

Understanding shared decision making for implementation in VA clinical & Research settings

Angie Fagerlin, PhD / VA Ann Arbor /
UMichigan

Why are You Interested in This Webinar?

- A. Research Interest
- B. Clinical Interest
- C. Other Interest

Shared Decision Making

- Involves at least 2 participants
- Both must actively participate
- Information sharing
 - MD must create atmosphere
 - MD needs to explain technical aspects so that patient understands risks/benefits.
 - Patients need to share preferences, values, and goals.
- Treatment decision is agreed upon

Concept Of Equipoise – Where Shared Decision Making is Most Relevant

- SDM is most relevant in clinical situations in which there is clinical *equipoise* about what to do next.
- These areas are also known as preference sensitive care.
- Preference sensitive decisions are those where more than one reasonable path forward exists (including the option of doing nothing), and different paths entail varying combinations of potential benefits and risks.
- Examples include therapy for early-stage breast cancer or prostate cancer, lipid-lowering medication for the primary prevention of coronary heart disease, and genetic and cancer screening tests.

What is a High Quality Preference-Sensitive Decision?

- Patient has high level of decision-specific knowledge.
- Decision reflects patient values for different outcomes associated with options.
- Example:
 - Woman diagnosed with early stage breast cancer
 - Has a strong preference for keeping her breast
 - Chooses breast conserving surgery

 - Woman with breast cancer wants to avoid radiation
 - Chooses mastectomy

(Sepucha et al., 2004, Health Affairs)

Steps in Shared Decision Making in Practice

- 1) Identify the situations in which SDM is critical
- 2) Acknowledge the decision to a patient
- 3) Describe the available options, including uncertainty
- 4) Elicit/construct patients' preferences and values
- 5) Agree on a plan for the next steps



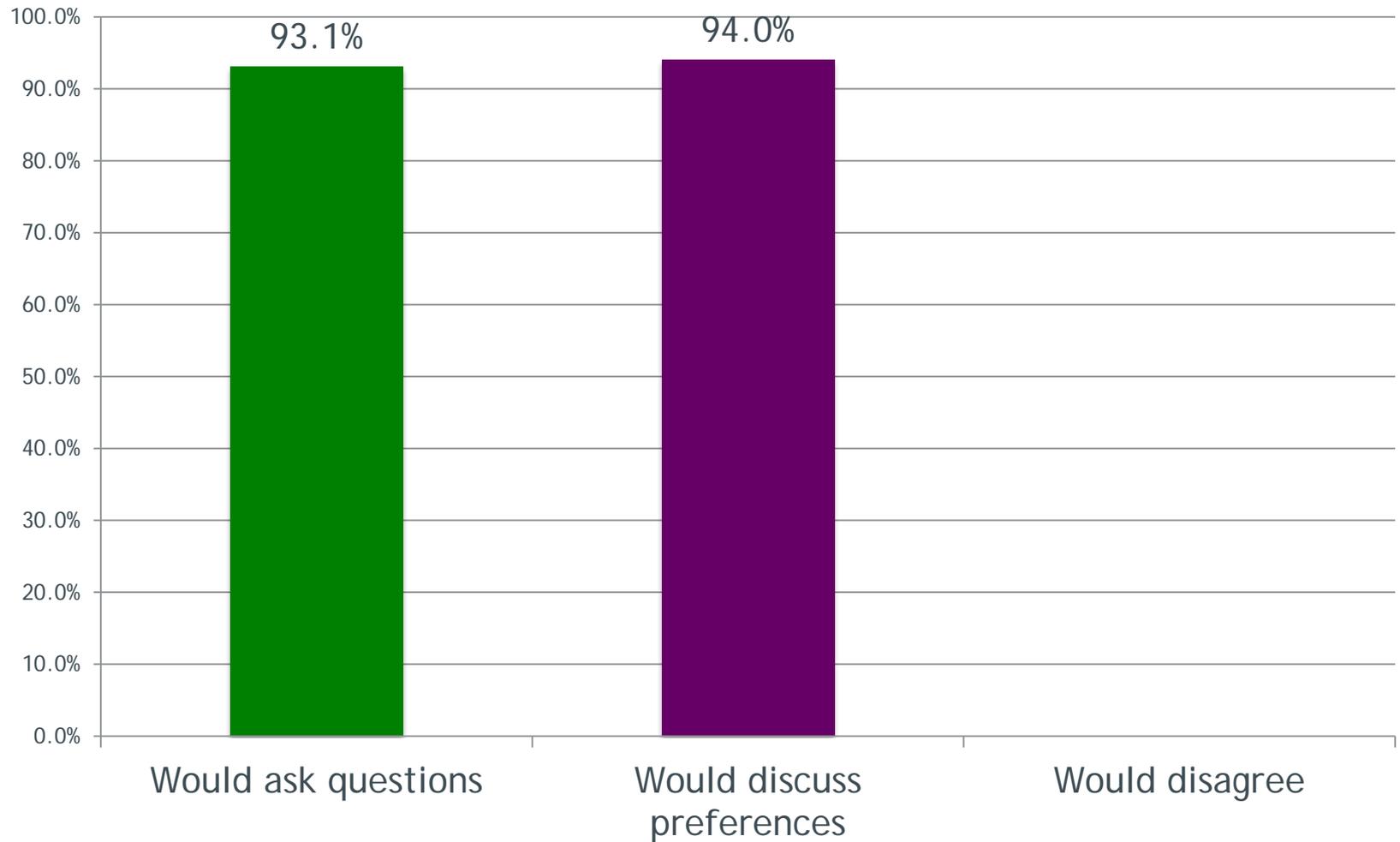
Are we
there yet?



A common sentiment
among healthcare
providers:

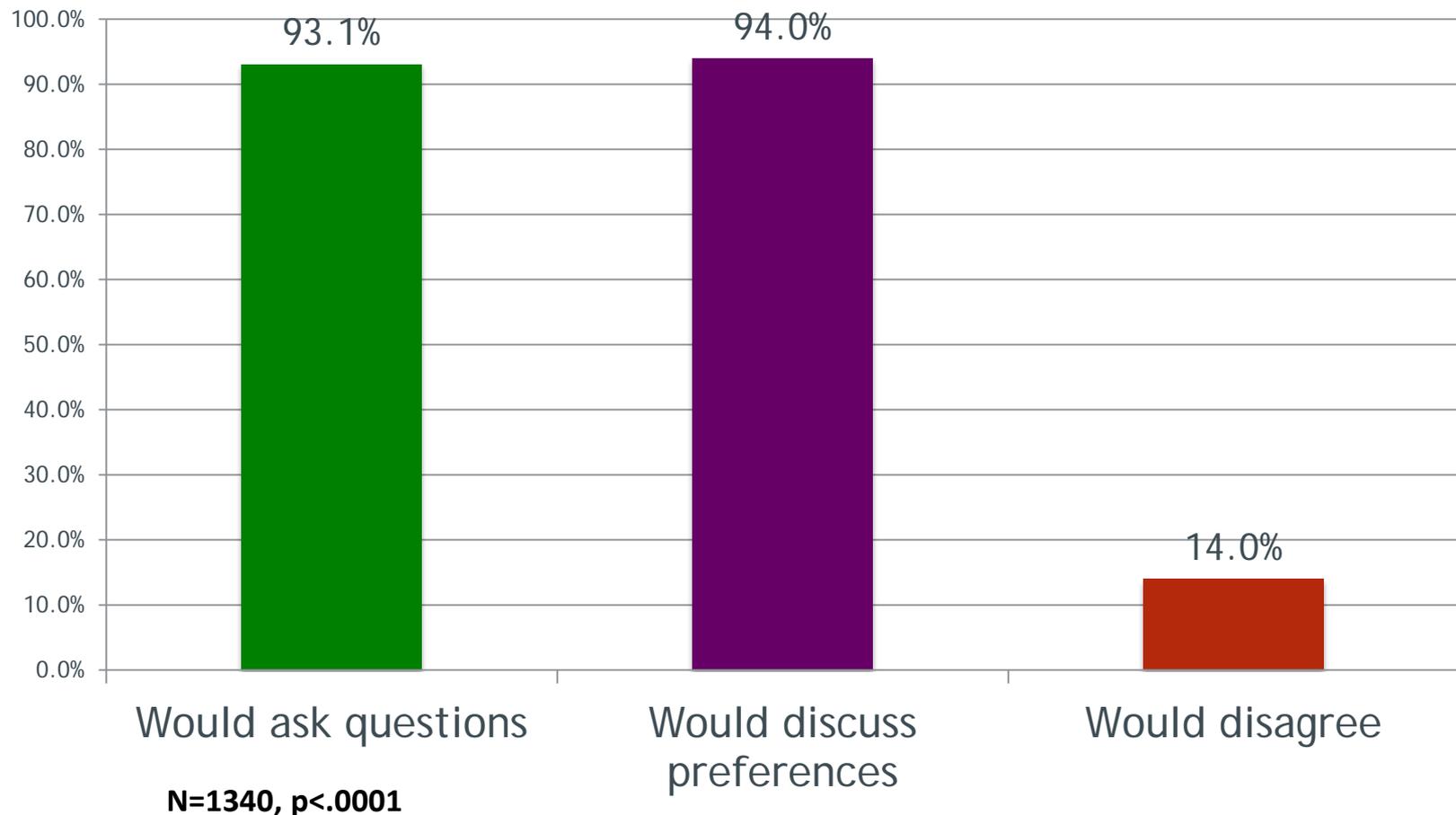
“We already do that all the
time.”

Reality Check



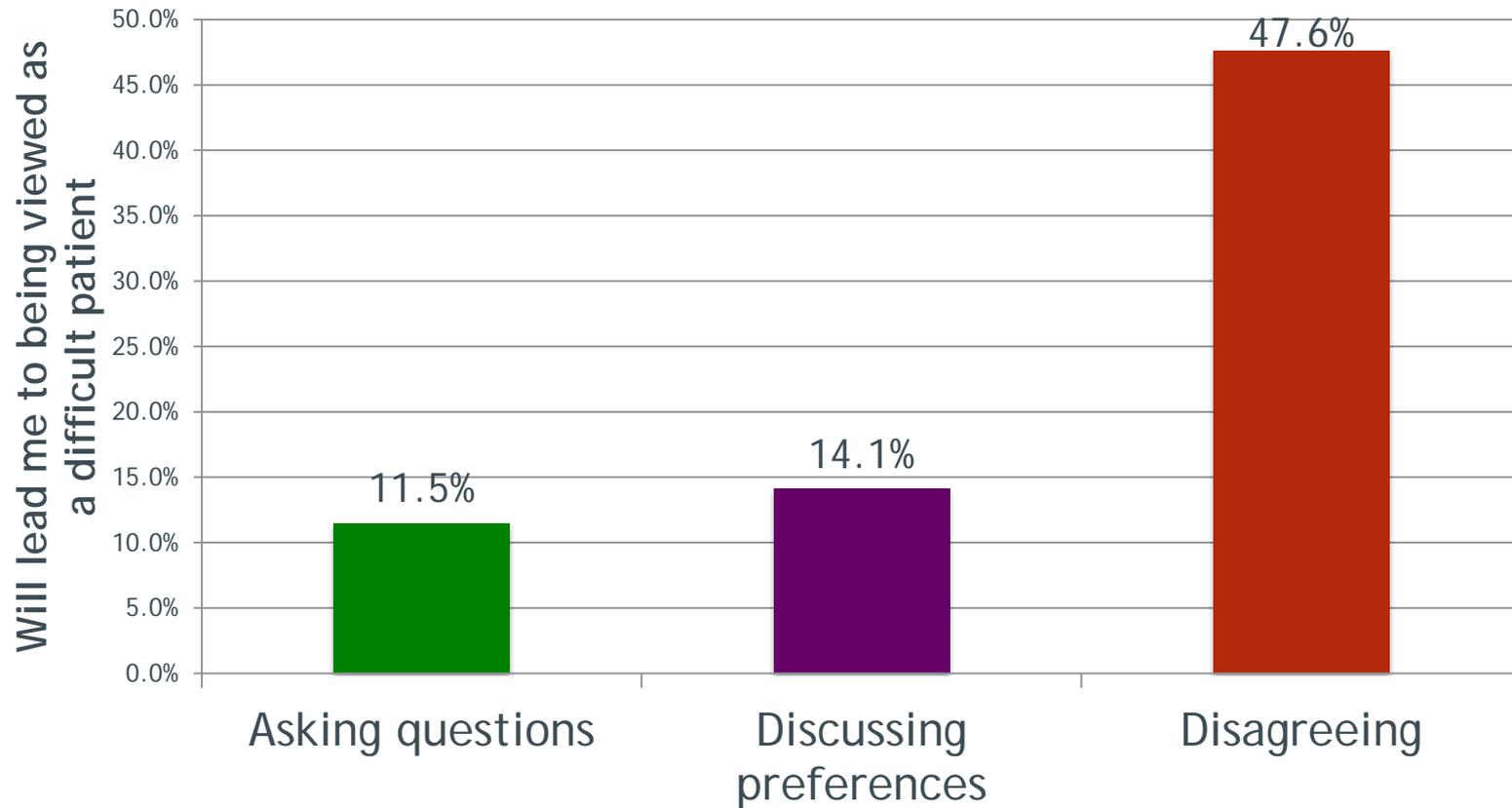
Reality Check

Most people don't feel comfortable disagreeing with a physician's recommendation



Reality Check

Because they fear being labeled a “difficult patient”



N=1340, p<.0001

Adams et al, 2012, Archives of Internal Medicine

Shared Decision Making: Benefits for Clinicians

- Improves informed consent procedures
- Can save time and make consultations more efficient and satisfying
 - By expanding counseling beyond busy office visits
 - By improving patients' baseline knowledge
 - Focusing discussion on key issues for the decision, rather than basic education
- May reduce malpractice claims or the success of malpractice lawsuits

Brooks & Cochran (2007) OCER,
http://dms.dartmouth.edu/ocer/pdf/shared_decision_making.pdf

King & Moulton (2006); Barry, Wescott, Reifler, Chang & Moulton (2008)

Bozic, Belkora et al (2013)

Challenges to Shared Decision Making

- Patient based
 - Knowledge
 - Literacy and numeracy issues
 - Disease specific
 - Biases in decision making processes.
 - Lack of awareness of values / goals / preferences (or how to communicate them)

Challenge: Patient Literacy

Health Literacy

- Average person reads at a 7th-8th grade reading level.
- Between 26%-60% of patients could not understand medication directions, standard inform consent document or basic health care materials.
- 80 million adults have limited health literacy.
 - Rates are higher among elderly, minority, and poor persons and those with less than a high school education.
- My recent study in 4 VAs (AA, Durham, Pittsburgh, SF) revealed that 27% of Veterans had inadequate health literacy.

Impact of Low Health Literacy

- Health Impacts
 - More hospitalizations
 - Greater use of emergency care
 - Lower mammography screening
 - Lower uptake of influenza vaccine
 - Among elderly: poorer overall health status and higher mortality rates.
- Health interventions
 - Often inaccessible to the very people who would benefit most from them.

Solution: Literacy

- Plain language
- Teach backs

Challenge: Patient Numeracy

What is Numeracy?

- The ability to comprehend, use, and attach meaning to numbers.

Putting Numeracy into Context

- Numeracy
 - What is a bigger risk: 1%, 5%, 10%?
 - What is a bigger risk: 1 out of 10, 1 out of 100, 1 out of 1000?

Why is Numeracy Important?

- Everyday decisions
 - What is a teaspoon of medicine?
- Cancer screening
 - Should I get a PSA test? Lung cancer screening
 - Mammogram before 50?
 - When should I STOP screening?
- Treatment decision making
 - What treatment is best for me?

**Solution:
numeracy**

Risk Communication Methods to Improve Understanding

Absolute vs. Relative Risk Presentation

Absolute vs. Relative Risk

- What if I told you a drug could reduce your risk of prostate cancer by 50%? (Relative risk presentation)
- What if I told you a drug could reduce your risk from 2% to 1%? (Absolute risk presentation)
- Drug has same effect in both cases, but in first description it sounds much better.

Recommendation

- If you are trying to inform a patient (and not persuade) a patient then you absolutely should use absolute risk presentation.

Graphical Format

Graphical Format

- To help improve people's ability to understand numerical information, graphical representations of risk are often used.
- But which format to use? Lots of choices, but little information about which is best for communicating health information.

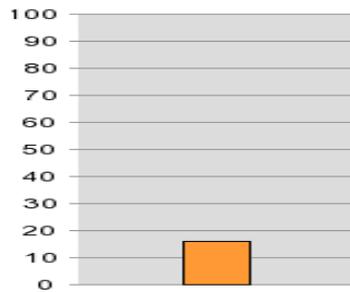
Which Graphical Presentation to Use?

- Bar graph
- Pie graph
- Modified pie graph “clock graph”
- Pictograph
- Modified pictograph “sparkplug”

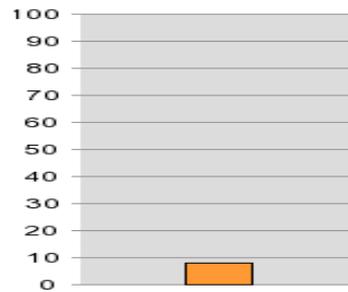
Bar Graphs

Decreased risk of needing bypass surgery caused by taking pills

Pill A:



Pill B:

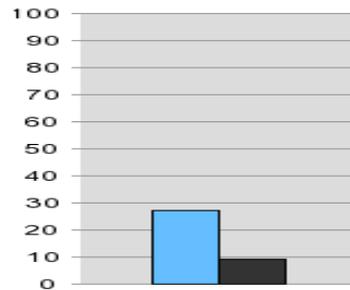


* Each graph represents 100 people

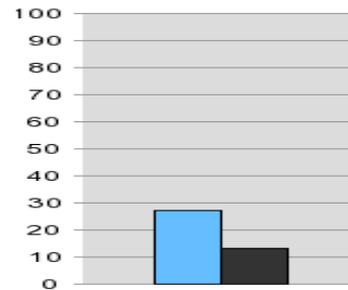
■ Need bypass surgery

Increased risk of headaches and nausea caused by taking pills

Pill A:



Pill B:

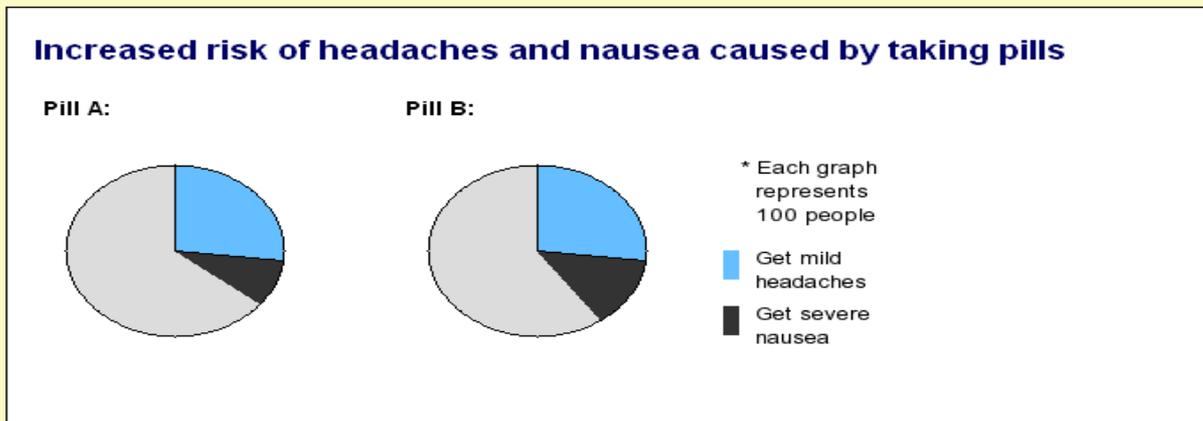
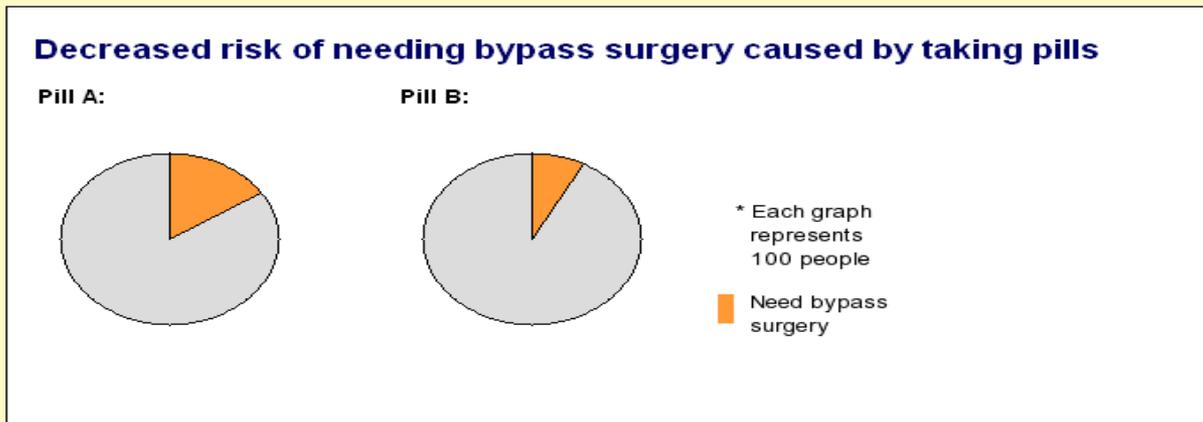


* Each graph represents 100 people

■ Get mild headaches

■ Get severe nausea

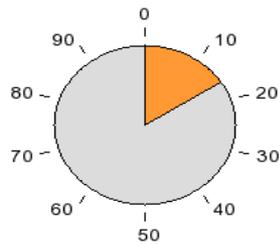
Pie Graphs



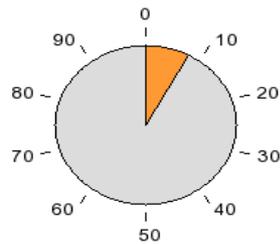
Clock Graphs (Modified Pie)

Decreased risk of needing bypass surgery caused by taking pills

Pill A:



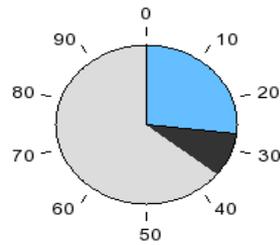
Pill B:



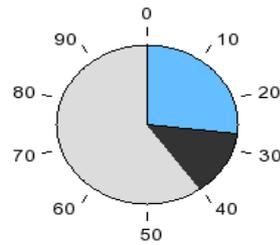
* Each graph represents 100 people
Need bypass surgery

Increased risk of headaches and nausea caused by taking pills

Pill A:

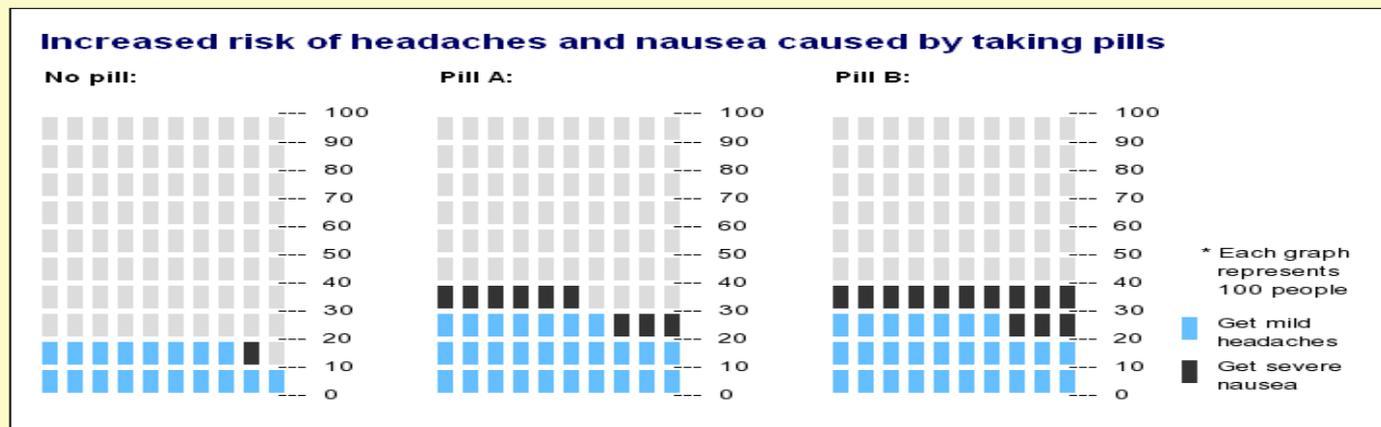
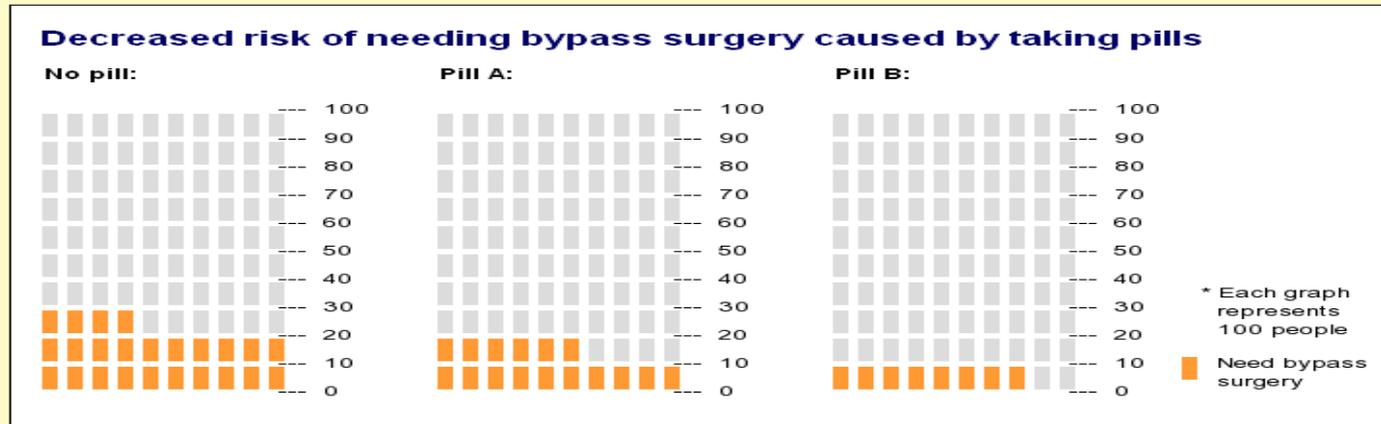


Pill B:



* Each graph represents 100 people
Get mild headaches
Get severe nausea

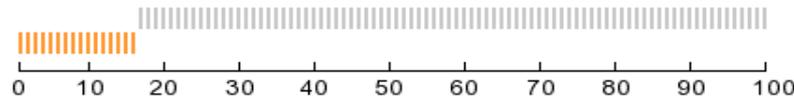
Pictographs



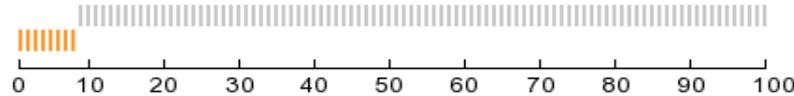
Sparkplug Graphs (Modified Pictograph)

Decreased risk of needing bypass surgery caused by taking pills

Pill A:



Pill B:

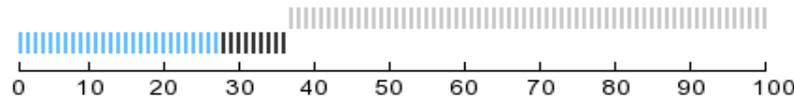


* Each graph represents 100 people

Need bypass surgery

Increased risk of headaches and nausea caused by taking pills

Pill A:

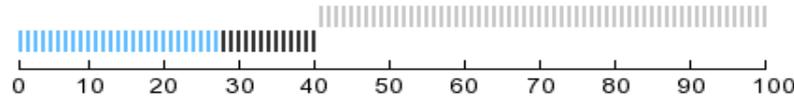


* Each graph represents 100 people

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.

What Graph Communicates Gist Best?

- A. Bar Graph
- B. Pie Graph
- C. Clock Graph
- D. Pictograph
- E. Sparkplug Graph

Accuracy of Responses: Gist Knowledge

| Pie M (SD) | Pictograph M (SD) | Clock M (SD) | Sparkplug M (SD) | Bar M (SD) |
|------------------|-------------------------|--------------------|------------------------|------------------|
| 1.59 (.66) | 1.56 (.64) | 1.55 (.66) | 1.50 (.69) | 1.45 (.77) |
| 1 | 2 | 3 | 4 | 5 |

Means = number of correct responses out of 2 questions.

Accuracy was greatest for pie graphs and pictographs
($F = 4.09$, $p = .001$).

What Graph Communicates Verbatim Best?

- A. Bar Graph
- B. Pie Graph
- C. Clock Graph
- D. Pictograph
- E. Sparkplug Graph

Accuracy of Responses: Verbatim Knowledge

| Pie M (SD) | Pictograph M (SD) | Clock M (SD) | Sparkplu g M (SD) | Bar M (SD) |
|------------------|-------------------------|--------------------|----------------------------|------------------|
| 1.27 | 2.46 | 2.20 | 2.25 | 2.55 |
| 5 | 2 | 4 | 3 | 1 |

Means = number of correct responses out of 4 questions.

Accuracy was greatest for Pictographs ($F = 321.03, p < .001$)

Which Graphs Produced Best Knowledge?

- People's gist and verbatim understanding of risk varied significantly across graphs.
 - For gist knowledge questions, pie graphs were effective, but pies were ineffective for verbatim knowledge questions.
 - Pictographs were the only graph that consistently led to more accurate risk knowledge across both gist and verbatim questions.

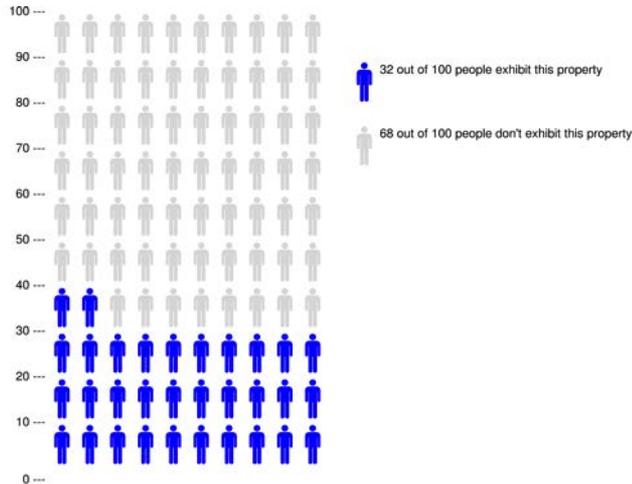
Recommendation

- If you choose to use a graph, use a pictograph to visually represent the risks and benefits of treatment.
- www.iconarray.com

Do the Icons in a Pictograph Matter?

- Many choices for an icon:
 - Shapes: rectangle, oval
 - Faces: real pictures, smiley faces 😊,
 - Restroom sign pictures
 - Head outlines (think facebook profiles without a picture)

Do the Icons in a Pictograph Matter?



- Risk recall was significantly higher with more anthropomorphic icons (restroom icons, head outlines, and photos) than with other icon types
- Participants rated rest-room icons as most preferred.
- Restroom icons resulted in the highest correlations between perceived and actual risk among more numerate/graphically literate participants, they performed no better than other icon types among less numerate/graphically literate participants.

Is less more?

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.

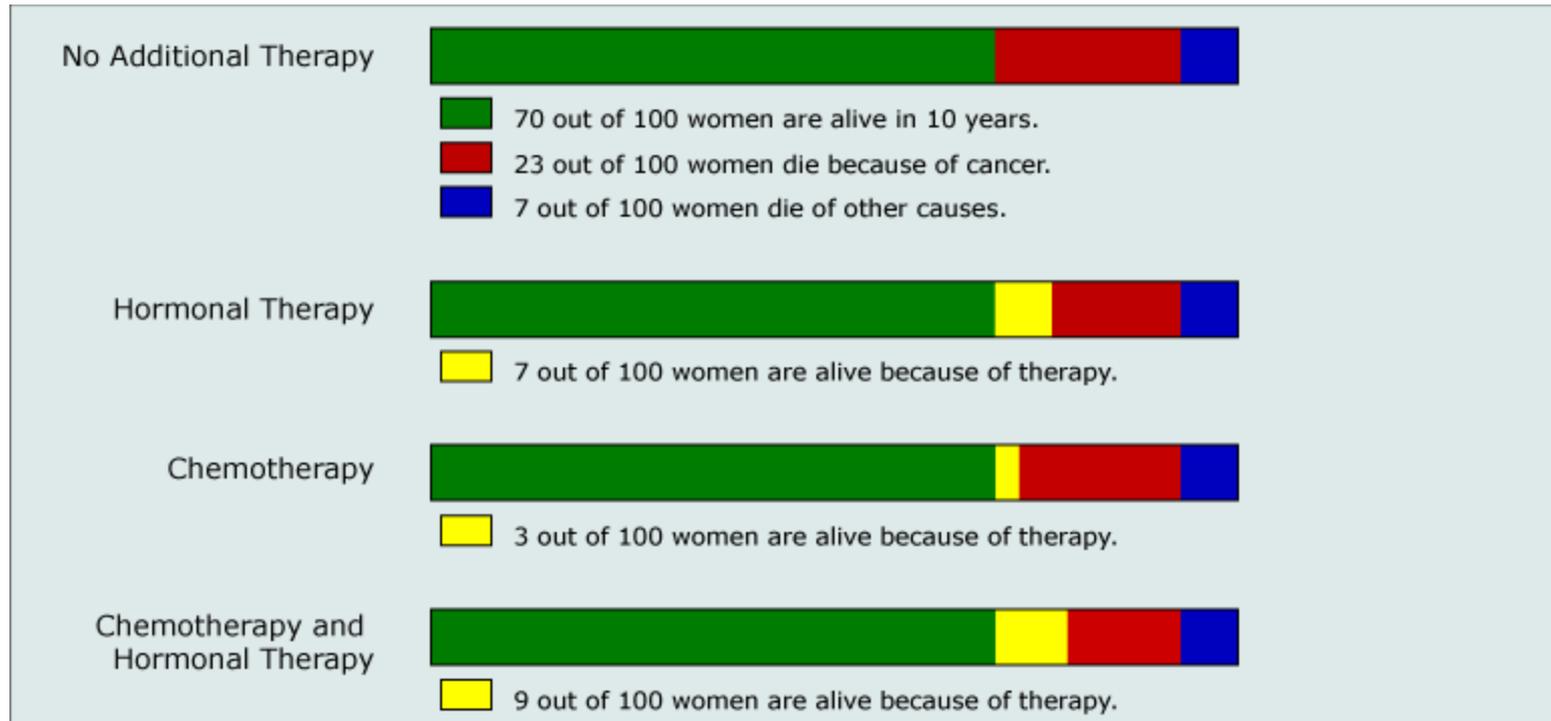
Can We Do Better?

- Four treatment options shown
- BUT: Only 2 options are likely to be relevant to a single patient
 - If ER+ (so hormone therapy is strongly recommended)
 - Hormone therapy only
 - Hormone therapy + chemotherapy
 - If ER- (so hormone therapy is not recommended)
 - No adjuvant therapy
 - Chemotherapy only

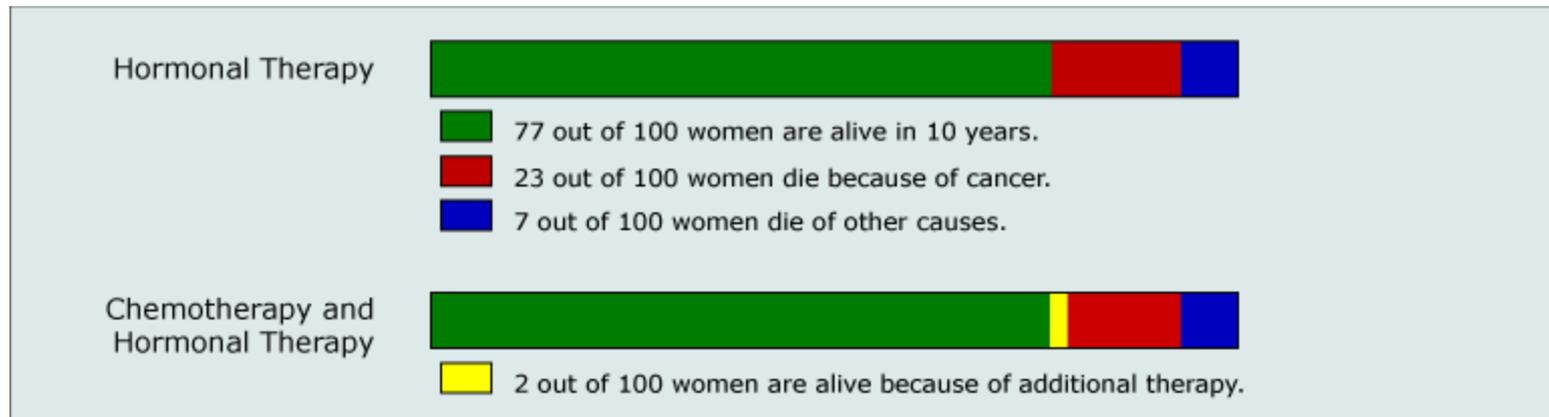
Less is More?

- Including *less* information can help comprehension of the *critical* information.

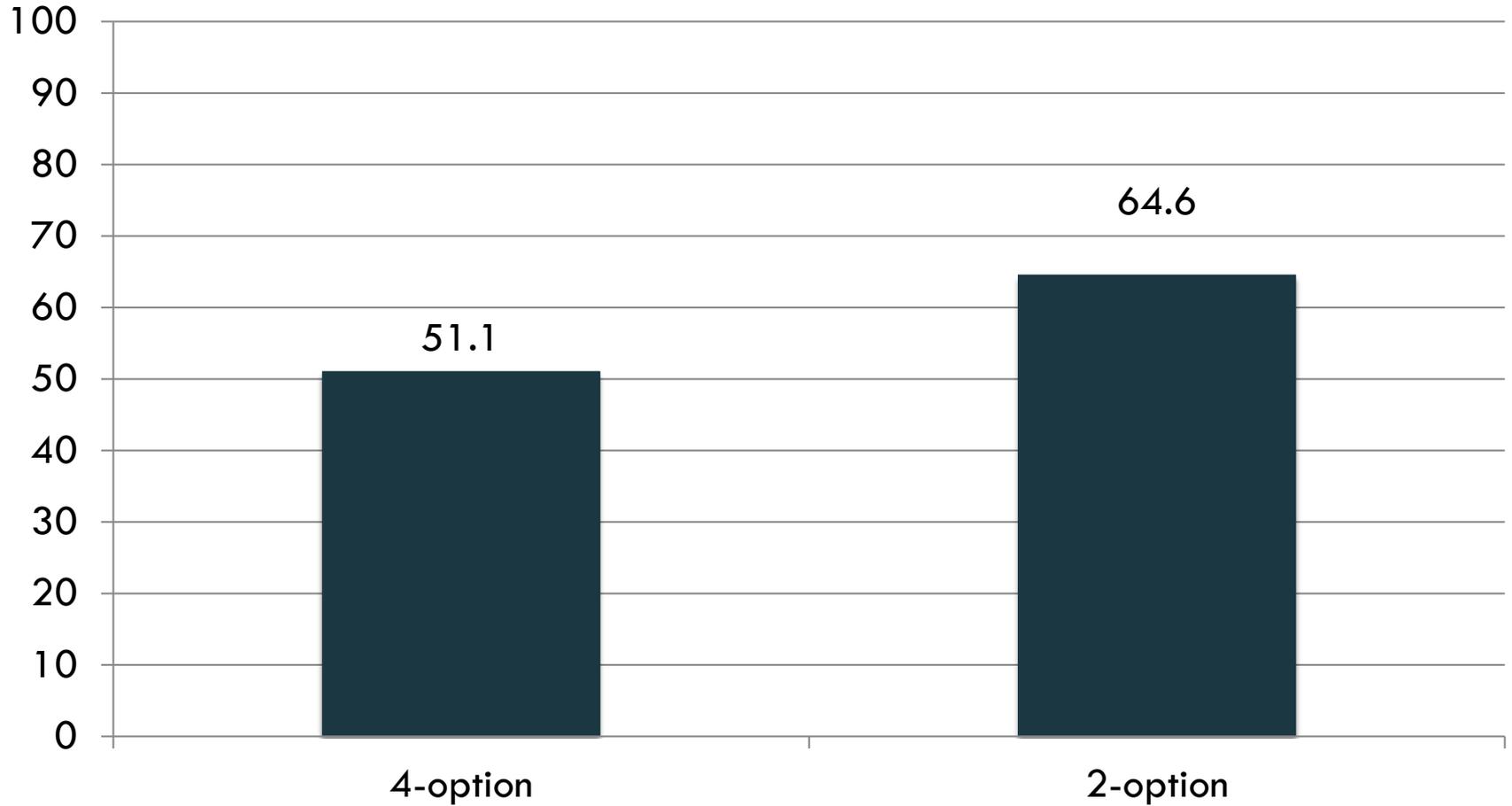
Original Format



Simpler Format



Knowledge of Incremental Benefit of Chemotherapy



Recommendation

- Less IS More: Showing fewer options is much better
 - Better comprehension
 - Take less time to understand

Other Resources for Visual Communication of Risk

- www.vizhealth.org

Challenge:
biases in decision
making

Availability

- Easier to recall something from memory, greater the perceived prevalence.
 - Probability of recent salient events is **overestimated**.
 - Probability of rare but vivid events is **overestimated**.
 - Probability of remote, less memorable events is **underestimated**.
 - Probability of common, ordinary events is **underestimated**.

Anchoring and Adjustment

- How should we make probability estimates when information comes in one piece at a time?
 - Ideally, base accurate estimate on initial info
 - Adjust estimate appropriately based on new info
- Frequently, the process has two flaws:
 - Inaccurate initial estimate
 - Insufficient weight given to the new information
 - Hence the **final** probability estimate depends too much on the **initial** estimate
- Result: Persisting in inappropriately low or high probability estimates after receiving new information

Anchoring and Adjustment

- Estimates of patient prognosis changed very little from day 1 to day 3 in the ICU despite new information.
- When two physicians gave estimates for the same patient, they often disagreed widely. However, two days later, each having received the same new information, neither would have adjusted the probability very much.

Anchoring and Adjustment

- Patient example
 - Preconceived breast cancer risk estimate (likely too high)
 - When receive results of risk models (e.g., Gail), fail to adjust their risk estimates.

Framing

- Imagine there was a surgical treatment for lung cancer that had a **90% survival rate**. Would you want the treatment?

Framing

- Imagine there was a surgical treatment for lung cancer that had a **10% mortality rate**. Would you want the treatment?

How Does Framing Affect Decisions?

- Significantly more people chose the treatment when told it had a 90% survival rate than when told it had a 10% mortality rate.
- Peters et al., (Psych Science 2006) found that framing bias was found primarily in lower numeracy individuals.

Solutions?

- Framing yes...
- Availability...No (at least not evidence-based)
- Anchoring...No (at least not evidence-based)

Challenge: Disease Knowledge

Learning Curve

- Stating the obvious: Patients often do not know much about their diagnosis, their treatment options, and the risks and benefits of their treatment options.
- Can be hard to learn:
 - Lack of available, credible, easy to understand materials
 - Emotions
 - Time pressure

Solution: Disease Knowledge

Use of Decision Support
Interventions

Why Need Decision Support Interventions?

- Explaining complex medical decisions to patients can be very challenging.
- Physicians often have little time to accomplish this task.
- Decision support interventions:
 - Explain what the problem is in language patients can understand.
 - Provide detailed information about the options, their risks and benefits.
 - Written record of this complex medical information.

What are Decision Aids?

- Tools that describe options, are designed to help people understand their treatment options, consider the personal importance of possible benefits and harms, and participate in decision making.
- They are used when there is more than one medically reasonable option - no option has a clear advantage in terms of health outcomes, each has benefits and harms that people value differently.
 - “Preference sensitive decision” “Clinical equipoise”
 - Though more recently used also for adherence

Types and Use of Decision Aids

- Formats
 - Brochures/pamphlets
 - Web-sites
 - DVD
- When used
 - Pre visit
 - During visit
 - Post visit

What are the Key Components of Decision Aids?

Required

- Description of medical condition
- Risks/benefits of tx
- Values clarification
- Next steps
- Glossary of medical terms
- Additional Resources
- Citations

“Bells and whistles”

- Personalized risk information /Other tailoring
- Testimonials/Anecdotes
- Decision coaching
- “Fancy” values clarification

Effects of Patient Decision Support Interventions

- Cochrane review of 115 RCTs of decision support interventions finds:
 - Patients are more satisfied
 - Decision support improves knowledge compared to usual care
 - Gives patients more realistic expectations of what care can accomplish
 - Changes preferences for participation in DM
 - Often leads to more conservative decisions

(Stacey et al, 2014)

Decision Coaching

- Agenda setting
- List of questions / knowledge assessment
- Values clarification

Benefits of Decision Coaching

Patient Benefits

- Increased...
 - Knowledge
 - Satisfaction
 - Decisional self-efficacy
 - Decision quality
- Decreased
 - Decisional conflict
 - Anxiety
- Better quality questions

Physician Benefits

- Does not increase consultation time.
- Less time on “spiel” more tailored communication.
- When note taker present, more confidence that patient will remember information correctly.

Challenge:
understanding of values

Values Concordance

- Lack of concordance between what people say is most important in their decision making and the treatment choice they make.
- In fact, patients often do not have an initial preference and how you present information can affect what a person's preference is.

Solution (?):
Values Clarification Methods

Values Clarification Methods

- Explicit process designed to help people explore, identify, organize and/or articulate one or more subjective feelings relevant to a health decision or set of health decisions.

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- Step or series of steps within a decision making process where an individual indicates what is important to the individual in the context of a health decision.

Values Clarification Methods

- Explicit process designed to help people explore, identify, organize and/or articulate one or more subjective feelings relevant to a health decision or set of health decisions.
- Step or series of steps within a decision making process where an individual indicates what is important to the individual in the context of a health decision.
- The process may or may not also include providing feedback to the patient about the implications of these values (e.g., recommendation)

Values Clarification Methods

- Explicit process designed to help people explore, identify, organize and/or articulate one or more subjective feelings relevant to a health decision or set of health decisions.
- Step or series of steps within a decision making process where an individual indicates what is important to the individual in the context of a health decision.
- The process may or may not also include providing feedback to the patient about the implications of these values (e.g., recommendation)
- Ideally leads to the integration of personal feelings about the attributes of a health decision into the decision making process.

Values Clarification

- IPDAS/ Decision Aids people strongly recommend inclusion in decision aids.
 - Later will discuss reasons why this might not be as helpful as advertised.
- Yet, no consensus how to best design values clarification exercises.
 - Huge variability across studies
 - No good evidence of which methods are best
 - In fact, lack of good evidence that there values clarification tasks improve decision making.

Fagerlin et al., BMC 2013

Wrapping it All Up

- Shared decision making is both beneficial and difficult.
- Numerous resources that can be used...
 - Graphical representation of risk
 - Decision aids
 - Decision coaching
 - Taking time...to ask questions, listen to patients.

Thanks To

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Contact Information

fagerlin@med.umich.edu

 @angiefagerlin

www.cbssm.med.umich.edu