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Mark Masselli: This is Conversations on Health Care. I am Mark Masselli.

Margaret Flinter: And I am Margaret Flinter.

Mark Masselli: Today, Margaret, and I are speaking with Dr. Jerome Groopman, and Pamela Hartzband about their new book *Your Medical Mind; How to Decide What Is Right For You* published by Penguin Press. Dr. Groopman is an oncologist at Beth Israel Deaconess Medical Center in Boston on the faculty at Harvard Medical School and staff writer for the *New Yorker*. Dr. Hartzband is a noted endocrinologist at Beth Israel as well as a faculty member at Harvard Medical School. Welcome to you both. Medical decisions are some of the toughest and most difficult decisions we need to make in our lives and your book is full of stories about how different people have made medical decisions. If there is one key idea that you would like people to take away from your book about making these decisions, what would it be?

Jerome Groopman: I think the key message is there is no single right answer for everyone. So unlike mathematics where you are posed a problem and there is one correct solution, in medicine there is a very, very large grey zone. So what is the right choice for one patient is not necessarily the right choice for another patient.

Margaret Flinter: So, I thought you both pointed out in very compelling ways different people bring different sets of biases to this decision making process and some people perhaps want the most intervention possible, others want the least. Can you tell us more about these biases and maybe explain this concept of availability bias and the role that anecdotes and stories and data all play in influencing health care decision making?

Pamela Hartzband: We found that patients made their decisions in different ways. Some people were maximalists; they wanted to be ahead of the curve, very proactive, and do everything and more to take care of their health problems. And other people were minimalists; they wanted to do just the absolute minimum that was necessary, for them less was more. And then we found that people segregated out. Some people wanted to follow more natural remedies things like acupuncture, herbal remedies, natural supplements and so on and at the other end of that spectrum were people with a technology orientation who wanted the latest greatest technological breakthrough in the laboratory and then finally, the last category were believers and doubters. So believers were convinced that there is a good solution for their medical problem and all they had to do was find it and then they would go for it and doubters are always worried about side effects, unintended consequences, maybe the treatment is going to be worse than the disease.

Jerome Groopman: So these mindsets then are sort of where you began with regard to your personal approach to health. And then we are influenced very deeply by stories. We all live our lives hearing stories and stories make the world concrete and accessible to us. And because stories are so powerful, they become deeply imprinted on our minds and therefore available. So when we are considering choices, we remember or we access what is most available in our minds. So if your Uncle Fred took a pill and had a terrible side effect from it it's not likely that you would want to take that medication. But if a friend at work had a surgery for a certain problem and came out just with a wonderful outcome, you would be predisposed to pursuing that treatment, that surgical approach. But that may not be what's right for you. So you need to step back and consider the stories but put those stories in the larger context of information.

Mark Masselli: You know in addition to biases that can shape our decision making, they also shape the way that we look at data. And I think our country is probably best captured, or culture of our country is best captured maybe by Mark Twain who said, "There are three types of lies: lies, damned lies, and statistics" so. But we really need to base our decisions on sound data, on sound stats and unfortunately, too often people only look at part of the data for example the probability of curing an ailment without looking at the probability of complications from the treatment. Can you tell us more about conflicting health care data and how patients and doctors should work together to fully understand data related to patient conditions?

Jerome Groopman: Well I think something that we propose in the book which should be the starting point and addresses your question is every patient should ask what is the likely outcome with no treatment. With regard to the Mark Twain for example, we tell the story of a woman we call Susan Powell who has a high cholesterol and her doctors gives her a statistic. This statin medication will reduce your risk for a heart attack by 30%. Now that sounds very impressive. And the reason it sounds so impressive is because when we hear that it's going to reduce our risk by 30%, our mind plays a trick on us. We imagine we are 100% at risk for a heart attack. But in fact Susan discovered when asking the question what if I do nothing, a woman in her 40s with an elevated cholesterol but no other risk factors that the likelihood that she would have a heart attack in the ensuing 10 years was one in hundred, 1%. So that's a place to begin. And then when you hear it reduces your risk by 30%, 30% of one is not a very big impact, not in her mindset because she is a minimalist, she is a doubter. So I think that you are completely correct that there are statistics that are framed or presented to us in ways that can be very misleading not only for patients but also for doctors.

Pamela Hartzband: There have been a number of studies that show that depending on how you present information whether it's absolute benefit or absolute risk versus relative benefit or relative risk that your understanding of

those numbers is very different. So for medications like cholesterol-lowering medications, patients would believe that a medication was 10 times more effective than it really was depending on how the information was presented. And what was even more surprising you said in a very recent study it was found that doctors were just as confused by the numbers of patients when information was presented as relative risk or relative benefit rather than absolute.

Margaret Flinter: This is Conversations on Health Care. Today, we are speaking with Dr. Jerome Groopman and Dr. Pamela Hartzband about their new book *Your Medical Mind: How to Decide What Is Right For You*. So one thing I think we would all agree on and we are sure recommendations do change and we have all seen this many times in the course of our careers. We have a very current example, the U.S. Preventive Services Task Force with their new recommendations advising against the PSA blood test screening meant for prostate cancer and this one of course has been debated for a long time in health care but now they are coming out against a recommendation for screening. So maybe you can take us through how you communicate and how your colleagues communicate with patients about recommendations which really don't even have the feeling of black and white at the time that they are being made because we have seen change before we know it may come. What's the communication with patients where we just aren't sure?

Pamela Hartzband: Prostate cancer is a great example of conflicting expert advice. There are three different groups looking at the same information and coming out with three different sets of recommendations.

Jerome Groopman: I think what hasn't come out clearly in a lot of the _____ 8:46 reports which struck us because we actually refer to it in the book and we have an extensive set of notes about PSA screening is that there were two very large studies, one done in the United States one done in Europe that were published in 2009 that were supposed to settle this, supposed to be a black and white answer. But both of these studies actually were not designed or executed in a way that gave definitive answers. In United States Study which showed no clear benefit to PSA screening, there was one group that had regular screening every year and then a control group which you would think would not have PSA screening but instead they left it to the discretion of the patient and the doctor. So, more than half of the men in the control group actually had PSA screening so this study is muddled. And in Europe, they didn't even have detailed information on the control group with regard to the active grouping, PSA tested, and the control group in one center, about a third of the men had a PSA screening. And in the European study, in younger man, there appeared to be a survival benefit saving lives. The other problem which I think is hard for the public to grasp but once it's communicated it's clear is that it's very easy to measure life and death, you are alive or you are dead. But how you weight for example someone who doesn't die from prostate cancer but the tumors grow in his lower pelvis, they move into his bones and so on, he may die of a heart attack or a stroke or whatever, but his life

can be made pretty miserable and you weigh that against doing surgery or radiation on a man where the tumor may never be a problem and that leaves him incontinent or impotent. So how do you weigh this? It's really a grey zone and I think that patients are really in the term empowered when they understand that there is no certainty here and the middle road is probably the wisest to try to figure out for you as an individual how you weigh the potential risks and benefits with information that is far from perfect.

Mark Masselli: I want to pull the thread a little on that because in your book you recognize that sometimes treatments don't work out as well as the doctor had hoped and when a patient felt pressured to follow that treatment in the first place they can wind up with feelings of regret and betrayal. But you argue that even when a treatment is not effective it's a better outcome for the patients when they are full partners in the decision making process. Tell us a little more about that.

Pamela Hartzband: So in our book we discuss two patients who both had orthopedic surgery for basically degenerative problems and problems that occur with aging and both had an unsuccessful result in that they were still left with pain. They were both disappointed but one had tremendous regret. So the patient Lisa, that we call Lisa, had foot surgery and she felt that she was pushed into this by the doctor and she wasn't following her own medical mind, her own way of doing things and when the surgery didn't work she was consumed with regret. Whereas Carl had a knee problem and had surgery for his knee and also had a bad result, was left with a lot of pain and couldn't do the things he wanted to do, and he was disappointed too but he didn't have regret because he had followed his own medical mind, he did things the way he thought he should and the process was right for him so he in the end felt it was the right thing to have done even though it didn't work.

Jerome Groopman: Regret is an enormous burden. I mean I can speak personally I did not understand my medical mind. I at a very younger age was a maximalist and a believer to the extreme and because I didn't have the language to understand myself and didn't have a physician who might challenge my thinking but just acted as a rubber stamp, I went ahead and had a back surgery for lots of back pain, I was a distance runner and so on but I didn't have a big blown disk or anything like that and the surgery was a catastrophe; it left me in more pain and debility than I was before. But as you say, you can't guarantee the outcome on the surgery but the regret that I felt was that I really had not gone through a process with my eyes open, I had made the decision blind. And what we hope with the book and the reason we show this to people in this particular chapter is that when you are not making decisions blindly, you really can unburden yourself of this terrible sense of regret.

Margaret Flinter: You know a while back on this show we focused on the issue of shared decision making and I think there is a general sense that that offers a lot of potential to both make patients more satisfied with their decisions, maybe even

to improve cost when people look at relative benefits and risks. But I think as clinicians, we have all had the experience of going through the relative risks and benefits and the information the patient turns to you and says so what do you think I should do, what would you do if you were me and that's a hard thing. And when we think about the diversity of our patients and I know Health Affairs is focused on the persisting health inequities this month in their issue. We think about patients who are challenged by speaking different languages, by low literacy levels at least in English, maybe other challenges, cultural differences, it's a complicated thing to explain all of this. Maybe you can speak a little bit to your experience, you are there in Boston it's certainly one of the great melting pots of the world. What's the experience in trying to work through these processes with people who represent many different cultures, languages and backgrounds?

Jerome Groopman: By giving people terms, by giving people words, language, and vocabulary to try to better understand their own thinking and how that thinking fits in with their own background and culture, there is a very strong naturalism orientation among people often who come from Asia and India. We have been told this by physician colleagues who come from that cultural heritage that you can connect with the patient in a much more direct way because you find the common language, you find the common terms. And in terms of someone saying to us well what would you do, often they say, "Well if I were your mother, what would you say?" And as you can tell from reading the book because Pam writes about her mother and I write about my own mother, my mother was a believer and maximalist so I mean if she had a problem, she would have taken care of it yesterday to the maximum.

Pamela Hartzband: My mother was a minimalist and a doubter. She was one of those people who feels that less is more and possibly the treatment is going to be worse than the disease. So the recommendation for her might be very different from Jerry's mother who was a maximalist and a believer. So you have to tailor the recommendation to the mind of the particular patient and keep in mind that doctors have medical minds too so the way they recommend things to you reflects their own medical mind or how they approach medical problems themselves.

Mark Masselli: And as you say that medical decisions are personal decisions that patients make with their family that speak a common language and understand each other. But on a personal note, in addition to working together at Harvard and Beth Israel Deaconess and collaborating on this book in many articles, you are also husband and wife, and in the beginning of your book, you say we realize that each of us had started our careers with a different conception of medical care, the old saying opposites attract applied to you. What did you learn from writing this book together and what do you hope both patients and doctors will learn about the role families play in making medical decisions?

Jerome Groopman: Well, I think what we hope is that people will understand their medical mind and that insight will help them with their doctors make the choice that's right for them. My medical mind as you say, as I write, was a believer and a maximalist so my mine initial inclination when offered a treatment option is yes, let's do it to the maximum, I am going to do it, let's get on underway. But by understanding myself, I can step back for a second and say wait, is that really the wisest choice for me as an individual.

Mark Masselli: Today, we have been speaking with Dr. Jerome Groopman and Dr. Pamela Hartzband about their new book *Your Medical Mind: How to Decide What Is Right For You* published by Penguin Press. Thank you so much for joining us today.

Jerome Groopman: Thank you.

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Mark Masselli: Each week *Conversations* highlights a bright idea about how to make wellness a part of our communities and everyday lives. This week's bright idea looks to churches to address disparities in health care. Immigrants tend to avoid the US health care system for many reasons. It may be language barriers, cultural differences, even fear. One health system in Virginia has been trying to help by working with churches in the state to promote health and wellness for Hispanic immigrant populations.

It is the best connection that we have because people rely on the faith communities and they trust their leader and they trust the community so it's the best way to communicate with them.

Mark Masselli: Most recently, Inova Health Systems has been training church volunteers to reach out to pregnant women in the congregations. In Virginia, one-third of Hispanic women don't receive any prenatal health care during their first trimester of pregnancy. In addition to teaching them about proper health and nutrition during pregnancy, the volunteers are able to answer questions the women have about documentation and where to go for care if they don't have insurance. Inova also helps congregations coordinate health fairs and screenings and support groups for chronic conditions. Stepping outside of the confines of the health system to connect with special populations who face barriers to care, now that's a bright idea.

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Loren Bonner: We close with the tech report, our weekly look at how people are using technology to improve and wellness. I am Loren Bonner. Many patients are going online to gather information about their conditions. These patients, or e-patients as they are known, are more empowered to make choices about their

own health care by confront issues of finding quality information. This week we want to highlight an individual who is bringing quality social media resources to doctors and patients. Bertalan Meskó is a recent medical school graduate living in Hungary, now a PhD candidate in clinical genomic and personalized medicine. Meskó's passion is to have e-patients and medical professionals know more about social media and to get them the best resources to use it effectively. In 2009, while he was still in medical school in Hungary, he launched Webicina.com, a social media guidance service for patients and medical professionals. Meskó joined me by Skype. I asked him why he wanted to create this service.

Bertalan Meskó: Whenever I tried to find quality cardiology blogs for genetic podcasts, it would be so much time and effort to find the best ones that I thought that there should be a service that does that hopefully for everyone.

Loren Bonner: Webicina seems to be paving the way. Mesko and his team go through thousands of social media resources daily and come up with lists of the most relevant ones in a medical specialty or a condition. They have covered over 80 medical topics with over 4,000 social media resources ranging from Twitter and YouTube videos to Facebook groups and blogs. On top of that, they have made these services available in 18 languages. While the number of e-patients is growing exponentially in many countries, the number of web savvy doctors isn't catching up. So Mesko is trying to fill this gap as well.

Bertalan Meskó: And the doctors maybe can do a (Inaudible 00:22:02) would like to help these patients more effectively.

Loren Bonner: Mesko has created the very first university course to help medical, pharma, and dental students know more about social media. He plans to offer the course online so that medical students and doctors from around the world can attend.

Bertalan Meskó: I am sure that they will be able to help daily patients or at least they will know that there are solutions for the problems of visiting patients.

Loren Bonner: Mesko says these are the most important steps for the next few years.

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Margaret Flinter: This is Conversations on Health Care. I am Margaret Flinter.

Mark Masselli: And I am Mark Masselli, peace and health.

Conversations on Health Care, broadcast from the Campus of Wesleyan University at WESU, streaming live at www.wesufm.org and brought to you by the Community Health Center.

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