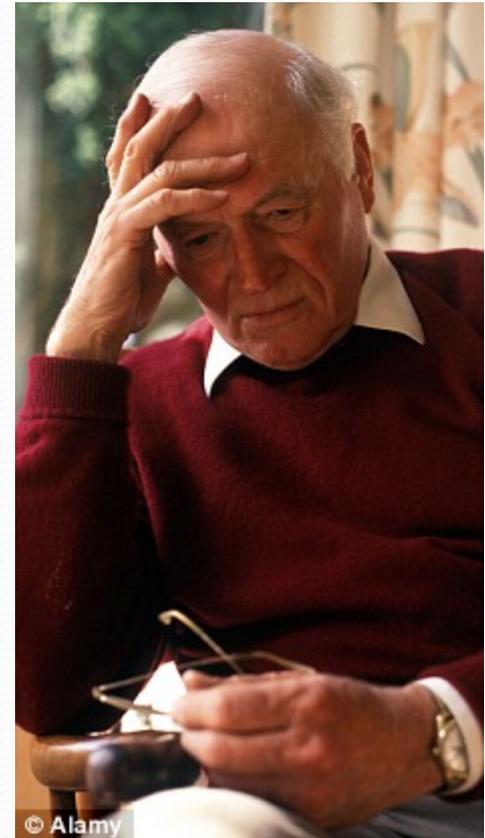


What Behavioral Science Has Taught Me About Clinical Ethics

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A Choice

- Localized prostate cancer
 - Watchful waiting
 - Surgery
 - Radiation
- What should I do?



"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

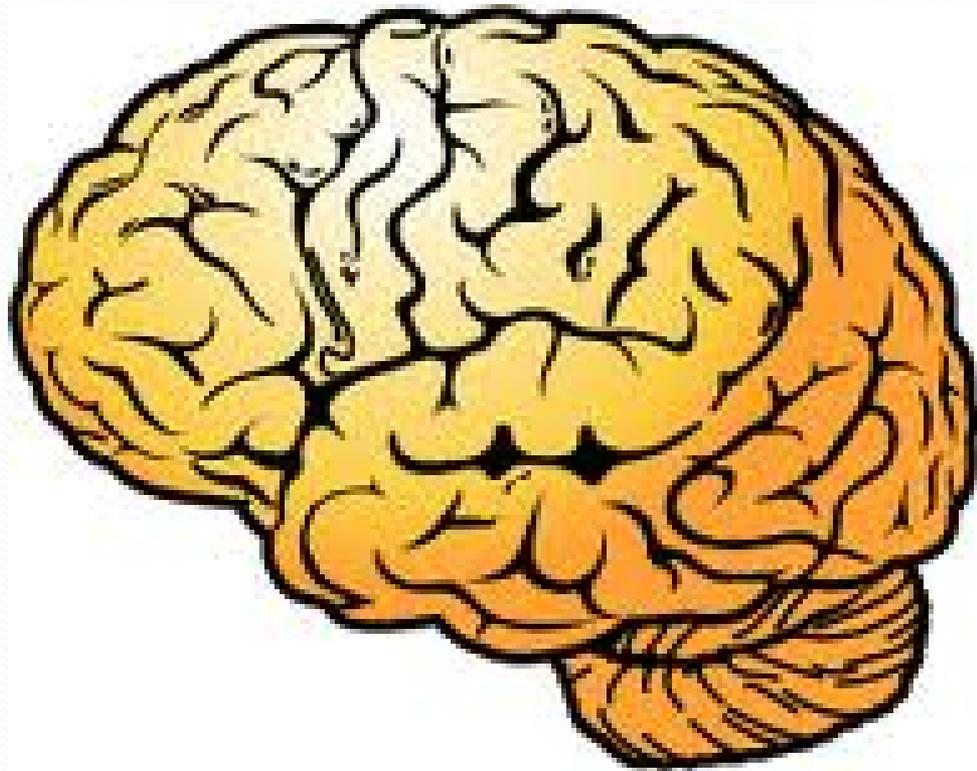
PETER A. UBEL, M.D.

My bioethics training

- I saw this situation as
 - Autonomy versus paternalism
- I needed to help this patient be
 - More autonomous
 - More of a “chooser”









VS



What K.A. Quinlan Case Was Really About

- Beginning of end for “Doctor knows best”
- 1960
 - Dying of cancer
 - “You have an infection. Take this medicine.”
- 1975
 - Treatment of breast cancer determined by surgeons, not patients

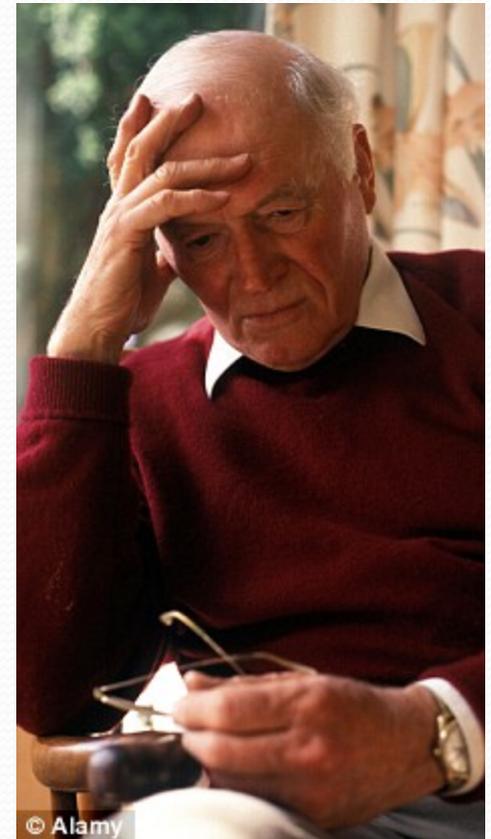


Ethics Taught Me That:

- The “right” decision
 - Often varies patient to patient
 - Depending on individual
 - Preferences
 - Values
- Thus, “experts” don’t necessarily have the answers

Helping Him Make the Choice

- No “best” treatment
 - Watchful waiting
 - Surgery
 - Radiation
- What should I recommend?









What would you do if you
were me?

Goal of This Talk

- Explore how behavioral science has influenced my thinking on
 - Autonomy versus paternalism
 - Shared decision making
- Point toward some ways to
 - Improve medical decision making
 - And come closer to the ethical ideals of the health professions



Good Decision Making

Some elements of good decision making

- Information: Patients understand
 - Pros and cons of their alternatives
 - Role of their preferences in determining correct choice
- Free decision: Patient has freedom
 - To choose among available alternatives
 - To cede choice to health professional



Getting Good Information

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.”

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?

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
- We have to make sure
 - They understand their decisions!!!

Consider

the meaning of
these words



High Blood Pressure

Consider

the meaning of
these words



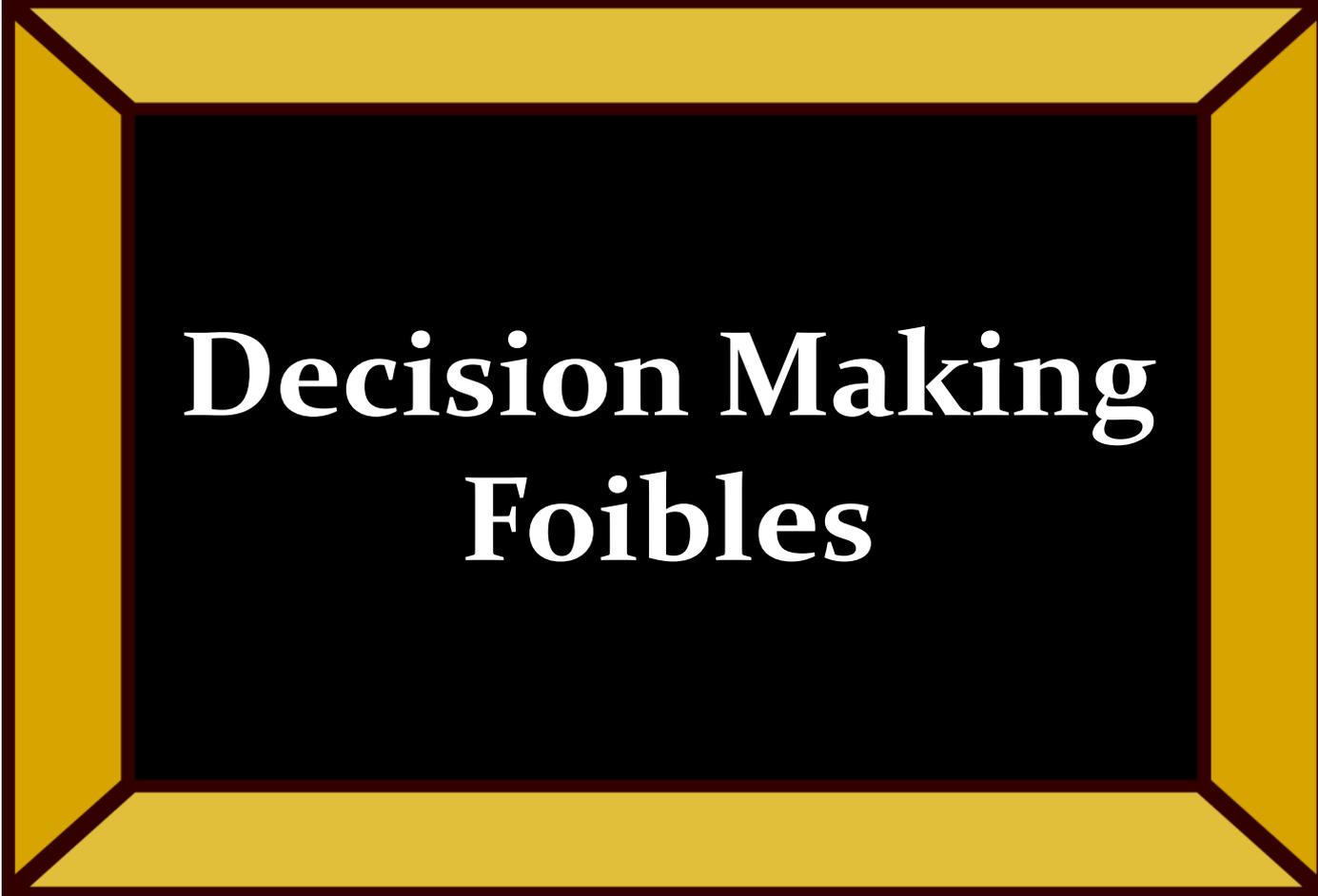
Noonan Syndrome

Good ethics means good communication

- Good communication takes
 - Time
 - To acknowledge and deal with emotion
 - To absorb and reflect on information
 - Ability to take patient's perspective
 - E.g Jargon

One Possible Solution

- Supplement clinical encounters
 - With “Decision Aids”
 - Designed to
 - Educate patients about choices
 - Inform them about importance of their values
- My short take
 - Big fan of these tools
 - But they force us to look at the next big topic
 - How do people use this information to make choices?



Decision Making Foibles

A pill to prevent breast cancer

- Suppose your 5 year risk of breast cancer was 6%
- Either Tamoxifen or Raloxifene can reduce that risk to 3%
 - With the following side effects
 - Endometrial cancer 0.3%
 - Heart attack or stroke 0.5%
 - Hot flashes, vaginal discharge 15%
- Would you take
 - Tamoxifen?
 - Raloxifene?
 - Neither?

What if I told you . . .

- The average woman's 5 year risk is 3%
 - And Tamoxifen would lower it to 1.5%
- Or that the average woman's risk is 12%
 - And Tamoxifen lowers it to 6%
- Would this change your decision?
- Should it?

Problem #1 With This Decision

- Lots of information
 - Three alternatives
 - Each with pros and cons
- And two of the alternatives
 - Tamoxifen and raloxifene
 - Pretty darn similar
- Could that create problems?

Too Many Choices?

- Supermarket testing booth
- A specialty jam company's products were chosen
 - **because they had lots of jams**
- Grocery stores randomized so that
 - **6 jams were displayed**
 - **24 jams were displayed**



Outcomes

- Which booth was visited most often?
 - **24 jams**
- Which booth did more people taste jam at?
 - **24 jam booth**
- Which booth led to more jam sales?
 - **6 jam booth**

YIKES!



Can three choices be too many?



Where Do People Go?

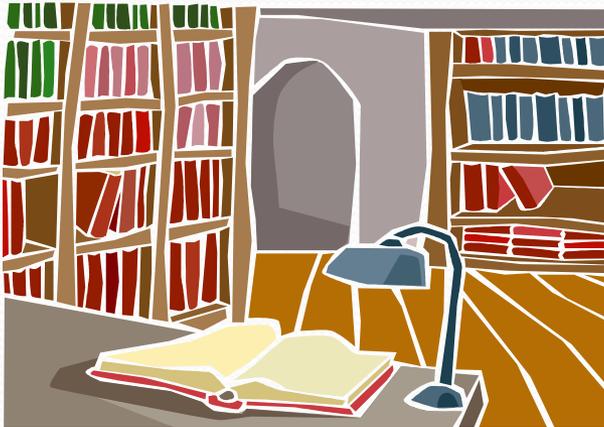


21%



79%

Suppose There Were 3 Alternatives



Now Where do People Go?



40%



9%

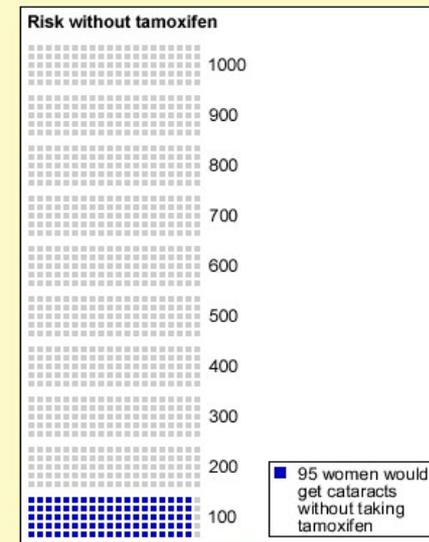


51%

Problem #2: Risk isn't just a #!

- Already know that these risk numbers
 - Hard for people to comprehend
- But that can be addressed with pictures and good writing
- Another problem
 - Numbers aren't just used as facts
 - They are wrapped up with feelings/intuitions

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



An Example of “Risk as Feelings”

- Asked women to imagine a 6% risk of breast cancer over 5 years
- Randomized to receive the following comparative risk information
 - 3%
 - 12%
- Asked for attitudes toward breast cancer and Tamoxifen

Our Results

1 – 5 Scale	3	12
Interest in Tamoxifen	2.8	2.2

Our Results

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Our Results

1 – 5 Scale	3	12
Interest in Tamoxifen	2.8	2.2
Breast Cancer Worry	2.8	2.4
Effectiveness of Pill	3.1	2.7
How helpful comparative info	3.8	3.9

This Study Shows That:

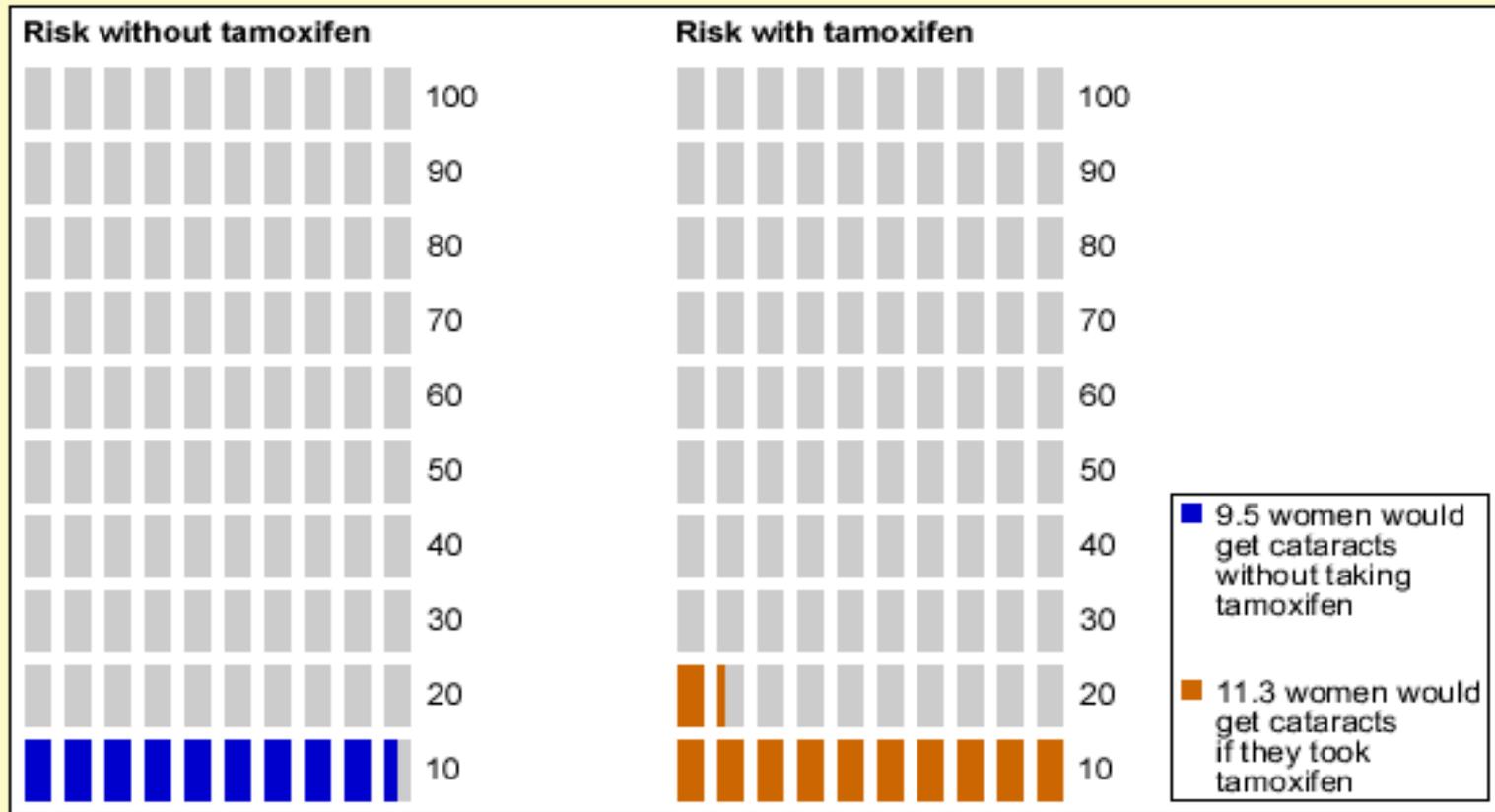
- People want comparative risk information
 - Even when it is uninformative
- And that information will change the way their own risk feels

The Feel of Risk Leads to “Unstable Preferences”

- Consider an earnest attempt to educate people about the risks of tamoxifen: e.g.
 - Endometrial cancer 0.3%
 - Heart attack or stroke 0.5%
 - Hot flashes, vaginal discharge 15%
- How should we present that info?

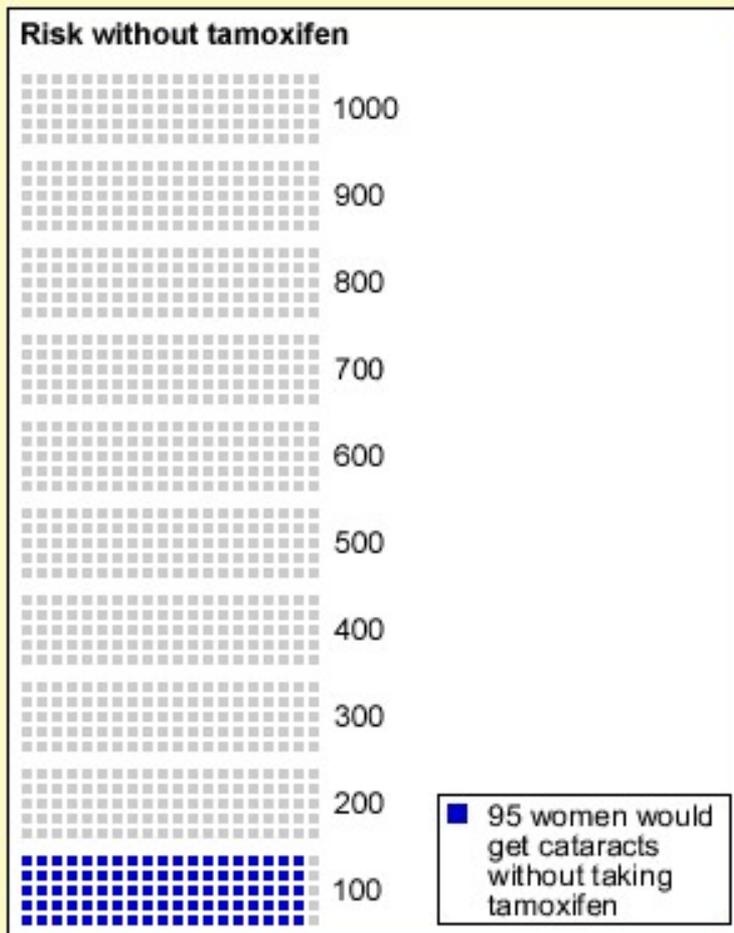
Risk out of 100?

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.



Risk out of 1000?

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



What information first?

- Tell folks about
 - Pros then cons of tamoxifen?
 - Cons then pros?
- Alternate
 - One pro, one con; another pro, another con . . . ?



Negotiating Decision Role

Decision Makers and Responsibility

- Consider
 - DNR discussions
 - Requests for advice
- Often patients and loved ones
 - Don't want to feel like decision maker of last resort
 - But this raises possibility of biased advice

Normal Biases

- Conflicts of interest
 - More surgery → more money
 - Financial relationship with industry making
 - Medication
 - Device
 - Test
- But consider a subtler psychological bias

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
- But majority
 - Choose this treatment

What would your doctor do?

- Review:
 - Mailed to primary care physicians in US
 - 40% chose surgery with
 - Higher death rate
- Ran experiment at same time
 - Half of docs asked to make Rx rec
 - Only 25% recommend that Rx

You catch the eye of an attractive stranger



Your FRIEND catches the eye . . .



Giving Advice

- Challenge 1:
 - It changes psychology of decision making
- Challenge 2:
 - It requires understanding of patient preferences
 - If stable ones exist



Improving Decision Making



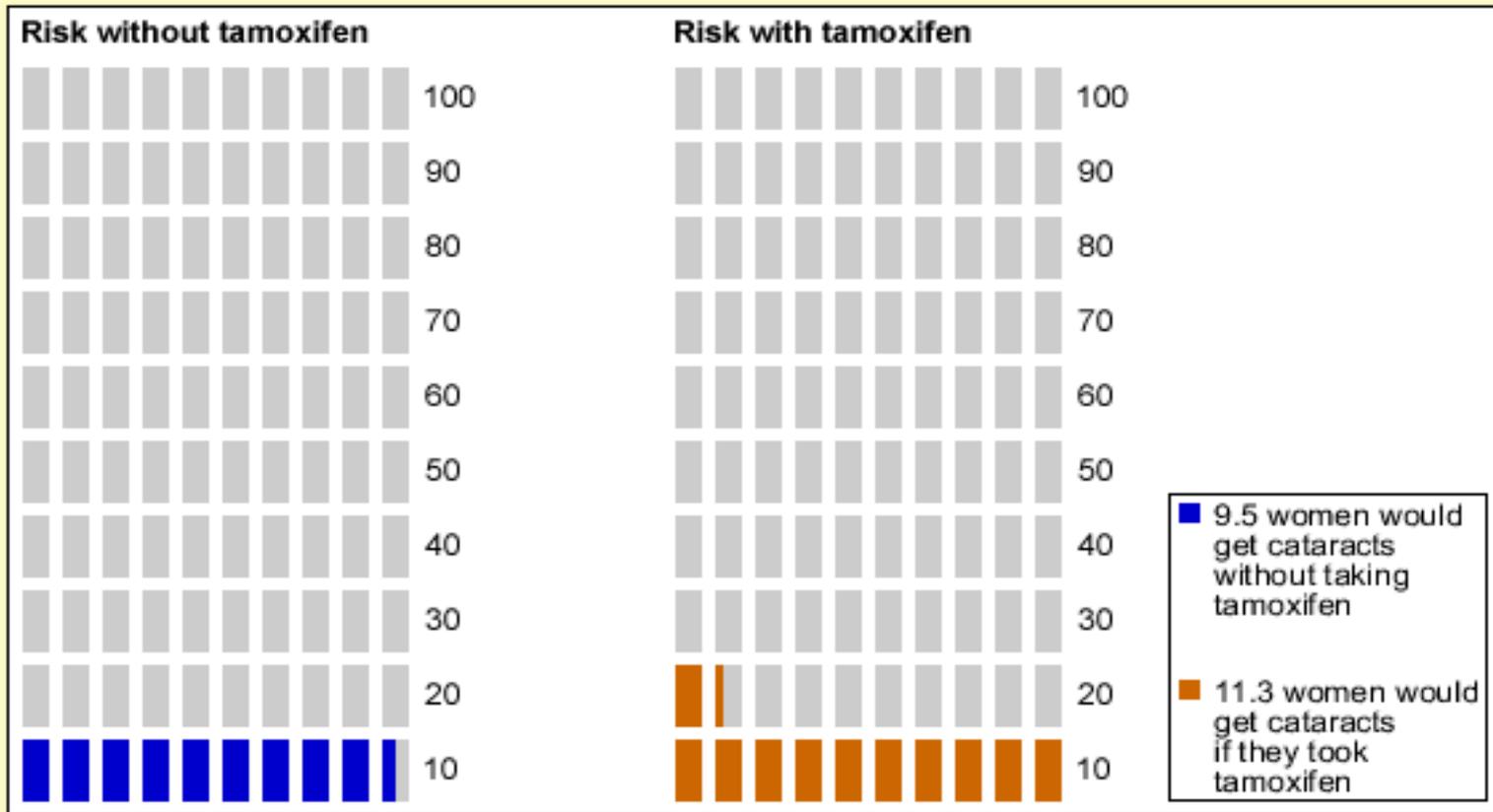
Let's look at how to improve

- Information provision

- Decision making processes

Side by Side Risk Info

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 This Info

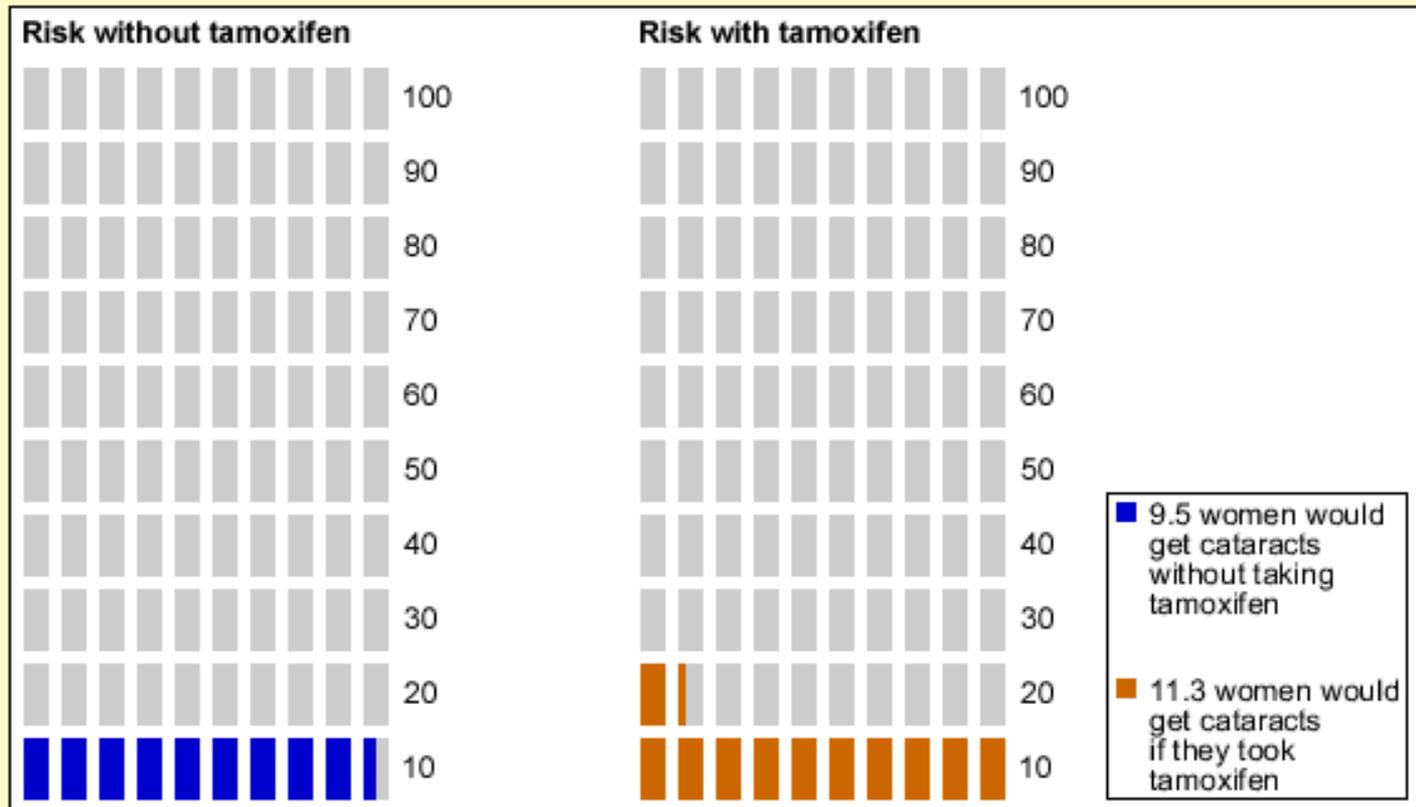
- **Ignore baseline risks:** People may fail to see the relevance of the baseline info
 - See *entire* risk as caused by treatment
- **Mental arithmetic:** People must add or subtract risk statistics to identify the *change in risk*.

An Alternative: “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**

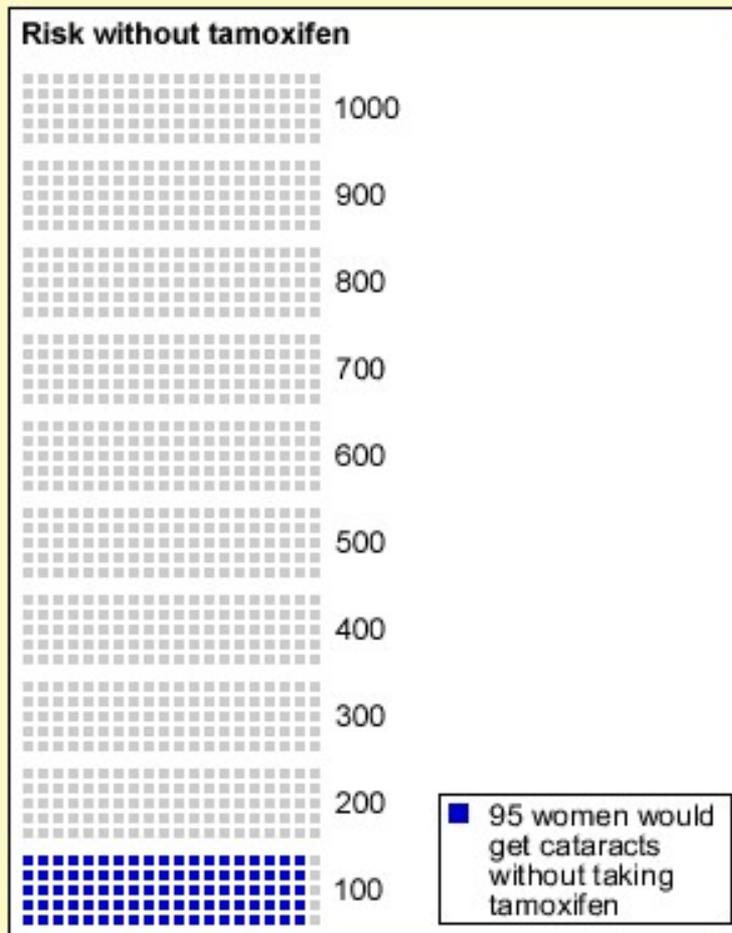
Side by Side

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.



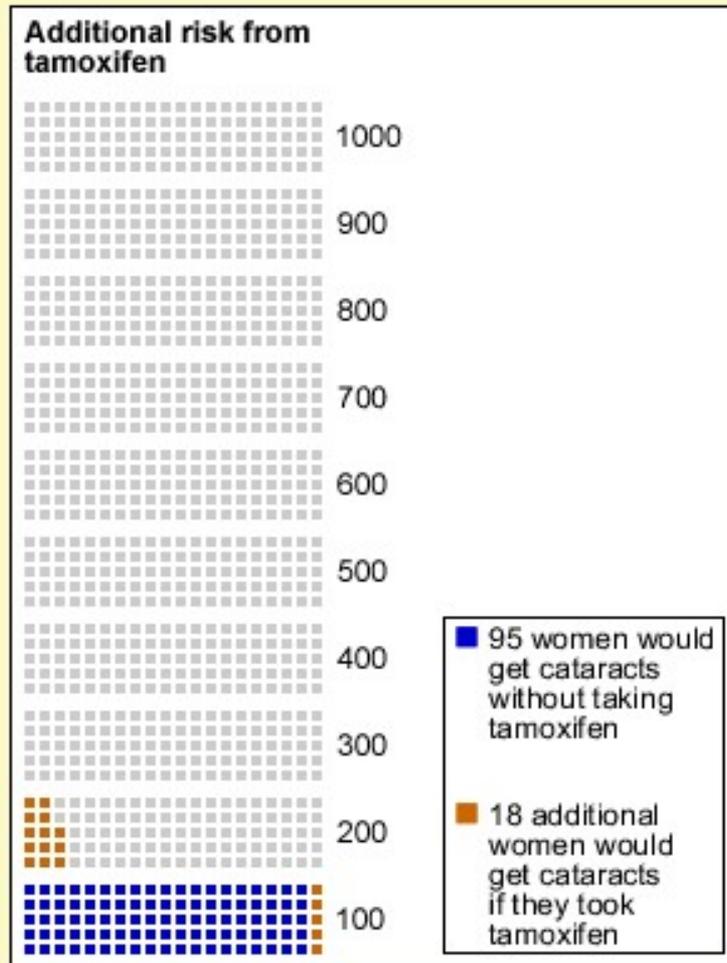
Incremental

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



Incremental

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

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

Effect of Probability Order on Worry

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

Behaviorally Informed Design

- In providing information to patients
 - In decision aids
 - In clinical encounters
- Information provision need to be informed
 - By behavioral science

Clinical Thoughts

- Two questions that should be part of every decision making encounter:
- Question No. 1:
 - “I’ve just said a lot of things to you, and I want to see if I’ve done a good job.
 - *In your own words, can you tell me what you heard me say?”*

Question 2: Diagnosing Preferences

- Question No. 2:
 - “Now that we’re on the same page about the pros and cons of your alternatives, I’d like to know:
 - *What can you tell me about yourself that will help me work with you to figure out which of these choices is best for you?”*

Putting Ethics Into Action

- Can't limit ourselves to debates about
 - Paternalism
 - Autonomy
- Need to emphasize
 - The moral and clinical value of
 - Good communication and “teach back”
 - And understanding of what matters to patient

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