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EISENBERG CONFERENCE SERIES: 2015 MEETING

Engaging Patients in the Uptake, Understanding, and Use of Evidence: Addressing Barriers and Facilitators of Successful Engagement

Patient Engagement and Clinical Evidence

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When we talk about patient engagement and shared decision-making there are a number of different problems that evolve.

Patient Engagement In Shared Decisionmaking

- Patients often do not have the information they need to make decisions nor are involved in the decision as much as they would like to be.

Zikmund-Fisher BJ, Couper MP, Singer E, et al. Deficits and variations in patients' experience with making 9 common medical decisions: the DECISIONS survey. *Med Decis Making*. 2010 Sep-Oct;30(5 Suppl):855-955. PMID: 20881157.

- Treatment choices often do not reflect their values or their knowledge.

Fagerlin A, Lakhani I, Lantz PM, et al. An informed decision? Breast cancer patients and their knowledge about treatment. *Patient Educ Couns*. 2006 Dec;64(1-3):303-12. PMID: 16860523.

- Patients are hesitant to disagree with their physician.

Frosch DL, May SG, Rendle KA, et al. Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012 May;31(5):1030-8. PMID: 22566443.



First, patients often do not have information they need to make decisions, nor are they involved in the decisions as much as they would like to be. My colleague, Brian Zikman-Fisher, and I conducted a study and many colleagues, as you can see from their author list, of the random-digit-dial study across the U.S. We had a pretty good national sample. And what we tried to do is ask them how much they knew about nine different health conditions. For example, “Have you ever experienced this health condition?” And if they said “Yes, in the last 2 years,” then we asked them about their decision-making experience. What we found, again and again, across these nine different conditions, is that they often didn’t have the information that they needed to really make a truly informed decision. They often said that they were given the pros of treatment, but not the cons of treatment and that they weren’t involved in the decision as much as they would’ve liked to have been. Additionally, in work that I’ve done, people will say, for example, with breast cancer, that the most important thing for them is that they reduce their likelihood of reoccurrence. So we asked them what was most important, and then we asked them how much they knew about it and there was very little relationship between their knowledge about the reoccurrence rate or survival rates across treatments and their knowledge and sometimes even their preferences for the treatment that they chose. But their treatment choices often are not reflected by what they say is the most important factor to them. So, for example, in prostate cancer, somebody might say, “The most important thing for me is not to become impotent,” and then he chooses a treatment that had the greatest likelihood of becoming impotent. So you see that there is a disconnect there. Dominique Frosch and his colleagues have found that patients are often hesitant to disagree with their physicians. One of the reasons is because they don’t want to be labeled as a difficult patient. And so if you come in with prostate cancer and your doctor immediately gives you a recommendation, “I really think that surgery is the right answer for you,” it is really hard for you to say, “well, you know, actually was thinking about radiation,” or “actually, don’t really want treatment. I want to do active surveillance,” because you don’t want to be labeled in that first encounter as a difficult patient.

If We Have Data, Will Patients Use It? (1 of 2)

- We have a lot of clinical evidence (i.e., from comparative effectiveness research [CER]), but people may not engage with it.



One of the questions that I think is really important, especially in these preference-sensitive decisions where the treatment options might not differ significantly in survival outcomes, but they might differ in terms of risks or side effects that come from that, is that we often have, probably not as often as we would like, a lot of good clinical evidence about the risks and benefits of treatment. And what is the most effective treatment or what is likely to have the most side effects, people may not engage in it. And there are a number of reasons for this.

If We Have Data, Will Patients Use It? (2 of 2)

- We have a lot of clinical evidence (i.e., CER), but people may not engage with it.
- Numerous barriers block patients from using CER In their medical decisionmaking.
 - Data may not be available to the patient.
 - Data may not be understandable.
 - Literacy/numeracy issues
 - Patients' decisionmaking may not always be influenced by CER data.



Firstly, the data might not be available to the average patient. Yeah, we can use PubMed, get the article that we want, and we can understand it, but a lot of patients don't know where to look and a lot of times the information is written in a way that patients can't understand, even for an average person forget the people with lower literacy or numeracy skills. This will probably comes as a shock to many, but people might not always make decisions based on comparative effectiveness research data, or the risks and benefits of treatment.

Challenges to Providing Patients With CER Information (1 of 2)

- While it is necessary to provide patients with CER information (e.g., risks and benefits across various treatments), it is not sufficient.
 - Needs to be provided to patients.
 - Journal articles are not enough.
 - Communication of the data must be appropriate and understandable so that patients can use the information.
 - Use state-of-the-art risk communication strategies so information will be available to those with high and low literacy.



I think it is necessary to provide patients with this kind of information. For example, the risks and benefits across various treatments is not sufficient. I just finished a study where we gave a whole bunch of people decision aids and we thought that this was going to activate them or engage them.

Challenges to Providing Patients With CER Information (2 of 2)

■ Information needs to be compelling to patients.

- Other information might be more compelling to patients than CER data.
 - Cognitive biases/heuristics
 - Affect
 - Anecdotes
 - Physician recommendations



We tape-recorded visits between prostate cancer patients and their urologists and we came up with all these great patient codes to see what patients said and the kind of questions they asked. Then we listened to the tapes and threw away the whole coding scheme because there was very little talking by the patients. But even though we gave them all this information -- and let me tell you it was low literacy, the numeracy was beautiful. It was the perfect decision aid, of course.

Well, even with that and calling them a couple days before the visit and reminding them to read and bring the decision aid with them, the patients still didn't talk during the visits. So we can give people information, but it might not be sufficient even if you make it pretty accessible. There is other information that might be more compelling to patients than this kind of data.

So these are the things I just want to talk about today: Cognitive biases and heuristics can influence how people interpret this information and how they make decisions. Affect and emotion can influence decision-making as well as anecdotes, things they see in the media, friends, sisters, brother, cousins, experience, et cetera; and then also physicians' recommendations.

Challenge 1: Literacy

- 14% of patients do not have even basic literacy skills, and 29% only have basic literacy skills.

Goodman M, Finnegan R, Mohadjer L, et al. Literacy, Numeracy, and Problem Solving in Technology-Rich Environments Among U.S. Adults: Results from the Program for the International Assessment of Adult Competencies 2012. NCES Publication No. 2014-008. Washington, DC: U.S. Department of Education; October 2013. <http://nces.ed.gov/pubs2014/2014008.pdf>.

- To put in the context of decision aids: Most decision aids are written at at least a 9th grade reading level (and most at a college reading level).

Fagerlin A, Rovner D, Stableford S, et al. Patient education materials about the treatment of early-stage prostate cancer: a critical review. *Ann Intern Med.* 2004 May;140(9):721-8. PMID: 15126256.



When we did our evaluation of every prostate cancer decision aid we could find, all of them are written at least at a ninth grade reading level. Most are written at twelfth grade reading level. And you all know in here that reading is around an eighth grade reading level. But all of us here are way above that. So that means a lot of people are way below an eighth grade reading level.

So, these decision tools that were designed to help people, who have the lowest literacy, who can't go onto Google Scholar, and who can't go onto PubMed, they were written at a level that people wouldn't even be able to read and use the information.

Challenge 2: Numeracy Issues

- Numeracy is the ability to comprehend, use, and attach meaning to numbers.
- Putting numeracy in context:
 - 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?

Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. *Med Decis Making*. 2001 Jan-Feb;21(1):37-44. PMID: 11206945.



Numeracy is an issue. So much of what we're talking about with this kind of data is risks and benefits. I'm going to put this in a context. So how many of you know what is a bigger risk: one percent, five percent or ten percent? Twenty percent of college-educated adults could not get that question correct. Similarly, what is a higher risk: one out of ten, hundred, a thousand? About twenty-five percent couldn't get this. And these are the college-educated. These are people who have bachelor's degrees. And so you can imagine what the people without bachelor degrees were doing or people who hadn't even graduated from college or from high school. And so if we think that we can just give a piece of information to people and say, you know, "Here's ten percent. Do as you will." People aren't going to necessarily understand that information.

Challenge 3: Poor Risk Communication Practices

- **Information is often presented in a way that decreases the likelihood that people will understand the information.**
 - Relative vs. absolute risk presentation
 - Lack of graphical communication
 - Presentation of too much information

Part of this problem is poor risk communication practices. Information is often presented in ways that decrease the likelihood that people will understand the information. I want to go through three examples.

Relative Versus Absolute Risk Presentation (1 of 2)

- **Relative risk presentation:** What if I told you a drug could reduce your risk of a breast (prostate) cancer by 50%?

First is relative versus absolute risk presentation. If I could tell you that a drug could reduce your risk of breast cancer or prostate cancer, by 50 percent, how many people would be kind of excited about this?

Relative Versus Absolute Risk Presentation (2 of 2)

- **Absolute risk presentation:** What if I told you a drug could reduce your risk of breast (prostate) cancer from 2% to 1%?



Now what if I told you that drug reduces your risk from two percent to one percent? Now how many want to take a drug every day for 5 years to get that one percent difference? I see a lot of changing of minds, but it is the same, exact data, right? It is framed in a different way. And there have been study after study.

Absolute Versus Relative Risk

- Same effect, but the first description sounds much better.
- Much research has shown that people's decisionmaking is different based on the presentation of relative versus absolute risk.

- Physicians: Are more likely to prescribe a chemotherapy when benefit presented using relative risk

Chao C, Studts JL, Abell T, et al. Adjuvant chemotherapy for breast cancer: how presentation of recurrence risk influences decision-making. *J Clin Oncol.* 2003 Dec;21(23):4299-305. PMID: 14581440.

- Patients: Prefer medications when the benefit is presented in relative risk.

Baron J. Confusion of relative and absolute risk in valuation. *J Risk Uncertainty.* 1997;14:301-9.

Malenka, DJ, Baron JA, Johansen S, et al. The framing effect of relative and absolute risk. *J Gen Intern Med.* 1993 Oct;8(10):543-8. PMID: 8271086.



There is been a lot of research that has shown that this can really bias decision-making. One of my favorite studies in the world gave two journal articles to oncologists. One journal presented the data about the effectiveness of chemotherapy using relative risks. Another group got another article communicating absolute risk, and I'm sure you can all guess the punch line here. Oncologists who got the relative risk information were more likely to say that they would prescribe this, that they thought this was effective. So this is a bias that goes from the lowest end to the highest end of people and education. People are really biased by this. And numerous studies have shown that patients prefer medications when the information is presented in relative versus absolutely risk conditions.

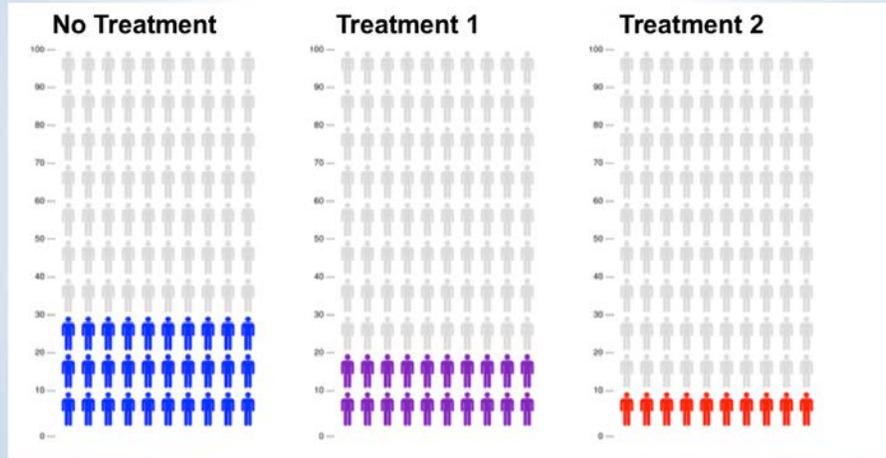
Graphical Presentation of Risk

- There are multiple ways to graphically present data:
 - Pie graphs
 - Bar graphs
 - Pictographs/icon arrays
- The risk format can have an impact on...
 - Gist and verbatim knowledge
 - Risk perception
 - Behavioral intentions



Another thing to think about -- this is work I did with Sarah Hawley and a number of colleagues -- is how do you present risk information to patients to understand it? People have been arguing for years that we should present information using graphs. If you ask patients, they say, "Oh, yeah, I really like pie charts." But we know from cognitive psychology, for example, that pie charts can not always be the most effective way to communicate information. So we wanted to see how we could communicate information best to patients to help them understand it and to have it not bias their decision making. We tested six different risk communication -- six different graphs: pie graphs, bar graphs, pictographs, which are also sometimes called "icon arrays."

Graphical Representation of Risk



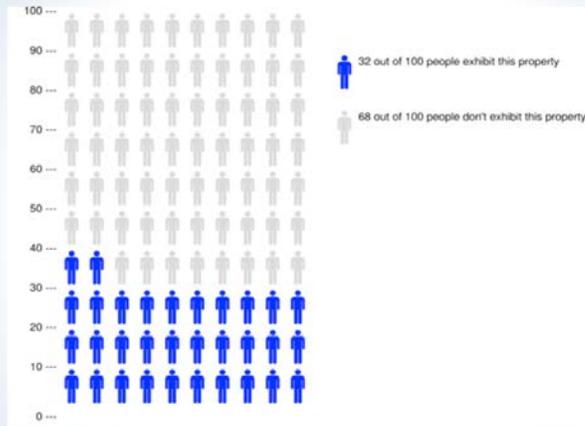
Hawley ST, Zikmund-Fisher B, Ubel P, et al. The impact of the format of graphical presentation on health-related knowledge and treatment choices. *Patient Educ Couns.* 2008 Dec;73(3):448-55. PMID: 18755566.



We looked at is people’s ability to understand the main point of the message and their ability to understand the numbers. And, we found that pictographs were one of the best ways to communicate to people, because you see a lot of different things in a pictograph. You see the number of people affected, you see the number of people not affected. It is easier to count; it is easy to figure out exactly how many people were affected. Usually we have like a legend that says the number; in the study we didn’t. But you have the number, 20 people have this side effect, 10 people have this side effect, et cetera.

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Hawley ST, Zikmund-Fisher B, Ubel P, et al. The impact of the format of graphical presentation on health-related knowledge and treatment choices. *Patient Educ Couns.* 2008 Dec;73(3):448-55. PMID: 18755566.



Does the icon matter? Does it matter if the icon is an oval, a square, or a person? If it is a real picture, does it matter if it is a real person? We tested about ten different icons and learned that the bathroom figures were the most effective way of communicating the information.

Making Graphs Easily

These Web sites can help. Both are hosted by the University of Michigan at Ann Arbor.

- Icon Array: <http://www.iconarray.com/>
- Visualizing Health: <http://www.vizhealth.org/>



IconArray.com will allow you to make a pictograph of any sort that you could possibly want; It is free. We received funding from the Robert Wood Johnson Foundation and have a whole bunch of other methods for presenting complex information on a Web site. There are probably fifty different evidence-based ways of presenting visual information using different data visualizations. This was a really cool project because we used actual, real artists from top magazines to help design the graphical tools. Some are better than others; so, read when you look at them.

The Curse of Too Much Information

- People with low numeracy are **less able to recognize the key pieces of information** when reviewing complex information.

- Example: Choosing highest quality hospital

- When characteristics were randomly listed, lower numeracy individuals had worse ability to determine which of three hospitals had the highest quality, particularly compared to when information was ordered.

Peters E, Dieckmann N, Dixon A, et al. Less is more in presenting quality information to consumers. *Med Care Res Rev.* 2007 Apr;74(2):169-90. PMID: 17406019.



This is work by Ellen Peters and Judy about the curse of too much information. Sometimes one of the things we really want to do when we are talking to patients about really complex information is to give them every piece of information as possible. Probably because a lot of us who design these materials have a high need for information, and we think everybody else does, too.

Ellen and Judy and their colleagues looked at people's ability to sift through a large amounts of information. The example was trying to help people figure out what was a highest quality hospital. When the characteristics were randomly displayed, people with lower numeracy skills couldn't figure out what was the best hospital. When the data were ordered with the more important things at the top -- they were better at doing it, but not as good as the higher numeracy individuals. So even when things were displayed pretty clearly, those with lower numeracy skills still have difficulty figuring out what the best quality hospital was, and this is a relatively easy task, much easier than picking out what kind of treatment to get for a health condition.

Original Format



Reprinted from Zikmund-Fisher BJ, Fagerlin A, Ubel PA. Improving understanding of adjuvant therapy options by using simpler risk graphics. *Cancer*. 2008 Dec;113(12):3382-90. PMID: 19012353. © 2008 John Wiley and Sons, Inc.



This is from Adjuvant Online. So if you have breast cancer, your doctor will often go to this Web site and give you information about the effectiveness of different treatments in helping you stay alive over 10-year time period. What's complex about this is there are four different options. If you are ER-positive, you will be encouraged to have hormone therapy; if you are ER-negative, there's no way they're going to recommend hormone therapy because it is not an effective treatment. So, for patients who are ER-negative, if you show just two bars. It may increase their ability to figure out how much benefit they are going to get from having chemotherapy.

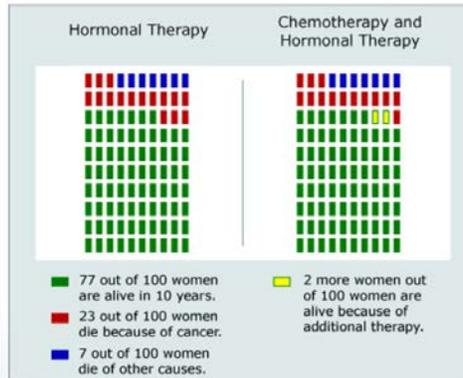
Simpler Format



Reprinted from Zikmund-Fisher BJ, Fagerlin A, Ubel PA. Improving understanding of adjuvant therapy options by using simpler risk graphics. *Cancer*. 2008 Dec;113(12):3382-90. PMID: 19012353. © 2008 John Wiley and Sons, Inc.

And indeed when we showed just two bars, we found was a significant increase.

Pictograph Format

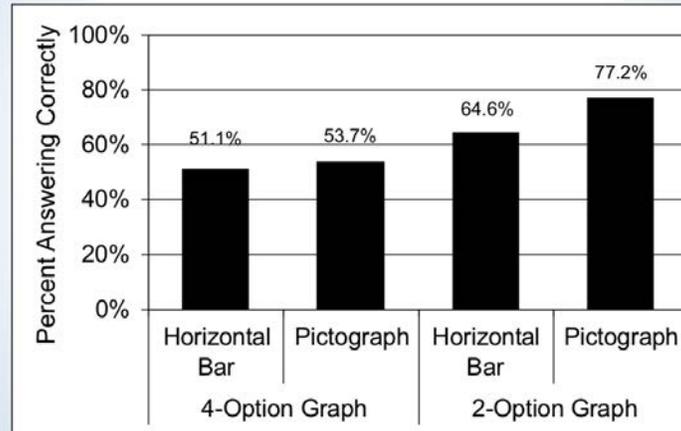


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We also presented the data in a pictograph because we like pictographs, based on our last evidence.

Knowledge of Incremental Benefit



Reprinted from Zikmund-Fisher BJ, Fagerlin A, Ubel PA. Improving understanding of adjuvant therapy options by using simpler risk graphics. *Cancer*. 2008 Dec;113(12):3382-90. PMID: 19012353. © 2008 John Wiley and Sons, Inc.



So we presented patients the options in both in bar and pictograph formats and tested how well they understood the incremental benefit of chemotherapy. When they were presented with all four options, their ability to understand how much chemotherapy would actually benefit them in terms of survival, was lower than when presented with just two options, because they knew what to pay attention to. And, the pictograph performed better than the horizontal bar graph.

Less IS More

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

This study showed that including less information might be helpful in comprehending the critical information. The idea here is that there was so much information, that people didn't know what to focus on. When there was less information, they're better able to understand it.

■ **How do biases affect people's decisionmaking?**



I just briefly want to go through cognitive biases.

Availability (1 of 3)

- What is more common: suicide or murder?

What is more common: suicide or murder? The answer is, suicide. A lot of people actually usually think murder because that's what we hear most about.

Availability (2 of 3)

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

Slide used with the compliments of the Society of Medical Decision Making.



Availability refers to something that can be recalled from memory; the easier it is to recall, the greater the perceived prevalence. The probability of recalling of really salient events is often overestimated as are the probability of recalling rare but vivid events. But the ability to recall remote, less memorable and common or ordinary events are often underestimated.

Availability (3 of 3)

- **Vividness/Emotionality**
 - Role of the media (Katie Couric effect)
 - New mammography screening guidelines
 - Missed diagnosis, bad resulting outcome
 - Personal experience



Peter Cram and his colleagues showed a huge increase in colorectal cancer screening after Katie Couric got screened live on TV about 10 years ago. Another example is the mammography screening guidelines that came out 2 or 3 years ago and people were really upset about them, because we all have stories of friends who got diagnosed with breast cancer at thirty or forty or because people talk about that. You see your friend going through therapy, but what you don't often hear about are the false alarms and the stress and anxiety of going through the false alarms.

Anchoring and Adjustment (1 of 3)

- **How should we make probability estimates when information comes in one piece at a time?**
 - Ideally, base accurate estimate on initial information.
 - Adjust estimate appropriately based on new information.
- **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: Inappropriately low or high probability estimates persist after receiving new information.**



Another bias that can affect individuals, including physicians, comes from anchoring and adjustment. We don't always get information at one time; it comes in over time. So, how do you adjust your probabilities and the likelihood of different outcomes. People often don't weight new information. There have been studies showing that when you get new information, especially if you've sought that information, you will put more weight on it than you would have if it had been presented the first time. What happens is that the final probability estimate often is most influenced by that initial estimate and not by the other information that you learned later.

Anchoring and Adjustment (2 of 3)

- Estimates of patient prognosis changed very little from day 1 to day 3 in the intensive care unit despite new information.
- When two physicians gave estimates for the same patient, they often disagreed widely. However, 2 days later after each physician had received the same new information, neither would have adjusted the probability very much.

Poses RM, Bekes C, Copare FJ, et al. What difference do two days make? The inertia of physicians' prognostic judgments for critically ill patients. *Med Decis Making*. 1990 Jan-Mar;10(1):6-14. PMID: 2325526.

Slide used with the compliments of the Society of Medical Decision Making.



One example of this is a study where physicians' predictions of how well somebody would do in the ICU were very different based on if the person came in at day one or if somebody came in at day three, even though they all had the same information at day three. But they were very different predictions from the person who had had seen the information come in a bit over time versus the person who just saw it come in at once.

Default Bias

- **Willingness to accept or reject an option just because it is the default. Probably would not have done so if it was not the default.**
- **Examples: Living wills, organ donation, catheters**



Another idea is default bias, which refers to patients' willingness to accept or reject an option just because it is the default. They probably wouldn't have done that if that wasn't the default.

Let me give you some examples. Organ donation is one of my favorite ones. We all know there's an opt-in or opt-out. If it is opt-in, they have much higher rates of organ donation. Gretchen Chapman has done some really great work where she buried whether the default was you get no treatment unless you indicate below what treatment you'd want or you get all treatments unless you indicate below what ones you don't want. People's preferences changed based on how the living will was designed. Another example is catheters, which catheters remained in people until a doctor wrote a note to have them removed. It led to a lot of infections. Then they changed the default. The default was after three days the catheter was to be removed unless indicated otherwise; and, the number of infections decreased greatly. So some of these defaults have a huge impact on behavior and what people's preferences are.

Role of Affect (1 of 2)

- **Risk-as-Feelings: Risk-related behaviors are influenced by both *beliefs* (re: cognitive appraisals) and *feelings* of risk.**

- Both beliefs and feelings of risks may be influenced by cognitive sources of information (i.e., anticipated outcomes; subjective probabilities); feelings of risk may also be uniquely influenced by affective sources of information.
- Related to Kahneman's (and many before him) System 1/System 2 dual process theory.

Loewenstein GF, Weber EU, Hsee CK, et al. Risk as feeling. *Psychol Bull.* 2001 Mar;127(2):267-86. PMID: 11316014.

- **Affect Heuristic: Patients use their feelings to infer information about risks and benefits.**

- When told that benefits of a test or treatment are high, they experience positive affect and subsequently believe that risks are low (and vice versa).

Finucane ML, Alhakami A, Slovic P, et al. The affect of heuristic in judgments of risks and benefits. *J Behav Decis Mak.* 2000 Jan;13(1):1-17.



Often, especially in cognitive psychology, we really think about the pure economist way of thinking -- that we're all rational beings, we're going to use risk-and-benefit analyses, and we're going to use subjective utility theory to make our decisions. We know that is not true. Decisions are often influenced by affect, but emotion. Behaviors are influenced both by beliefs and by the feelings of risks. Both beliefs and feelings of risks may be influenced by cognitive source of information, anticipated outcomes, subjective probabilities, and the likelihood of risk-and-benefits. The feelings of risks may also be uniquely influenced by affective sources of information.

For those of you who have read Kahneman's latest book, we have two different systems of processing information. One is a very intuitive system and the other a cognitive system; both combine to help you make your decisions. One explanation is then this affect heuristic, which is the idea that patients use their feelings to infer information about the risks and benefits. So when they're told that the benefits of a test or treatment are high, they experience positive affect and subsequently believe that risks are low. So it is actually the exact opposite. Usually treatments that have a lot of high success also have some pretty significant risks as well. But this idea is like, "Oh, this is going to save me! This is going to be really good. So it must be that the risks are really bad because," Trying to reconcile that can be really difficult.

Role of Affect (2 of 2)

- Emotions, especially worry and anxiety, can influence medical decisionmaking.

Diefenbach MA, Miller SM, Daly MB. Specific worry about breast cancer predicts mammography use in women at risk for breast and ovarian cancer. *Health Psychol.* 1999 Sep;18(5):532-6. PMID: 10519469.

Dillard AJ, Ubel PA, Smith DM, et al. The distinct role of comparative risk perception in a breast cancer prevention program. *Ann Behav Med.* 2011 Oct;42(2):262-8. PMID: 21698518.

- Maximizers versus minimizers

Scherer et al., in preparation



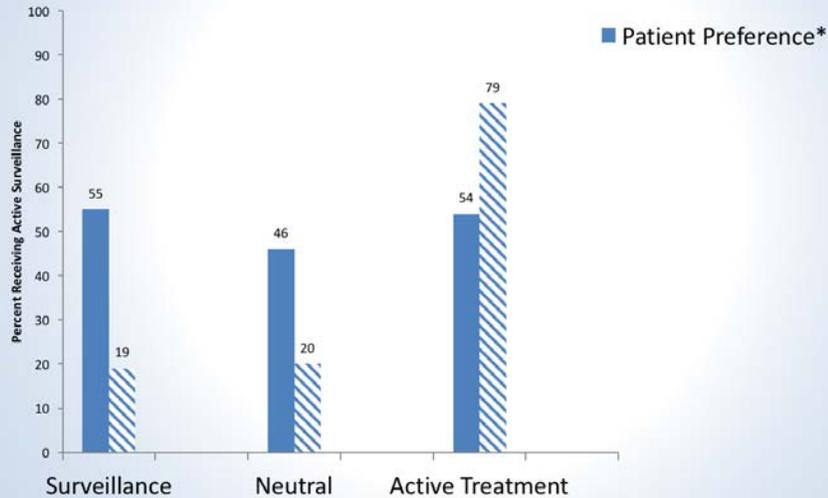
Emotions, especially worry and anxiety, can influence medical decision-making. There is a great amount of work regarding the role of anxiety and worry in decision-making; regressions show that they are the leading factors in what people chose -- not the risks and benefits, not their preferences, but their worry and anxiety.

Also, there are people who really like every treatment possible and people who are really anti-interventionist. We have this great measure that can kind of predict that. This can also influence how you interpret this information, how much you worry about the risks and benefits.

Physician Recommendation

Physician recommendation can have a huge impact.

Relationship Between Patient Preference & Treatment Received



In this study of V.A. veterans at four different sites in the U.S., we looked at what predicted the treatment that the patient got. We surveyed patients across three time periods, baseline, ten minutes before they learned their diagnosis, and a week after they learned their diagnosis.

Predictors of Treatment Received: Active Treatment Versus Active Surveillance

	Step 1	Step 2	Step 3
Preference	.00	-.03	-.02
Anxiety	.14*	.08	.08
Interest in sex	.03	-.03	-.02
Age		-.24***	-.19**
Gleason		.58***	.40***
Recommendation			.32***
Cox & Snell R2	.01	.38	.45



What we found was that nothing predicted the treatment that they got – not their preferences, their anxiety, their interest in sex. Nothing really predicted what they got except for their physician’s recommendation; and the physician’s recommendation was always really highly correlated with the Gleason score and their age. So, once you added in the recommendation it didn’t matter what the patient wanted right before their diagnosis. Their values at that point, didn’t matter. Whatever their physician said, basically, was the treatment that they got. A lot of times that can be really good, but it was a little concerning to us that the patient’s voice got lost. We’re still looking through that data – this is from three hundred taped conversations and rating what the physician actually recommended.

Summary (1 of 2)

- **Engaging patients in using CER—or even just shared decisionmaking—requires significant facilitators.**
 - Information Requirements
 - Information needs to be easily available.
 - Information needs to be written in low literacy and incorporate appropriate risk communication strategies.
 - Information architecture should be used to decrease the likelihood of cognitive biases.
 - Compelling reasons should be provided so patients can base their decisions on “statistics” and not on more readily accessible information (e.g., anecdotes, celebrities).
 - Physician Changes
 - Take time to present the evidence (or have support people do it).
 - Take care with physician recommendations, which may not be based on CER.



So engaging patients in using risk-benefit information, comparative effectiveness research, or even just getting introduced to shared decision-making requires significant facilitators. Information needs to be easily available to patients and written at low literacy and incorporating appropriate risk communication strategies. An information architecture should be used to decrease the likelihood of cognitive biases. We need to provide compelling reasons for patients to base their decisions on statistics rather than on more easily or readily accessible information. And we need to work with physicians on how to better present the evidence or to help engage patients in shared decision-making.

In our audio tapes, from the prostate cancer study, the physicians did a phenomenal job conveying the risks and benefits. Margaret Holmes-Rovner just published a paper in *Medical Decision Making* looking at Braddock's informed decision model and found that physicians were giving information but they weren't asking the questions, they weren't doing teach-backs, they weren't asking for their preferences, their values and goals, which is why we had no patient voices on those tapes.

Summary (2 of 2)

■ Challenges for Researchers

- How do we get this information to patients?
- How do we communicate this information effectively to people who have lower literacy or numeracy skills?
- How do we help patients prioritize CER over anecdotes, affects, et cetera?
- How do we make CER compelling and an integral part of patient and physician decisionmaking?



There are a lot of challenges from this to investigate. For example, “How do we get this information to patients better?” “How do we communicate this information effectively?” There has been a lot of research done but more is needed on some of these complex things. “How do we help patients prioritize the ER over anecdotes or affect,” et cetera? And. “how do we make this information compelling and an integral part of the patient-physician decision-making process?”