefer each of the four complications to death
- To be consistent with these preferences
  - <10% should choose the uncomplicated surgery

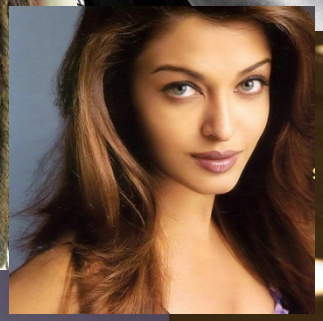
Our Survey says . . .

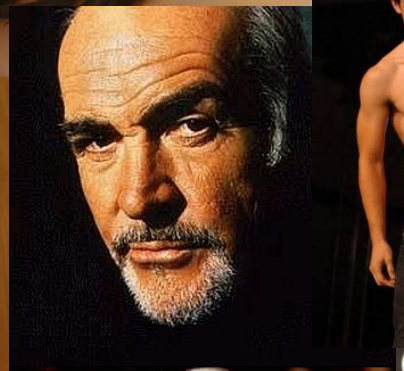
- 50-60% choose
  - the uncomplicate surgery

What is going on here?

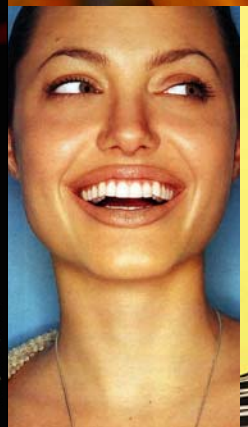
- To understand these inconsistent choices
  - It is time to think about your favorite movie star crush!







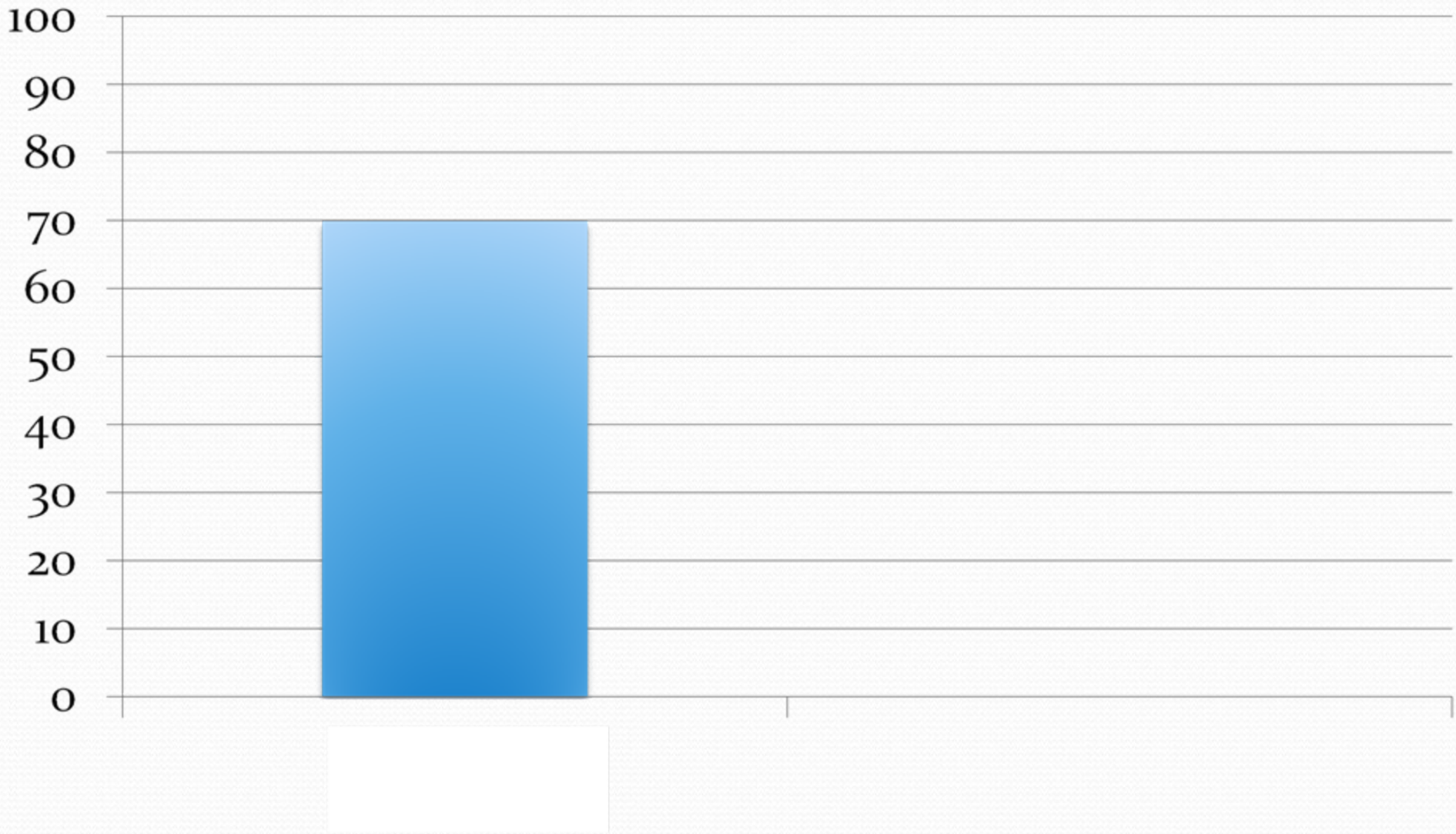

Kiss

$50


50
FEDERAL RESERVE NOTE
50
EE 00000000 T
E5
THE UNITED STATES OF AMERICA
EE 00000000 T
50
50
FIFTY
DOLLARS

?

% favouring money



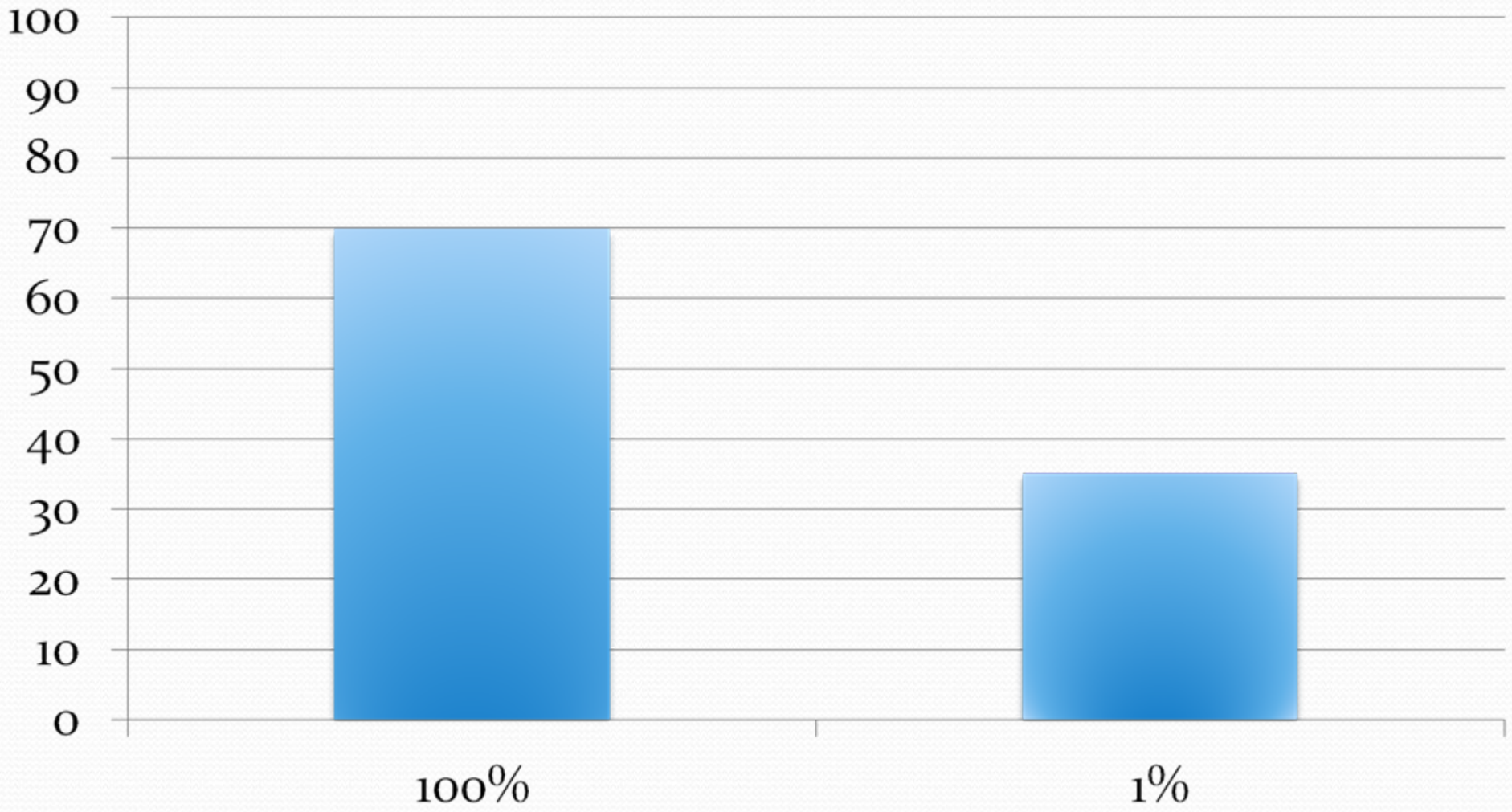
Rottenstreich & Hsee, Psychological Science, 20

1% chance of kiss

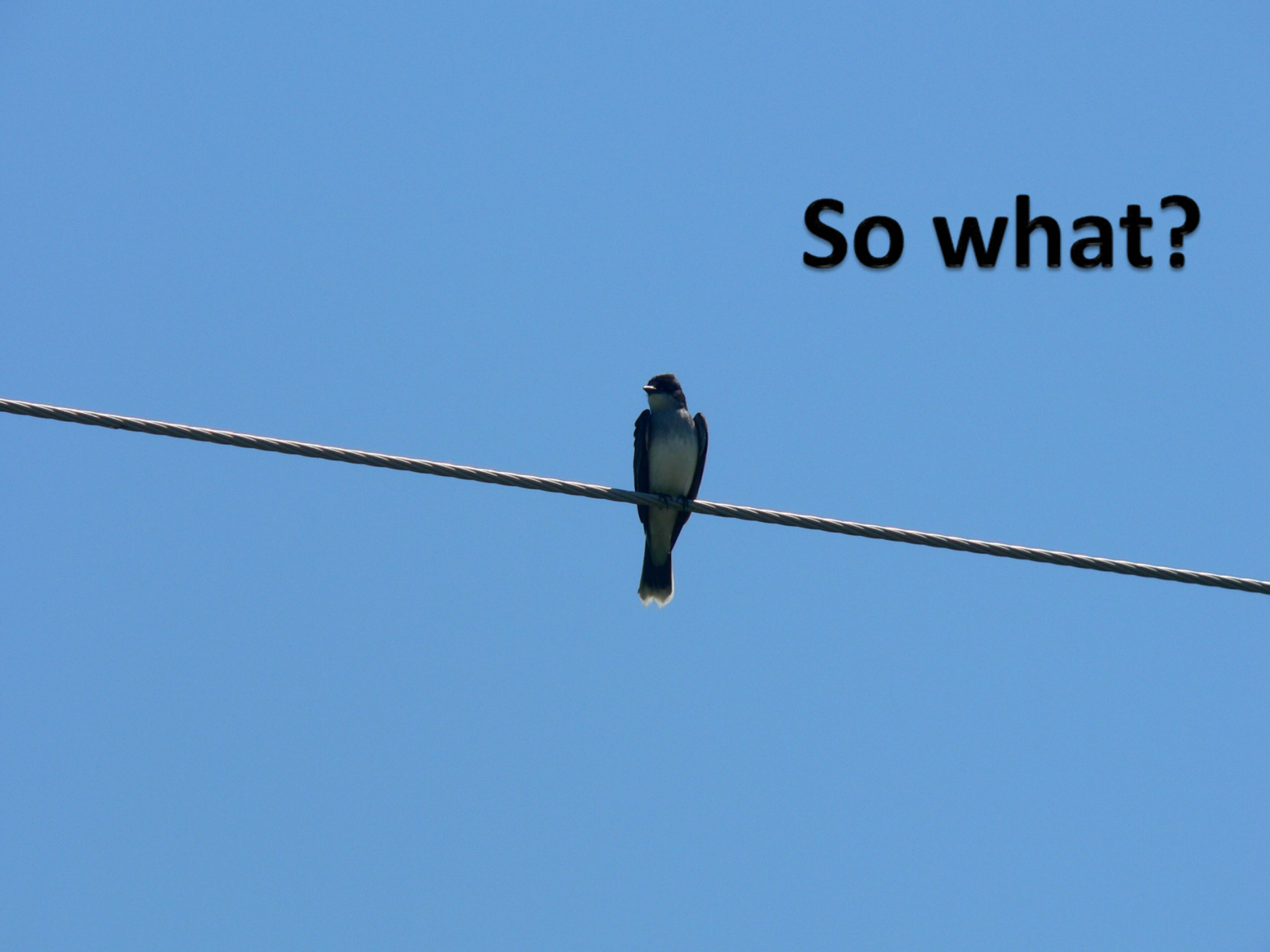
1% chance of $50

?

% favouring money



Rottenstreich & Hsee, Psychological Science, 20


So what?

death

colostomy

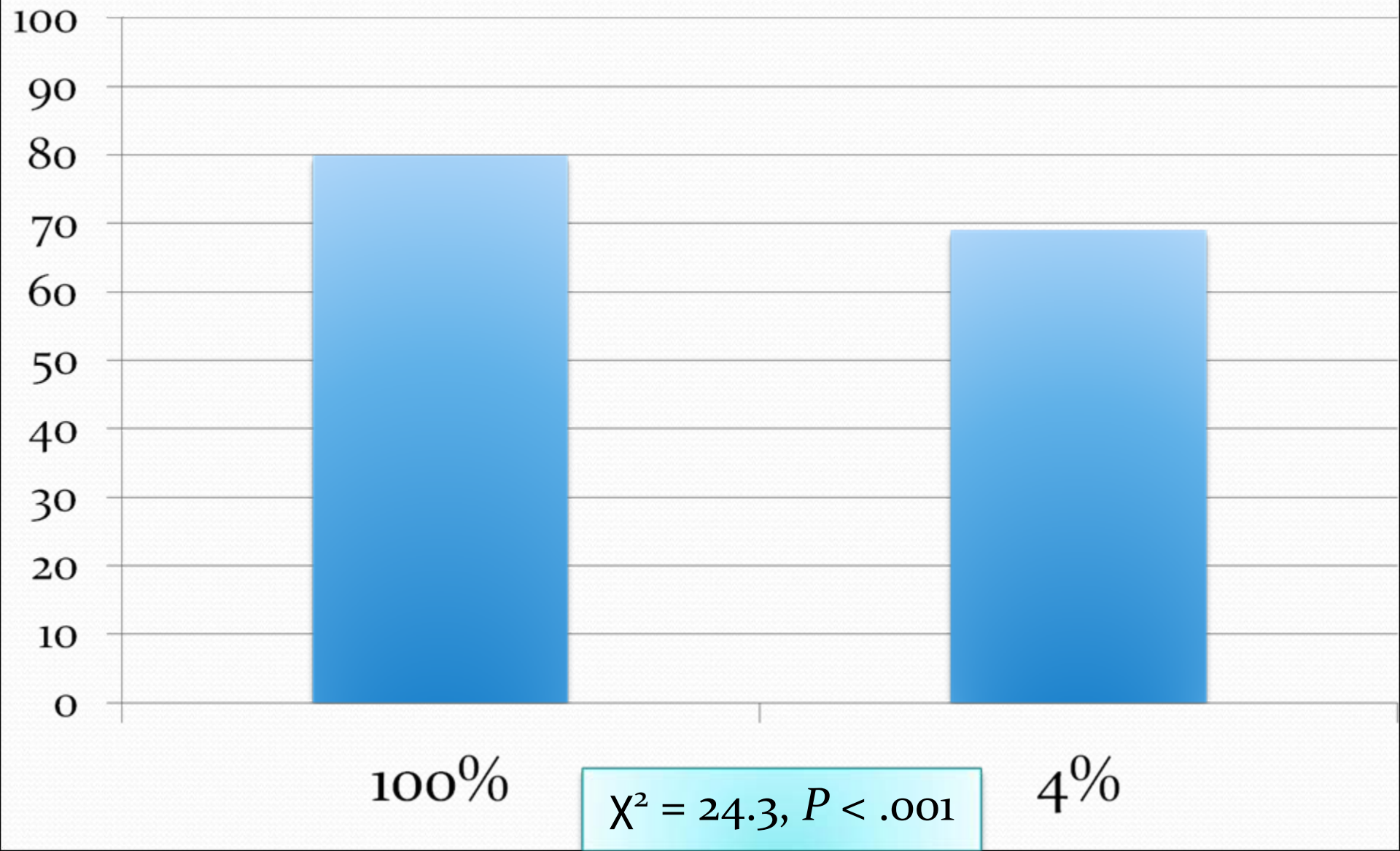
?

4% chance of death

?

4% chance of colostomy

% favouring colostomy



Problem #3

- When the consequences of a decision
  - Are emotional
- Small chances
  - Feel large!
- Too often we think of CER info
  - As “information”
  - And forget the SAME information
    - Feels different when combined with emotional outcomes

Simplifying

A CER Informed Decision: Whether to take Tamoxifen as Primary Prophylaxis

- If individual risk of breast cancer elevated
  - Age
  - Family history
  - Medical history, etc
- Might be worth considering tamoxifen
  - Cuts risk in half
  - But carries side effects

Side Effects of Tamoxifen

- Endometrial cancer

  0.3% => 0.6%

- Cardiovascular events

  2.1% => 2.8%

- Cataracts

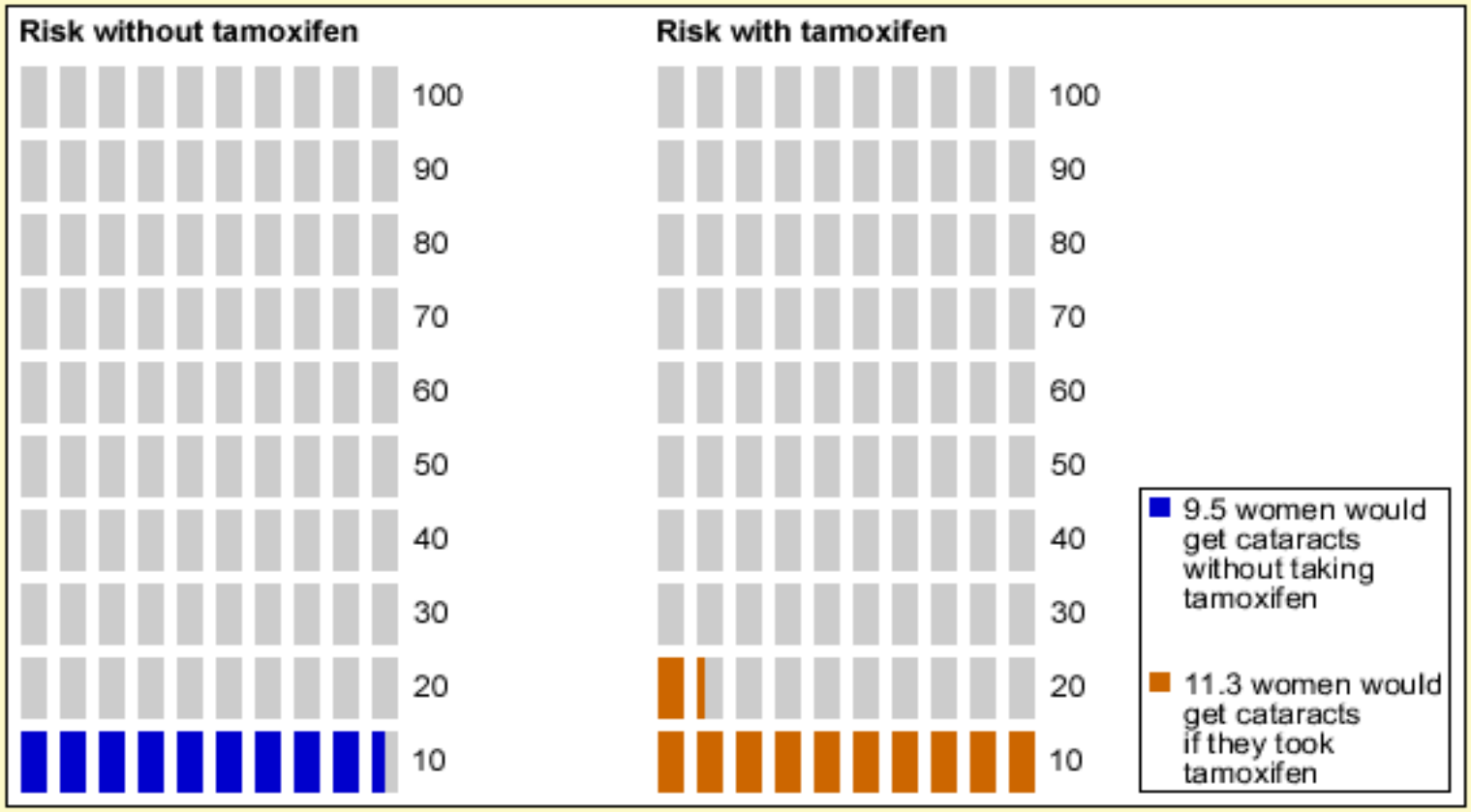
  9.5% => 11.3%

- Menopausal symptoms

  68% => 86%

Total Risk Comparisons

The graph on the left shows the number of women out of 100 who would get cataracts without taking tamoxifen. The graph on the right shows the number of women out of 100 who would get cataracts if they took tamoxifen.



Problems with Total Risk

- **Ignore baseline risks:** People may fail to see the relevance of the baseline info
  - See *entire* risk as caused by treatment

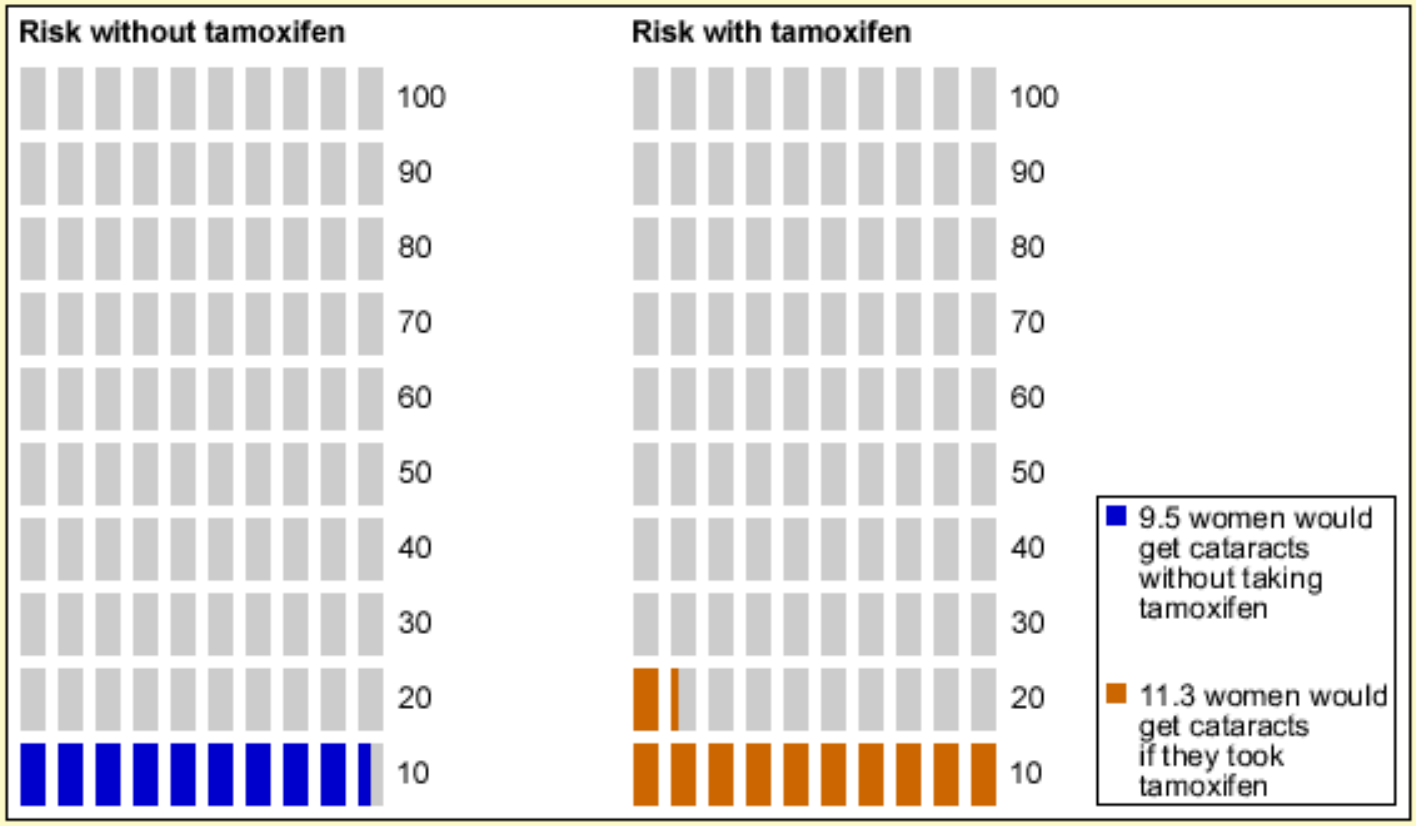
- **Mental arithmetic:** People must add or subtract risk statistics to identify the *change in risk*.

"Incremental" Risk

- When a treatment adds side effect risk, describe it *in those terms! e.g.*,
  - 9.5 women out of 100 get cataracts without tamoxifen
  - 1.8 *additional* women out of 100 would get cataracts with tamoxifen

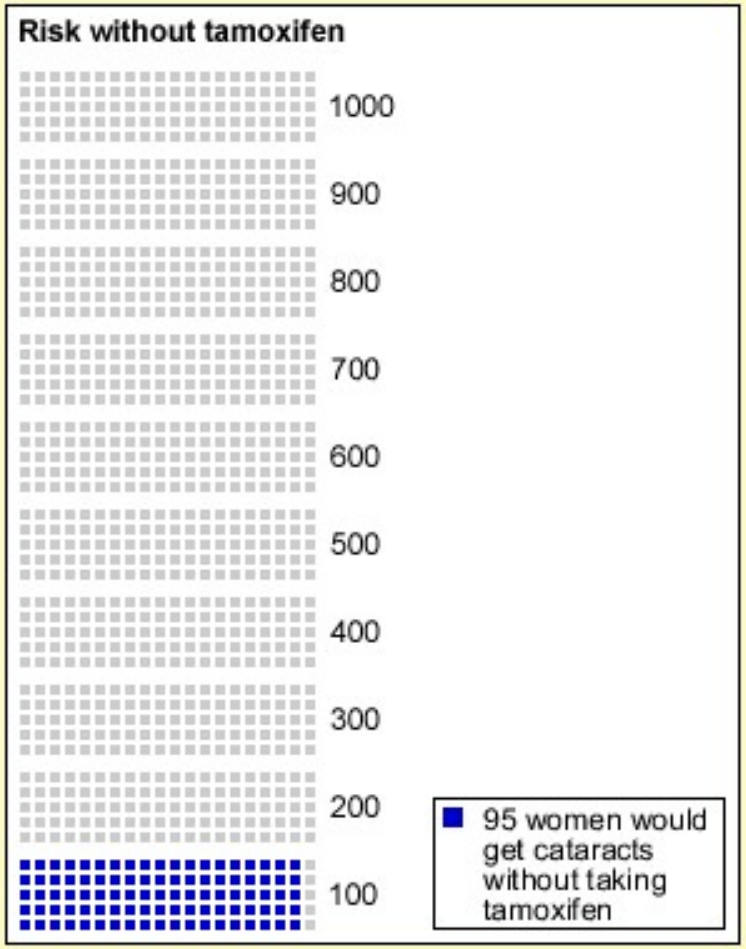
Total Risk (Pictograph)

The graph on the left shows the number of women out of 100 who would get cataracts without taking tamoxifen. The graph on the right shows the number of women out of 100 who would get cataracts if they took tamoxifen.



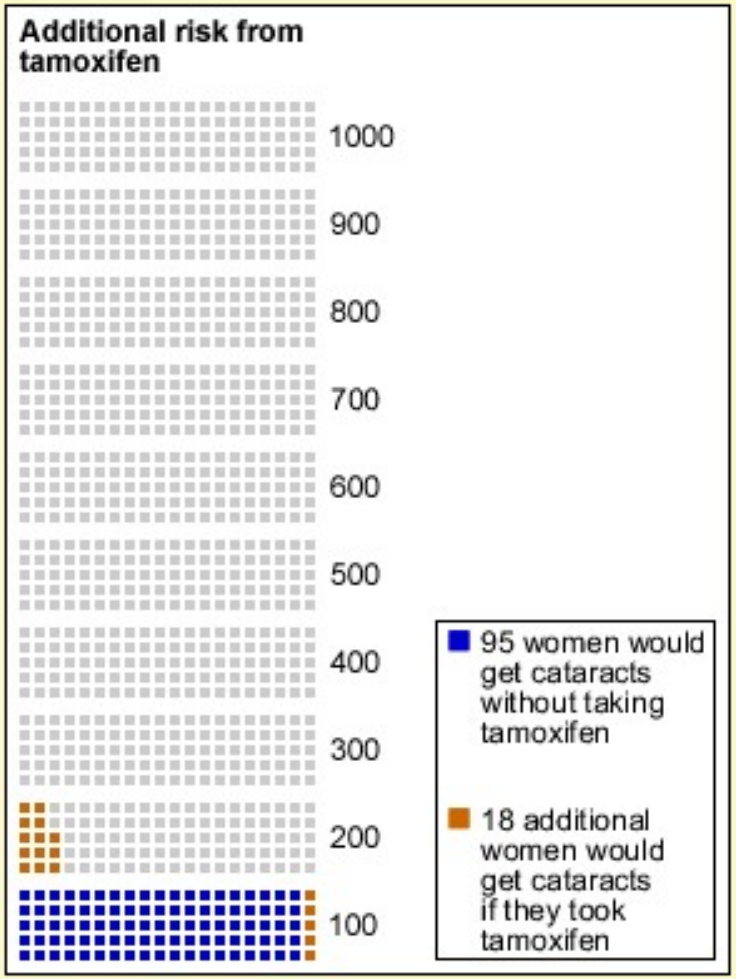
Incremental Risk 1 (Pictograph)

This graph shows the number of women out of 1000 who would get cataracts without taking tamoxifen.



Incremental Risk 2 (Pictograph)

This graph shows the number of women out of 1000 who would get cataracts without taking tamoxifen, and the additional number of women who would get the conditions if they took tamoxifen.



Secondary Factors

- Risk denominator
  - Risks “out of 100” versus “out of 1000”
- Probability order
  - Low P, high severity risks first versus last

Total vs. Incremental Risk: Worry

Worry about side effect (0-10) :

Total	4.6
Incremental	4.0
p	<.01

Effect of Risk Denominator on Worry

	Out of 100	Out of 1000	p-value
Total	3.9	5.2	<.001
Incremental	4.1	3.8	n.s.

Effect of Probability Order on Worry

	Low P first	High P first	p-value
Total	4.9	4.2	<.05
Incremental	4.1	3.8	n.s.

This study shows that

- Incremental risk presentations…
  - Evoke less worry than total risk presentations
    - Emphasize how much risk exists at baseline
  - Are more resistant to denominator and probability order biases

Another Example: Adjuvant Online

Shared Decision Making

Name: _____ (Breast Cancer)
Age: 59 General Health: Good

Estrogen Receptor Status: Positive Histologic Grade: 3
Tumor Size: 2.1 - 3.0 cm Nodes Involved: 0
Chemotherapy Regimen: CMF-Like (Overview 2000)

Decision: No Additional Therapy

70 out of 100 women are alive in 10 years.
23 out of 100 women die because of cancer.
7 out of 100 women die of other causes.

Decision: Hormonal Therapy

7 out of 100 women are alive because of therapy.

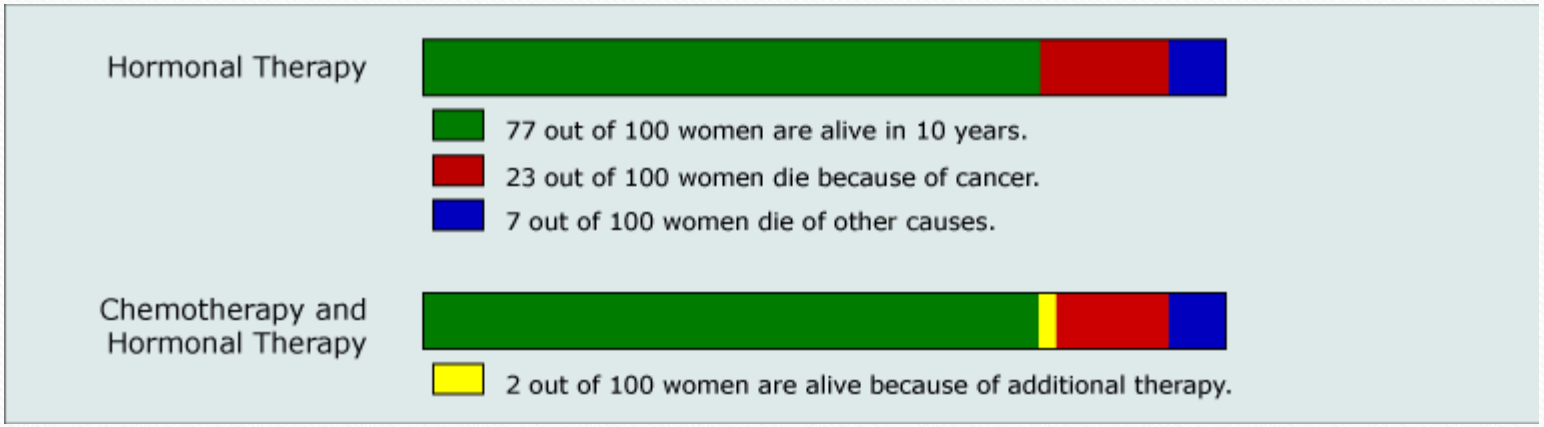
Decision: Chemotherapy

3 out of 100 women are alive because of therapy.

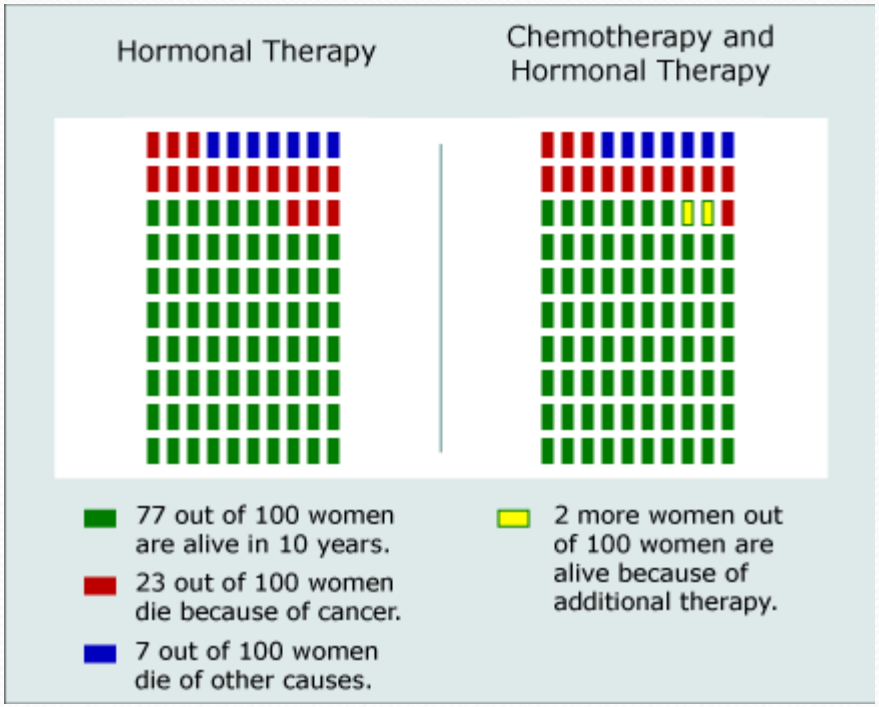
Decision: Combined Therapy

9 out of 100 women are alive because of therapy.

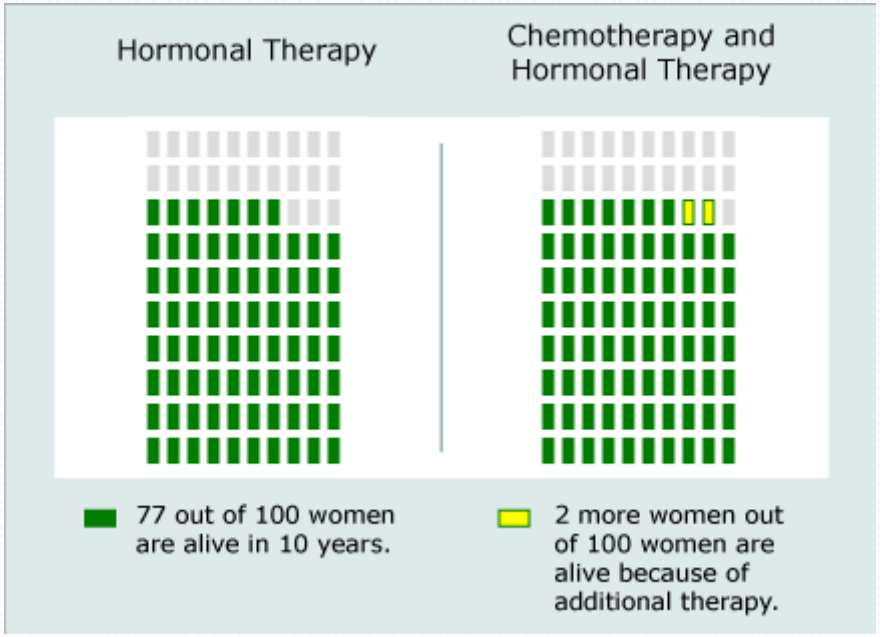
Simpler Format



Pictograph Format



Even More Simplified Pictograph



Final Thoughts

- We need to consider divvying up the jobs
  - Some folks collect CER info
  - OTHER folks figure out how to communicate it to patients
- The last step in putting CER info to good use
  - Is to have it appropriately inform medical decisions

- Check out my blog
  - www.peterubel.com
- Follow me on Twitter
  - @peterubel
- Contact me:
  - peter.ubel@duke.edu