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WHEN EXPERTS DISAGREE: THE ART OF MEDICAL DECISION-MAKING

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WHEN EXPERTS DISAGREE:
The Art of Medical Decision-Making

MR. GERSON: Good morning. This is Elliot Gerson and I’m welcoming you all to something you may not recognize as a historic event in Aspen Institute history. This is a first. It is the first ever Aspen lecture.

During our planning for the 10th anniversary of the Aspen Ideas Festival, we decided we wanted to do a number of different things this year and one of the things we thought would be very well appreciated was to inaugurate a series of very distinguished lectures.

Those of you who’ve been to Ideas Festivals before know that the Aspen style is informal conversation, and that of course will remain the norm. But many people have told us that they yearned for an opportunity to have a deeper dive with some of our outstanding speakers, something more extensive than is allowed in a typical moderated conversation.

So we decided over the course of the Ideas Festival and of course the Spotlight Health section, which this is now a part of the Ideas Festival, to ask a small number of very distinguished people to give us a longer presentation, something in more depth that would allow those here at the Festival to deep – to dive more extensively into an important topic.

And this is the only Aspen lecture of Spotlight Health. For some of you who will be on at the next session of the Ideas Festival, we will have I think an additional six lectures over the course of that Festival.

Dr. Jerome Groopman is a professor at Harvard Medical School and the chief of experimental medicine at Beth Israel Deaconess Hospital. In addition to his prolific medical publications especially in cancer, blood disease and AIDS, he writes regularly, as I’m sure all of you know, for nonprofessionals like most of us in The New Yorker, where he has been a staff writer for more than 15 years, and in the New York Review of Books.

Dr. Pamela Hartzband is also at Harvard Medical School and at Beth Israel. She is a highly distinguished endocrinologist. She heads
the Thyroid Biopsy Center. She writes frequently in the New England Journal of Medicine. And as we were just discussing, she also happens to be both Walter Isaacson’s and my college classmate.

They co-wrote Your Medical Mind: How to Decide What Is Right for You. And now they are going to speak to us on When Experts Disagree: The Art of Medical Decision-Making. And I might add, they also happen to be husband and wife. So perhaps we should invite them back next year to speak on When Spouses Disagree:

(Laughter)

MR. GERSHON: – The Art of Successful Marriage.

MR. GROOPMAN: That’s a two-hour lecture.

(Laughter)

MS. HARTZBAND: Well, thank you so much for inviting us here today to talk about medical decision-making and we are honored to be presenting the first Aspen lecture.

As physicians, Jerry and I spend a lot of time working to stay up-to-date on the latest medical advances and information. And one thing that we find striking is that despite all the medical advances and breakthroughs, all the application of scientific principles to modern medicine and all the sophisticated data analysis that we have now, there’s increasing controversy among experts about how to prevent or treat even the most common medical conditions.

So why are these experts disagreeing? Why isn’t there a clear right answer? And how do patients make a decision in the face of all this controversy? This is the question that we set out to answer.

Now controversy in medicine is not new, but what is new is how medical controversy is endlessly featured in the lay press. So it’s not just medical professionals who are struggling with all these issues. Everyone is now directly confronted with medical information and advice
through media.

You can’t pick up a magazine or a newspaper, turn on the radio or the television or certainly you can’t surf the Internet without encountering medical advice. In fact we ourselves often read about medical controversies in the lay press even before we see it in medical journals.

So because of this, patients are increasingly aware that experts disagree and we would like to show you a few slides to illustrate this. So this first slide is from The New York Times just a few months ago: "Should everyone with elevated cholesterol be treated with a statin?" Last fall around the time this came out, new guidelines came out to address this question and almost immediately there was intense debate, with many experts arguing that too many people would be treated with statins without clear benefit.

This is from The Philadelphia Inquirerer and this came out around the time that new guidelines, controversial new guidelines about the treatment of high blood pressure came out: "What blood pressure needs to be treated?" Another controversy that has been very much in the news centers on vitamin D: "Should everyone take vitamin D, and if so, how much? What’s the normal level of vitamin D and should you even be measuring vitamin D levels?"

So this slide is from November 30, 2011 and what happened at this time was that the Institute of Medicine came out with their report, new guidelines about vitamin D. And on the same day - you can see the headlines from The New York Times and from The Wall Street Journal. The New York Times said extra vitamin D is not necessary and The Wall Street Journal reading the very same information concluded triple the vitamin D intake.

I’m sure you are all aware of the conflicting recommendations about cancer screening: at what age and how often should a woman have a mammogram and do mammograms even save lives? The debate about PSA screening has been everywhere. You can see there the Family Guy up in the corner. Should a healthy man have PSA screening? This
debate was highlighted in an October 2011 PBS NewsHour, and almost a year later, the very same debate with a point-counterpoint was in The Wall Street Journal and this continues today.

Technical malfunction here. Oh, there we go. Finally, Alzheimer’s debate: should you test for Alzheimer’s disease if you can’t treat it? So every one of these issues and many more remain an active controversy both in medical journals and in the lay press. So how does a patient make the best decision for themselves in the face of all this controversy, all this conflicting expert advice? We didn’t have a ready answer, so we began to search.

MR. GROOPMAN: So we went back to the textbooks and we looked at classic medical decision analysis, which is drawn from economics. And a formula is used to calculate what is the best decision and the formula is derived from the work of Daniel Bernoulli, who was a mathematician in Holland in the 1700s.

Now, Bernoulli was looking at decision-making in the marketplace and he said that the best decision is calculated by looking at the probability of a certain outcome and multiplying it by the utility or the impact that that outcome has. Now, in economics the probability of an outcome might mean the chance of selling a certain number of products, and utility is basically the profit in dollars or more specifically the impact that it has on the bottom line of the company.

Now, this formula underlies much of economic decision analysis and it has been imported and applied to medicine. In medicine you can estimate the probability of an outcome. For example, consider treatment of prostate cancer. You can look at the probability of an outcome, for example, urinary incontinence.

But then the question becomes: how do you put a number on that second part of the equation, on the utility, the impact it has on your life? Now, there are three different methods that have been used in classic medical decision analysis. The first is a linear rating scale from zero to one, where zero is death and one is perfect health. And you are supposed to look at the scale and say, "Well, if I developed urinary
incontinence my life would be at this point between zero and one."

Another method is called the time tradeoff. Here you are asked how many years of life would you be willing to tradeoff or give up in order to avoid incontinence. And the third is called the standard gamble, which comes from game theory. And here you are asked to imagine there’s a magic pill. This magic pill can completely prevent a certain outcome, say, urinary incontinence, but in a certain percentage of cases it immediately kills you, and you are supposed to estimate what odds you would be willing to take to completely avoid a certain outcome versus the chance that it might kill you right off the bat.

Now, recent research in cognitive science has shown that all three of these methods are severely flawed. The problem is you cannot reliably forecast your life in the future. You can’t accurately understand the impact that a certain outcome will have if you’ve never experienced it. Also, medical conditions are not static. They are dynamic. Diseases change over time. And importantly, people adapt to their condition so that their lives are changing over time.

Despite this, these three methods are broadly used in terms of deciding what is best. They are used to calculate so-called QALYs, quality-adjusted-life-years. They set priorities for the National Health Service in the United Kingdom, where they ask healthy British citizens how much time would you tradeoff for a certain medical condition. And in the United States, they have been proposed as the basis of calculating so-called cost effectiveness as part of health care reform.

Now, what happens when you actually ask people who have a certain medical condition or a problem? For example, in Britain people say that being blind is on a scale of 0 to 1, 0.5. That is if you are blind it reduces the utility of your life by 50 percent.

Now, I happen to have a first cousin who is blind. She has been blind since birth. She was born in the late 40s and exposed to a lot of oxygen as a premature infant, which hurt her retina. Now, my first cousin worked her whole life as a teacher. She speaks four languages. She’s currently retired. She serves as one of the – on the board of her
synagogue and volunteers in an assisted living facility, helping sight impaired elderly people learn how to use a Braille keyboard so they can access computers for information. If you told my first cousin that her life was a 0.5 on a scale of 0 to 1, she would slug you.

(Laughter)

MR. GROOPMAN: So when you speak to people who actually have a certain medical condition, their assessment of their own life is very, very different than what people who are healthy, who have never experienced the medical condition believe. So this entire structure of decision-making is deeply flawed. And Daniel Kahneman, the Nobel laureate in economics who has pioneered a great deal in cognitive psychology, recently gave an address to an international medical decision-making meeting and he said this classic paradigm of measuring utility is like measuring the ether in 19th century physics when the ether did not exist.

MS. HARTZBAND: So we realized the textbooks were not giving us the answers that we were looking for, and then we thought about William Osler, one of the most famous physicians of all time. He practiced in the late 1800s and early 1900s. And he made the following comment about making a difficult diagnosis, a difficult medical diagnosis. He said listen to the patient because if you know how to listen, he is telling you the answer.

So we decided to listen to patients. We interviewed scores of patients in great depth, patients of different ages, different parts of the country, different religions, different ethnicity, different socio-economic backgrounds and with different kinds of medical problems. And we asked them how they made their medical decisions. And although we found that patients were individual in how they made their decisions, there were also common threads in the approaches that they took to their health and their medical problems.

And to explain these common threads, we would like to involve all of you right now in a thought experiment. And we are just going to begin by asking you a few questions. So first raise your hand if you
yourself over the past year have been a patient? And what I mean by a patient is not only have you been in the hospital or in the emergency room, but have you just been in for a checkup or a minor medical issue and seen by a doctor.

Okay, so pretty much everybody. So now try to remember the experience of being a doctor. Put your mind -

MR. GROOPMAN: Patient.

MS. HARTZBAND: Oh, excuse me. I'm saying a patient.

(Laughter)

MS. HARTZBAND: I mean put yourself into the mindset of being a patient and imagine now that you are sitting in your doctor's office and your doctor tells you that your blood pressure is too high and that although you've been exercising, you've changed your diet, you've lost weight, your blood pressure is still too high. And so your doctor says now you need medication for this elevated blood pressure.

So raise your hand if you want to be proactive, you want to aim for perfect blood pressure control and you'll do whatever it takes to get that? Okay. So now raise your hand if you feel that your blood pressure does not need to be perfect, you just want the minimum amount of medication? So the first group we apply the term maximalist. You want to be ahead of the curve, do everything and more. The second group, that's the minimalist, less is more.

MR. GROOPMAN: So your doctor prescribes a blood pressure medication and it turns out that the medication comes in two forms. One is extracted from an herb, a natural source. The other is synthesized in a laboratory using the latest technology. Both pills are chemically identical and they cost the same. The doctor offers you a choice. Raise your hand if you prefer a medication that comes from a natural source? Okay. And now raise your hand if you prefer a medication synthesized using the latest technology? Okay.
Now, the first group we term as individuals who have what’s called a naturalism orientation, and this actually in surveys comprises about 60 percent of the population in the United States. And when there’s a medical condition, they first look towards a natural solution. If it’s amendable, they want an herbal medication, an acupuncture massage, meditation, whatever can be taken in that context.

And the second are individuals who have what’s called a technology orientation. They seek the latest treatment, high-tech breakthroughs, cutting edge therapies.

MS. HARTZBAND: So finally your doctor gives you a prescription for the medication that you choose and you fill the prescription and now you are sitting down and about to take your first pill. So raise your hand if you swallow it down confident that you are on the right path to solving your problem of high blood pressure? Now, raise your hand if you take the pill out of the bottle, stare at it for a while, read the package insert, all the side effects again and wonder if you should really take it?

So the first group, that’s the believers. Believers are certain there is a good solution for their problem whether it be a naturalism or a maximalist or a minimalist, whatever that might be. Once they decide, they are ready to go. Doubters worry that the treatment will be worse than the disease.

So the terms for these mindsets came out of the many interviews that we did with patients. These were the common threads that we found that reflected their approach to their health and to medical problem when they arose. And these mindsets applied not only to issues like high blood pressure or high cholesterol, but also to decisions around surgery or even treatment of cancer.

But it’s not just patients who have these mindsets. Doctors and experts have them too. So now we want to get a little personal and talk about our own mindsets. So, Jerry, you go first.

MR. GROOPMAN: Okay. So I was raised in a family with a strong Eastern European Jewish tradition where doctors were on a
Physicians like Jonas Salk and Albert Sabin were heroes for their work with polio. Science and technology were greatly honored as well, and anything that was thought to be "natural" was seen as a throwback to ignorant village life in Europe.

So I was raised as a believer with a very strong technology orientation. And being a believer meant doing everything to the maximum. The attitude in my family was that every medication, every pill must mean better health.

Now, my father in his early 50s had a massive heart attack and died. He may have died because he did not get intensive cutting edge treatments and possibly he could have survived if he had. Of course he may have died even if he had been in an ICU. But this reinforced my belief in intensive interventions and that maximalist mindset extended not only to heart disease, but basically to all of medicine.

And my choice in the 1970s to become a hematologist, an oncologist fit with this maximalist point of view, where bone marrow transplant was being developed - one of the most intensive therapies - and people with leukemia who otherwise would have died some of them were saved. So I have a medical mind as a maximalist and a believer.

MS. HARTZBAND: And I had a different upbringing. I was the first child in my family and when I was a baby the doctor explained to my parents that the new scientific way to feed a baby was every four hours by the clock. And my dad, who was an engineer, was very enthusiastic about applying scientific principles to child rearing. So he made out a very detailed chart for my mother so that she could check off every four hours after she had done the feeding and then he went to work.

And my mother was home with the screaming baby and it didn't take too long before she decided to take matters into her own hands and feed me when she thought I was hungry. And when my dad came home, he was scandalized: "How can you not follow the advice of the experts?" And her response was the doubter response: "Experts don't know everything."
Now, my parents were ahead of their time with respect to a healthy lifestyle. They never smoked. They were avid exercisers. My dad got my sisters and I up early every morning to do the Royal Canadian Air force exercises.

(Laughter)

MS. HARTZBAND: And my mother was in the forefront of healthy eating and had us all eating whole wheat bread, which in the 1950s was not a very tasty item.

My parents have had the good fortune by virtue of their genes and/or lifestyle to live long and healthy lives with a minimum of medical intervention. My dad will be 90 next month. He still works out in the gym everyday and then works on his computer. My mom is a few years younger, but also an avid exerciser. And this background has contributed to my minimalist, doubter orientation.

So Jerry is a maximalist and a believer while I’m a minimalist and a doubter. And we maintained these mindsets about our own health despite the fact that we went to very similar medical schools. He went to Columbia. I went to Harvard. And we trained at the very same hospital, Mass. General Hospital in Boston.

So why are we telling you this? We are pointing it out to show you that doctors and experts have medical minds too and that this can impact the advice that they give. But of course when you are making decisions about treatment, we must also consider the science, the numbers, the evidence, the data from clinical trials. Shouldn’t these numbers give you all the information that you need to figure out what is the best?

MR. GROOPMAN: So one of the first patients we spoke with is a woman we call Susan Pell (phonetic). Now, all the patients we talk about with you today are real, but we changed their names for the purposes of confidentiality and they gave us permission to tell their stories.

Susan is in her 40s, works as a nursing assistant and on her routine checkup with her primary care doctor was found to have an
elevated cholesterol level of 240. And this was confirmed on a repeat test and the normal cut off is 200.

Now, Susan is a very active person. She walks regularly, follows a healthy diet. She does not smoke, doesn't have hypertension or diabetes. Her doctor said, "Susan, you need treatment for your high cholesterol. You need a statin medication. This will decrease your risk of a heart attack by 30 percent."

Now, that made an impression on Susan. She said she will think about it, but she did not immediately fill the prescription. And she surfed the Internet and came up upon a website which has what's called a risk calculator. And a risk calculator answers a key question that every patient should ask himself or herself regardless of the condition and that is what is my risk of a certain outcome without any treatment.

Now, in Susan's case, a woman in her 40s with a cholesterol of 240 and no other risk factors, the chance that she would have a heart attack in the ensuing 10 years is 1 in 100 or 1 percent. Now, even if she were in her 50s and her cholesterol rose to 280, her risk of a heart attack in the ensuing 10 years would be 2 percent, 2 in 100.

So you see how your mind plays a trick on you. When you hear that a statin medication will reduce your risk of a heart attack by 30 percent, it sounds to you as though you are at 100 percent risk for a heart attack. But for a woman like Susan it's really 30 percent of 1 percent. Or if she were in her 50s with a cholesterol of 280, it would be 30 percent of 2 percent, which is clearly much different in terms of impact than what she had originally heard.

Now, we spoke with patients like a woman we call Michel Bird (phonetic). Michel is a maximalist and a believer. And Michel said, "I would immediately take a statin. I could be that 1 in 100 who is going to have a heart attack over the next 10 years. I'm taking the drug." But Susan was a minimalist and a doubter and was not convinced by the numbers.

MS. HARTZBAND: But there's more to Susan's story than just
numbers. Shortly after she was given the statin prescription she went to a dinner at her church and there she met an acquaintance who was hobbling around, looking very uncomfortable and ill. And Susan spoke to her and it turned out that this woman had been taking the very same statin that had been prescribed to Susan and the woman had developed a side effect, the most common side effect, which is myopathy or muscle pain, muscle inflammation.

So as you know, stories like this have powerful effects on all of us. Cognitive scientists call the effect of stories availability bias or just availability, because the dramatic story stays in your mind and is readily available. These kinds of stories led us to overestimate the likelihood or probability of the same thing happening to us. So although stories can sometimes be helpful, they can be misleading, making something rare appear likely.

So when you hear a story like this you need to go back to the numbers, to know the numbers: how common is this side effect of myopathy when taking a statin? Well, it turns out that the number ranges from as low as 1 percent to as high as about 10 percent depending on the type of statin, the dose, other medications and other medical problems that the patient may have.

Now, 10 percent, that might sound like a pretty high number. But if we present or frame the information in the opposite way: between 90 percent and 99 percent of patients who take a statin will not have this side effect of myopathy. So this sounds better although the information is the same. So when you are making a decision or helping somebody else make a decision, it’s important to frame the information in both the positive and the negative.

Now, you might think that framing is primarily a problem for patients, but a recent Swiss study showed that physicians are just as susceptible to framing as patients are.

So how do patients get numbers and other information about medical treatments? Well, one way is through drug advertisements. And a study from UCLA showed that if you watched the evening news and
about two hours of primetime television, you will see more than 1,000 advertisements for drugs. That works out to about 16 hours, which is a lot more time than most people spend with their doctors. And these ads are effective. It has been estimated that for every $1,000 spent 24 new prescriptions are written.

So drug ads are carefully constructed to use the power of numbers to sell the product. So let's look at how it's done. Numbers are framed in the most positive way. For example, for a statin, as Jerry said, an ad might say there is a 30 percent decrease in the risk of a heart attack, but it won't say that it's 30 percent of 1 percent or 30 percent of 2 percent.

So I would like to show you an ad. Can you just – that's great. So this is an ad for a new medication that was approved not long ago to treat patients with atrial fibrillation, an abnormal heart rhythm. And this medication is dabigatran, which is sold under the trade name of Pradaxa. And this is an ad on an Internet site for patients. So the ad uses numbers very effectively. It shows a doctor, a cardiologist, presenting the information to you, the patient. And he gets your attention immediately by stating that if you have atrial fibrillation, you are up to five times more likely to have a stroke.

So five times. This sounds very threatening, clearly implies that you need treatment. But what are the real numbers; in other words, what is the baseline risk for stroke if you have atrial fibrillation and you are not treated?

So many of you know that this depends on what's called a CHAD score, whether or not you have other medical conditions like heart failure, high blood pressure, diabetes, your age and whether or not you've had a prior TIA or stroke. And the number varies between 0.5 percent per year, at the lowest CHAD score, up to about 6 percent per year, at the highest score for ambulatory patients. And these are much less impressive sounding numbers than 5 times increased risk.

But now let's frame those numbers in the opposite way: the vast majority of patients, between 94 and 99.5 percent of patients, will not
have a stroke each year despite having untreated atrial fibrillation.

Now, the ad goes on to say that the risk for a stroke associated with atrial fibrillation is decreased by 35 percent more with this new treatment than with the traditional treatment, which is warfarin. Again, what are the actual numbers? So if you look at the RE-LY trial, which was the clinical trial used to approve this medication, the risk of stroke was 1.7 percent per year with the traditional treatment and 1.1 percent with the new treatment, which is a difference of 0.6 percent.

So although the relative decrease in risk was 35 percent, the absolute decrease in risk was 0.6 percent. And I think you will all agree that if I reconfigured this advertisement to say that the new medication was 0.6 percent better than the old medication, you would be a lot less impressed. Again, the information is accurate. It’s just presented in a different way.

It turns out that when patients hear numbers the way that they are presented in drug advertisements, a study from Dartmouth showed that they typically think the medication is 10 times more effective than it really is.

But this is not just a problem for drug advertisements. It’s also an issue when you look at the results of clinical trials. So I would like to show you in this slide – this is the abstract. And I’m sure you all saw reports from this study, which was published in The New England Journal, on the Mediterranean diet, published not long ago. So what you are looking at is the abstract.

And the authors describe that patients who followed the Mediterranean diet had an adjusted hazard ratio of 0.7, which means a relative risk reduction for cardiovascular events like heart attack and stroke of 30 percent by following the Mediterranean diet, which is an impressive number, which was in every news report.

But now let’s look at the actual numbers from the study. In the controlled group, 4.4 percent of the patients had a cardiovascular event. In the diet plus extra virgin olive oil group, 3.8 percent. And in the nuts plus diet group, 3.4 percent had a cardiovascular event. So the absolute
decrease in events was 0.6 percent for the olive oil group and 1 percent for the diet plus nuts group. And I think you will all agree that if we reconfigured the abstract to say the absolute decrease in risk on the Mediterranean diet was 0.6 percent or 1 percent, you would be a lot less impressed than you were when you heard there was a 30 percent decrease in risk.

So we all need to be very careful when using relative numbers rather than absolute numbers. But even more importantly, returning to what Jerry talked about right at the beginning, the Bernoulli equation, making the best choice involves not only knowing the numbers but knowing how you value those numbers.

So it turns out that there’s many areas of medicine that fall into a grey zone, where there’s not a clear right answer that’s right for everyone. And I will give you an example from my own practice. As an endocrinologist, I frequently see patients with thyroid nodules, lumps in their thyroid gland. The vast majority of these are benign, but a small number are malignant. So in order to evaluate these nodules we do a needle biopsy.

But sometimes these biopsies don’t give us a definite answer. Sometimes we can’t even get enough cells, even on repeated biopsies. So then we need to decide whether or not to do surgery.

So recently I saw a patient who had been to all three of the major Harvard teaching hospitals. She had had a biopsy at every one of these hospitals and none of them gave adequate cells to be able to make a diagnosis.

So the ultrasound showed no particularly worrisome findings. So what are the numbers? The risk of malignancy in this setting is somewhere between 2 percent and 12 percent. So she said to me, "What would you do?" "Now, what would you do?" That’s a question we get asked all the time as doctors. So looking at these numbers I said, "Well, if it were me, I’d watch and wait. But if it were my husband, he would have had surgery yesterday."
(Laughter)

MS. HARTZBAND: So we are both looking at the same numbers, but we have different medical mindsets. Now, we are not suggesting that the doctor and the patient need to have the same medical mindset. Sometimes being challenged can help you make a better decision. But doctors need to understand the patient’s mindset and patients need to be aware that the doctor has a mindset too.

MR. GROOPMAN: So let’s return now to the subject of controversies among experts in medicine. And we all look to experts to help guide us. Who are these experts? Recently, insurance companies have been marketing themselves as having the experts who will look at data and guide your medical decisions.

And this is an advertisement from UnitedHealthcare, which is one of the largest insurers in the country. And what you see here is a woman whose story is told in the ad. And she is an active woman. She is a jogger and she had a knee injury like a lot of us have when you run. And then she had a recurrent knee injury and now it looks as though she needs a procedure. And the insurer says to her and to the public, "You would like to know that you are choosing the right doctor."

So the insurance company says, "We have the experts who will tell you who is the right surgeon. You would like to know you are choosing the right procedure. We have the experts who are telling you what is the right procedure to do." And finally, "You would like to know that you will have the right outcome." Now, that is impossible. It is impossible to know for any surgery procedure, medication that you will have the right outcome; meaning, a clear benefit without any complications or side effects.

Now, in terms of cancer screening, as Pam talked about earlier - we are having a little high-tech indigestion here.

MS. HARTZBAND: I'll try and you talk.

MR. GROOPMAN: Is there a way to advance it?
MS. HARTZBAND: Okay. Okay, just go ahead.

MR. GROOPMAN: Well -

MS. HARTZBAND: Okay -

MR. GROOPMAN: Okay, so we’ll talk about mammograms and PSA screening. So a recent review in The New England Journal of Medicine looking at recommendations and all of the evidence, all of the data, noted that four different expert committees came up with four different recommendations with regard to when a woman should begin to have a mammogram, what age and how often.

The controversy over PSA screening for prostate cancer pivots on two randomized control trials published in 2009 in The New England Journal of Medicine. The American trial had a PSA screened group and a controlled group. Now, you would imagine that the controlled group would not have had PSA screening. But in the American study the controls were assigned to receive "usual care" and more than half of the controlled men actually had PSA screening.

Now, the American study showed no benefit in terms of reducing mortality with PSA screening compared to this controlled group. A large multicenter European trial did show a benefit in terms of reducing mortality, but there were no uniform criteria from center to center with regard to how often should a man be screened in the trial and what cut off should be used for a biopsy.

Now, one center within the European group from Sweden showed a highly significant reduction in death with PSA screening, and the controls in that group no one basically went - underwent screening.

Now, three different expert committees: the United States Preventive Services Task Force, a government panel; the American Society of Clinical Oncology, which are cancer specialists; and the American Urological Association. Each one came up with a different opinion looking at the same studies.
The government appointed panel, the USPSTF, made a grade D recommendation against screening of healthy men. The American Society of Clinical Oncology recommended considering screening for men with a life expectancy greater than 10 years with an individual decision made between the patient and the doctor. And the American Urological Association made a grade B recommendation, recommending considering screening for men 55 to 69 years old, where you get the maximum benefit from treatment, they believe, but again with an individual decision between patient and doctor. Three different committees, three different opinions.

MS. HARTZBAND: So why did these expert committees disagree? We believe they disagree because they represent different mindsets. With regard to mammograms and PSA screening, the United States Preventive Services Task Force represents the minimalist, doubter point of view, less is more. And this has become an increasingly popular point of view in part due to the rising costs of health care.

Other professional societies represented more maximalist, believer point of view. But none of these recommendations is strictly objective. Everyone is looking at the same data but they value the information differently due to different mindsets.

MR. GROOPMAN: Now, finally, some of the most difficult decisions that we all face involve end-of-life care and many people believe that an advance directive will basically take care of this dilemma. But studies show that more than half the people with an advance directive change their minds when they become ill. Next line?

MS. HARTZBAND: I’m trying.

MR. GROOPMAN: Now, they choose differently than what they wrote in their advance directive sitting in the quiet of their lawyer’s office when they were healthy. And this again is because you cannot forecast how you will think, how you will weigh risk and benefit in the future under circumstances you’ve never experienced.
Also, advance directives including even the new modified what's called POLST, which was featured recently in The Wall Street Journal, these cannot encompass every clinical scenario. For example, you enter the hospital with pneumonia and you have in your advance directive or you write in POLST, "I do not want to be on a ventilator. I don't want to be incubated and put on a respirator."

But then the doctor says, "You know, your pneumonia is so bad. We need to support you on a ventilator for a few days until the antibiotics take effect, and then hopefully we can get you off the ventilator and you'll go back to living." Should you not change your mind? So it's very complicated and not simple to predict.

Also, there's a lot of talk about futility; that people are treated and there's no prospect of improvement. But formulas, algorithms have been devised and tested in the United States, in the United Kingdom and in France to try to define futility, when it's not worth treating very sick people.

It turns out you can do this for a group of a thousand, but you can't identify who within that group will actually survive and go on and have a good quality of life. You can't amend the formula for the individual.

And finally, there's what's called surrogate decision-making and this occurs when we have to make choices for others: someone is in a coma, someone might be demented, someone might be on medication that's prevents clear thinking. How do you do it? There's no simple answer, but we believe that going back and considering what was the mindset of that person who cannot decide for himself or herself now. Was he maximalist or a minimalist? A believer or a doubter? Have a technology or a naturalism orientation? That can at least give you a framework to begin a conversation about what choices might be made as a surrogate for him or her.

So how can a patient who can think and can judge make a decision when all these experts are disagreeing? We think it's essential to assess three dimensions. First, just begin with your mindset: are you a believer or a doubter, a maximalist, a minimalist, you orient yourself.
towards naturalism or technology. That’s just the starting point. Then look at the numbers and try as best you can to understand how the numbers apply to you as an individual.

And finally stories. Now, in terms of evidence-based medicine, scientific thinking, often stories are dismissed as anecdotes. But it turns out that research done by Daniel Gilbert, an eminent cognitive scientist at Harvard and published in the Journal of Science, in terms of how to better estimate the impact that a certain outcome will have on your life, that second part of the Bernoulli equation, the utility, is best done by talking to someone who has had that outcome, specifically someone who is similar to you in background, sensibility and so on. And that can help inform your idea of what your life might be like in the future.

And in fact in our national surveys when we went around talking to patients around the country, we found particularly for men, for example, struggling after a diagnosis of prostate cancer, should they just wait and watch, should they have radiation, should they have surgery, talking to other men who had made different choices was enormously helpful in what they ultimately decided.

So you have to be careful. Stories are an end of one. But on the other hand, they do give you a palpable concrete sense of what life may be like in the future.

So we believe in what’s called shared decision-making; that it’s - when we are the patient with our decision, we try to understand how to make a choice in the midst of all of this controversy and disagreement among experts. And we hope that the language that came out of our research in terms of different mindsets can help a patient communicate to the doctor whether he or she is a maximalist or a minimalist, a believer, doubter and so on.

And then the doctor can have a sense of his or her own mindset and then together the two of them can make a decision that’s best for that individual. Thank you.

(Applause)
MR. GROOPMAN: I think we have a little time for questions.

MS. HARTZBAND: Yeah. I guess the front row.

SPEAKER: I would like to know when is it appropriate or how should one think about a decision when it comes to doing a procedure far distance from your home in order to get “the best doctor”?

One issue is where does one recover, so that one has to travel from that far distance to come back to your home to recover there and you don’t have access to that doctor? But then how much better are these best doctors from your local doctor performing the same procedure?

MS. HARTZBAND: Well, that’s a question that comes up a lot, and I think that the best doctor as applied to procedures is a little bit different than best doctor when applied to decision-making or diagnosis, for example. So there have been numerous studies that have shown that the more experienced technically a surgeon is or an interventional radiologist, for example, doing a procedure, the better – you know, the better the outcomes are.

But how much better after a certain point is debatable. So this is a very tricky question and I think you bring up some really important points about balancing the benefits of going to so-called best and the downsides of being far away from your family and any other supports, and when you return home, if you have a problem getting back to be seen.

So I think that’s an excellent example of your personal weighing of risks and benefits. But I do think it’s a real issue in surgery that below a certain cut off there is a difference in outcome in terms of experience.

MR. GROOPMAN: Yes?

SPEAKER: Thank you. You talked a little bit about the influence of stories in making a decision. Did you look at a patient’s belief in that they had made the right decision and how that influenced the outcome of
treatment?

MR. GROOPMAN: Yes. We actually didn’t have time to talk about everything that we looked at. But we looked at the issue of regret, which is a huge issue in medicine, because you can go to the best of the best of the best and have a poor outcome. It happens. It’s real. There is no perfection in medicine, and you may not even be able to identify the reason why.

And we profiled two patients, both of whom who had orthopedic procedures. They were both very active and so on and they had come to the point where they needed surgery it was believed.

Both did not have - neither one had a good outcome. One, though, had felt that he had gone through real due diligence. He had checked on the surgeon in terms of how - you know, the frequency, as Pam said, of how many procedures, had looked at the numbers, had thought about how long he had delayed this, what it was doing to the quality of his life and so on and felt he had made a very considered decision with eyes open.

The other was a woman who felt she had been boxed in. She had not really wanted to have this and had been pressed by the surgeon to have a procedure which was actually more extensive than she might normally have wanted. And her outcome was not good.

The first person, the first guy, he wasn’t happy, but he didn’t have this extra burden of regret. The second, not only was she dealing with a bad orthopedic outcome, but she was wracked with self blame and frankly anger. So that these kinds of decisions and retrospect is very, very powerful in medicine.

And in terms of learning from stories, I think the key is it’s not that you are going to have a good outcome or a bad outcome - one always hopes for a good outcome - but that you really have to think and understand as best you can your mindset and the mindset of the doctor and express your preference.
MS. HARTZBAND: I was just going to add one small point to that, that we did speak to one patient who had an excellent outcome from a procedure and she still regretted that she had done it. She felt that she had been pushed into it and she would have been fine if she never had it.

SPEAKER: How do you best measure the success of your informed consent procedures?

MR. GROOPMAN: I didn’t hear –

SPEAKER: So how would you best measure the success of your informed consent procedures then if that’s the case?

MR. GROOPMAN: Well, I think that it’s important to measure. But the first is what we were just talking about. I think it’s – you know, people have a physical dimension to their lives and a psychological dimension to their lives and the two of course interact. I think it’s important to measure not only if an informed decision, shared decision-making in, say, the context of an orthopedic procedure resulted in a lot less pain and a lot more mobility. That of course everyone wants.

But also the level of patient quality of life, satisfaction and understanding that they had real – one wouldn’t call it control, but significant input and meaning in terms of the ultimate choice. And I – let me just finish. And I think that both of those are very important.

Now, these are very complicated to measure. Quality of life is incredibly complicated. And again, I'll refer back to Daniel Kahneman. He did studies where he looked through the course of a day of how people measured their quality of life. And if a patient had – an elderly patient had their grandchildren visit the hospital on Tuesday, their quality of life was very high. And if they didn’t hear from their grandchildren for another five days, their quality of life went down.

So, you know, there is no easy way to measure this, but at least you can get a sense of people’s level of satisfaction in terms of having real involvement and autonomy.
Now, there are also people who don't want to be involved in decisions and we talk about that as well.

MS. HARTZBAND: Right.

SPEAKER: I supposed my question is, is before you operate on somebody, how do you know that (inaudible)?

MR. GROOPMAN: How do you know? First, you have to -

SPEAKER: What's (inaudible).

MR. GROOPMAN: Right. So first is - often we say to someone tell me what you've heard or tell me how you see this, right - a very open-ended question. Not, you know, are you framing it with 0.6 percent versus, you know - just a general question. And if a patient is able to give back to you an answer that shows that he or she really understood risks and benefits in a substantial way - one of my teachers said also that, "You know, medicine is not rocket science." You know, almost every doctor should be explaining to anyone risks and benefits in an understandable way.

MS. HARTZBAND: But I think you are focusing on something that is a very big issue in medicine right now, which is metrics: how do you measure, where is the evidence. And what we are trying to bring out in part by this talk is that there are things that are very difficult to measure, maybe you can't even measure them. And even if you have every metric that you are able to measure, you are not going to capture some element of this experience. That's really what we are trying to say.

SPEAKER: (Inaudible). You said something about different mindsets and that really fascinated me and troubled me, which was that they had different mindsets. But it seems to me they have the same mindset, which is that we've already made up our decision ahead of time, please don't confuse us with any data or facts. So what I'm wondering is when it comes to national guidelines - and as an emergency physician I confront this all the time. We have to do what the guidelines say. But many of these guidelines are written by experts who have huge financial conflicts of
interest and they don't know how to read the data without the mindset that they had coming in.

So should we do away with guidelines that are supposed to help us, but really all they do is answer the question, "You know, dear cardiology, dear neurology, what was your bias"?

MS. HARTZBAND: Yeah. I think – you know, first of all, I think guidelines are a very helpful thing. Guidelines involve a very extensive review of the available data and discussion of how they came to their conclusions and they are really helpful. But when guidelines became mandates, which is what you are talking about, then you have a problem because you are not able to individualize to the patient.

So we are – you know, I think this is a very, very important issue. And as we said, you know, you can have three sets of guidelines by three separate different committees, expert organizations. So, for example, you know, are you supposed to follow this guideline or that guideline or the other guideline? So I think it's very, very important, sort of along the same idea that we were just saying, where you can't always measure and check off the check box that you did everything right. Sometimes you have to individualize. Sometimes you have to be specific to a situation that doesn't fit quite into the guidelines.

You have to – as doctors and clinicians you have to be able to think, not just follow the guidelines. I think that's so important in terms of medical education now and something that we really try to bring out to our residents and students that you are required to think. Just because it says this doesn't mean it applies in any particular setting. I think it's a great point you bring out.

MR. EPSTEIN: For many doctors it's even – you know, they are even more restricted than that. "Let's follow protocol." I'm Keith Epstein with AARP, strategic advisor. So some doctors are confined by the protocols they must follow. Realistically, many doctors have very limited time they can spend with each patient to go through this sort of process of shared decision-making that you described.
Are there other tools, services, methods, approaches that one could develop to enable patients - even on the prevention side - to actually make good decisions that work for them that incorporates some of your thinking?

MR. GROOPMAN: Well, I think first is that what we hope - and, you know, some of the writing we've done and other people is that patients before they come to the physician if they have knowledge of this kind of language - this is not complicated maximalist, minimalist, believer or doubter. To have at least a sense of where they are coming from, what their mindset is.

But I also believe that medicine is being severely damaged by this whole efficiency and compression of time. It really is. And when you go with a real medical problem to a physician, you need time to think this through and you may not even make a decision or shouldn't make a decision on the first appointment.

So the idea that there are now - you know, everything is - and it's called taylorism; you know, this high efficiency like you are in some sort of Toyota plant and you are just knocking out cars, you know, that are all identical, mind you, and all new. And that's the paradigm for modern medicine that it's industrialized. And people have written that in The New England Journal of Medicine: "This should be the new medicine." We feel that is absolutely wrong. It's wrong because it's not the way that medicine should be and it's not the way that good decisions are made for individuals.

And the reason it's configured that way is because there is this shift now away from thinking about individuals to talking about populations. There was an article in The Journal of the American Medical Association: "The care of the individual is obsolete." That's ridiculous. Medicine is all about us being individuals and making choices that are meaningful in our lives.

(Applause)

MR. GROOPMAN: Thank you. Okay, I think we are - we just
MS. HARTZBAND: We got the word.

MR. GROOPMAN: - the cut. So thank you very much.

MS. HARTZBAND: Thank you.

(Applause)

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