

Sarah Alger:

Welcome to Proto, a podcast that explores the frontiers of medicine. And welcome to diagnosis, a series about the past, present, and future of a medical cornerstone. I'm Sarah Alger.

Dr. Leigh Simmons:

And I'm Dr. Leigh Simmons. The moment of diagnosis can be a relief for many patients, the turning point when physicians pinpoint what's wrong and can start fixing it.

Sarah Alger:

But diagnosis is not always a positive inflection point. In some rare cases, just hearing what's wrong can start a patient on the road to poorer health.

Dr. Leigh Simmons:

The modern treatment landscape has grown more and more complex, and patients are increasingly saddled with the responsibility in navigating through it. A diagnosis can lead them to a time of anxiety, and they might make medical decisions that aren't in line with what they want out of their healthcare if they'd been fully informed.

Sarah Alger:

How can we shore up negative effects of medical information? When diagnosis hurts, coming up on this episode of the Proto Podcast, brought to you by Massachusetts General Hospital.

Sarah Alger:

In the 2019 movie *The Farewell*, a Chinese family decides not to tell their elderly relative that she has terminal lung cancer. The movie is based on a true story, and in fact, a 2018 survey in the Shandong Province of China found that 82% of Chinese physicians said they would also withhold a terminal diagnosis from a patient if the family wished it. In the movie, a relative explains the decision: They are only protecting the woman from her own grief, they say, because knowing her diagnosis wouldn't fix anything. The information might actually make her health worse. It is curious to think of a diagnosis causing damage to health, but some do. And the question is increasingly of interest to physicians. In the United States, some patients claim the "right not to know", a preference to be spared from the anxiety of knowing about a genetic disease they can't avoid. Another more common way a diagnosis might cause damage is through so-called overdiagnosis. Dr. Scott Podolsky, an internist at Massachusetts General Hospital, wrote in a recent article for the *BMJ* that overdiagnosis could be defined as "correct diagnoses that match established disease definitions, but which don't in fact help the patient and may cause harm." Here to talk about damage from diagnosis and how it might be avoided is Dr. Leigh Simmons. Dr. Simmons is the medical director of the MGH Health Decision Sciences Center, where she studies ways in which physicians and patients talk about disease. Dr. Simmons, welcome.

Dr. Leigh Simmons:

Thank you, Sarah. I'm so glad to be here.

Sarah Alger:

At the Health Decision Sciences Center you look at ways that medical decisions get made by clinicians and patients. Before we jump in, can you give us a quick description of the term shared decision making?

Dr. Leigh Simmons:

Of course, there are a couple of definitions I like. One is: A shared decision and the process to get there takes two parties, a patient and a clinician, or maybe a team of clinicians and maybe a patient in their family, but two parties coming together to talk about a significant medical decision. The clinicians are armed with important medical information about the patient and a reasonable set of options for either

diagnosis or treatment. And the patient comes ready to talk about their values and preferences, or even if not ready to talk about it. That will be elicited during the conversation where these options are shared, preferences are elicited, and a shared decision is made. Another shorter definition that I like is one that describes shared decision making as a decision that results from clinicians and patients bringing their expertise to the table. The clinicians bring what they know about the medical decision at hand, and the patient brings their expertise in themselves, and they come together to make a decision on the course of action.

Sarah Alger:

As I mentioned before, we'd love to explore this idea that some diagnoses can cause harm. Let's start with the term overdiagnosis. Overdiagnosis seems to embrace two large areas of concern. The first is when the definition of a disease broadens. Some argue that this has happened with diabetes, chronic kidney disease, ADHD and certain allergies. Is it a cause for concern when the parameters of these diseases draw in more people? And if so, why is that? What could go wrong?

Dr. Leigh Simmons:

I think it's a cause for caution. I think it's important to be aware that any time the parameters for definitions of a disease are broadened, you are going to bring in more people who technically have the diagnosis but will never suffer the harms of the illness. But certainly if everyone in that group is treated, you're more likely to harm some people with those treatments. Similarly, if you constrict back to that narrow definition, you'll miss some people who might stand to benefit from that treatment or from knowing about that diagnosis. So it's something that we must be honest about as clinicians that when these definitions, especially for asymptomatic conditions that might better be called risk factors than diseases themselves--a good example of that is high blood pressure--we know that it can predispose a person to having strokes and heart attacks, but certainly not everybody with high blood pressure will develop those complications. And we may harm more people than we help when we treat them aggressively for those conditions trying to prevent a dreaded disease.

Sarah Alger:

Another use of the term overdiagnosis refers to something quite different. It happens in the case of certain cancers. The patient is told they have a cancer, but this information might harm rather than help them. And you've published about prostate cancer in this regard. What happens here?

Dr. Leigh Simmons:

There are a few ways that that information might be harmful rather than helpful. The first is, you may have given a patient a diagnosis of a prostate cancer that is indolent, that means very slow growing. They would've never known about it. They would've died with it, but not of it. That's someone who truly, probably would've been better off never knowing. The other circumstance is you diagnose a prostate cancer that unfortunately would not be responsive to treatment. You diagnose it at a time where treatment isn't going to help extend the life or reduce complications or side effects. Both of those would be considered harms potentially of making that diagnosis. Here's the challenge. When you do that test, when you do that counseling, you often don't know if your patient's going to fall into one of three buckets: the person who has an indolent cancer that was never going to be a problem; the person who has a very aggressive cancer, and no matter when you picked it up, you really wouldn't change the course of the disease; or that sweet spot. I found it right at the right moment in this window of time where offering appropriate treatments is going to spare my patient suffering from the cancer, maybe even extend their life.

Sarah Alger:

I'd like to get back to shared decision making and how that can help in these cases. But first, can you give us a little history of shared decision making? Where did the field come from and why was it needed?

Dr. Leigh Simmons:

The field of shared decision making really came from the recognition that there was a lot of overdiagnosis of a lot of conditions and not a lot of understanding about what the right rate of diagnosis of some illnesses was and the right rate of treatment choices and treatment decisions based on those diagnoses. This field really started looking back at, I believe in a previous podcast, you've covered the Dartmouth Atlas and Jack Wennberg's work, looking at really variable rates of tonsillectomy depending on what the doctor's preference was in different counties to do tonsillectomy in children. Surely children just miles apart didn't have higher rates of recurrent tonsillitis and realizing that there was in fact overdiagnosis of a problem with tonsils and an overapplication of a dangerous operation of tonsillectomy, potentially dangerous operation, in those children who perhaps didn't need it. From that work on overdiagnosis and studying rates of diagnosis and treatments that varied so widely by geography, Al Mulley and Michael Barry here at Mass General started working closely in looking at overdiagnosis and also shared decision making strategies to offer treatments and diagnostic approaches for prostate cancer, treatment of benign prostatic hypertrophy. That work led to the development of some of the first decision aids tools he designed to help clinicians and patients make significant medical decisions together. For example, decision aids on prostate cancer screening featured patients who had decided to do PSA testing or to not do PSA testing after a careful discussion of the risks and benefits with their clinicians. And these decision aids included interviews with doctors and patients sharing their stories and how they came to those decisions together.

Sarah Alger:

So I think you've largely answered this here, but it sounds like shared decision making can very much help combat overdiagnosis.

Dr. Leigh Simmons:

Well, it depends on the type of overdiagnosis you're talking about. I think a nice broad definition of overdiagnosis might be a diagnosis that harms more than it helps. And sometimes we know when we're going down a path of making an overdiagnosis, if you will, for example, finding early prostate cancers that would've never become a problem, can be curbed by using a decision aid, having that to guide your conversation with patients. But there are other circumstances where blood tests are simply drawn for routine purposes. And a good example of this would be the use of the A1C level to make a diagnosis of diabetes. In recent years, we've started to use the A1C both as a diagnostic tool for diabetes, saying a certain percent of 6.5 and higher is a diagnosis of diabetes. And if you have an A1C percentage of 5.7 to 6.4, you have an illness called prediabetes.

One might go to a doctor's office and have that test run without any conversation. In fact, I suspect it often doesn't have a conversation. And then your patient is reading a visit note or looking at their electronic medical record and sees something called a problem list and a problem of pre-diabetes has been added to it. One might say that that's an example of overdiagnosis where there's really very little patient engagement in the process, and it's something we have to look out for, especially with greater transparency and patients' ready access to their charts. All sorts of terms and words and diagnoses are popping up that are going to force some important conversations about how patients are handling these diagnoses, what the significance is of that diagnosis in their overall health plan. And also for clinicians, ordering responsibly and diagnosing responsibly is an important new task for us in the coming decade, I think.

Sarah Alger:

And actually, can you talk for another moment about that? It's relatively new, I think, at least in this state, that patients have been given more access to their records. Can you talk a little bit about what that access looks like now and how that has affected your work?

Dr. Leigh Simmons:

Yes. So that's actually a nationwide policy. This is part of the Cures Act that unless there are circumstances, and these should be very rare, where we feel that a patient would be harmed by having ready immediate access to test results, all results available in electronic medical records should be available to patients via patient portal immediately. Now, of course, patients could always request their records from medical records departments, but that took a lot of faxing and requests and releases. This is instantaneous. This may come up the moment I type in a diagnosis into the problem list and hit Enter. That would be available for a patient to review right away. So every diagnosis that a patient has been given may be listed in those charts. Other things come up, for example, reports in radiology, studies that mention concern for or changes suggestive of cancer. These kinds of things are raising a lot of concern for patients, raising a lot of anxiety, and put a lot of burden on clinicians to do preemptive counseling about what patients might encounter in their medical records and in radiology reports, and thinking about how they'll handle the outcomes of studies that are done.

Sarah Alger:

To bring up another example you've also published about certain orthopedic conditions and you've noted that certain tools from your center have led people to be less likely to have surgeries. What's going on there?

Dr. Leigh Simmons:

Yeah, I think this is a great example of how having a diagnosis of knee osteoarthritis as one example can mean so many things to so many people. So a couple of the important questions we ask patients who are suffering from, in this case, osteoarthritis of the hip or the knee, is, first of all, How bothered are you by this problem? How bothered are you by this stiffness or the pain? Interestingly, bother and pain don't always completely correlate. Someone can say, Oh, I'm in a lot of pain. It doesn't really bother me. It doesn't get in the way. And other people might say, It doesn't hurt so much, but the fact that I cannot ski like I usually do or play with my grandchildren, that is very bothersome to me. I am ready to take a step to fix this problem, even if it means a substantial recovery time after a major operation.

It turns out when patients get full counseling in a shared decision making process, in this case aided by decision aids, these tools that explain the pros and cons of the different options, that the decisions they make, they're more informed when we test them on their knowledge about the decision at hand, they know more. They know more about the likelihood of benefit from the procedure, they know more about the side effects, and they also have a clear sense of their own preferences. I can recall years ago, having a patient who had had a hip replaced on one side. Things had gone pretty well in the aftermath, but immediately postoperatively, he'd had a lot of complications. So a few years later when he was contemplating getting the other hip replaced, I had asked him, How bothered are you by it? And he said, not really that much. It's a bit stiff. It wasn't getting in the way of too much else. But his response to me was, I need to go see the surgeon. He'll tell me if it's time to replace it. And I found it so interesting trying to get across the concept that you will need to tell him how bothered you are or not. It's not gonna be just looking at the x-ray. Our orthopedic surgery colleagues always tell us, you can't necessarily tell just by the x-ray. You've gotta ask about the bother, the pain, the interference with daily activities and the patient's willingness to undergo major surgery and recuperation to get to the function that they would like to. So that's the signal you saw there. Patients when they were fully informed with their options and they understood that they also had a role to play in making this decision, understood that

this was something that didn't have to happen right away, it could be postponed, and maybe there are things they could do in the meantime on their own, such as changing their exercise regimen so that it wasn't so painful, losing weight so there wasn't as much pressure on that painful arthritic joint, and trying other medications to manage pain, and they could put off the surgery or maybe never have it.

Sarah Alger:

How do patients think differently from physicians about a diagnosis? You've talked a lot already about sort of how they would feel. How would they sort of think about certain diagnoses, what influences their decisions?

Dr. Leigh Simmons:

It's hard for me to make a general statement about all patients. And I'll tell you why. We as doctors are very, very poorly skilled at predicting how our patients are going to respond to a diagnosis or make a treatment decision. A few years ago at our center, we did a small study as we were developing some paper decision aids to make common treatment decisions in primary care settings. And I developed a short decision aid to look at patients with mild to moderate depression and listing treatment options. One treatment option was not doing anything at this time. The second was starting an antidepressant. The next was initiating talk therapy. And I did a small series in my practice of about 12 patients, and I handed them the decision aid and we would walk through the options. But before I, and this was all real, these were my patients and they were coming to me with a new problem of depression, I would guess in my mind what I thought they were going to choose.

I was wrong 80% of the time. And everybody chose either medicines or talk therapy. Nobody in that group was choosing not to do anything at that time. Now that's worse than chance, really. And isn't that illuminating? It was for me. I knew these patients, that's the trap we fall into. We think we know more than we do. We have to ask the questions. Using this simple aid really highlighted for me how my patients were thinking through things. And the same goes, that's for a treatment decision. But the same goes for a diagnosis. Years ago, I had a patient who I had done regular labs on. She had gained a little bit of weight. I sent an A1C level that test I was telling you about that tells you your average blood sugar level and can be used to make a diagnosis of diabetes or prediabetes.

And she had an A1C level of 5.8% barely over the line to pre-diabetes. I sent her a letter, maybe a little delayed, maybe it got to her a couple of weeks later, saying blood sugar is slightly higher. We'll check it in a year. Focus, as you said, on weight loss in the coming year. It's called pre-diabetes. I got a phone call from her very upset saying, this is serious to me, I don't ever wanna get diabetes. I'm going to make a major lifestyle change. And, you know, I had had the experience of so many of my patients either not caring about it or not being particularly motivated by it. And I was applying that lens to this and those experiences when in fact for her, this led to a major change. She met with a dietitian. She lost 35 pounds and sure enough had reversed the prediabetes.

Now, part of this is my own skepticism about: Is this even an illness that we need to be treating? But for her, that was an incredibly important thing. And it turned out that a friend had had diabetes and suffered a lot of complications. She couldn't imagine going through something like that herself. We probably need to be asking more about even something that seems minor to us could be a major impact for a patient. And just being aware that people are coming to things with different knowledge and life experiences, asking more questions, providing more information is probably the better approach from the physician's standpoint.

Sarah Alger:

Physicians spend a lot of time studying how to make a diagnosis. How much time do they spend learning how to deliver a diagnosis?

Dr. Leigh Simmons:

That's a great question. And it makes me smile because we have a course at the medical school in interviewing skills. This is at Harvard Medical School for our first-year students. And for years they've had a session done with a standardized patient called Giving Bad News. And so much of training and communication skills training on diagnosis is focused on how you might handle giving really devastating diagnoses in this scenario. The case they use is someone who had a treated cancer, they've developed a back pain symptom, and it's a sign that the cancer has returned...a devastating diagnosis and a patient with a painful, symptomatic condition that should be addressed in that visit.

Sarah Alger:

And I should add that a standardized patient is basically an actor who has been specially trained to play a patient in certain scenarios with medical students.

Dr. Leigh Simmons:

And then throughout residency training, those examples are used for training situations. And actually, what I think we probably don't spend enough time on are some of this more seemingly mundane situations I mentioned to you about the pre-diabetes and thinking about how can we artfully deliver diagnoses in ways that may in fact be helpful or motivating for patients. Not a devastating diagnosis, but an important diagnosis that could help them make good changes toward better health. And how do we avoid making a diagnosis when it's not necessary? How do we avoid testing a patient for cancer when they have many other competing health priorities and don't need to have that colonoscopy now that they're 82? How do we, uh, think about backing off from even giving a diagnosis? How do we make sure that we're not always pushing toward diagnostic testing, when in fact sometimes we can back off? And those are some, uh, advanced diagnostic skills to avoid overdiagnosis, actually, that I think we could improve upon.

I do think one of the issues is we spend a lot of time as medical educators training young physicians for highly dramatic situations, and we don't give enough attention nor credit to the trainees who are spending a lot of time avoiding those dramatic situations. Having careful, thoughtful conversations with patients and agreeing together that we don't have to go down that road. We don't have to make that cancer diagnosis because you have other things you need to focus on with your health. You seem to be well. We don't have to do that colonoscopy, we don't have to check that test. I'll let you know if there's something I really disagree with you on as your doctor that we must do, but I'm listening to what matters the most to you right now, and I think we can avoid checking on that because you've told me what the limits are.

Sarah Alger:

Thank you so very much for this discussion, Dr. Simmons. It's been terrific.

Dr. Leigh Simmons:

Thank you.

Sarah Alger:

And listeners, thank you for tuning in to the Proto podcast. Today's podcast was produced by Joshua Krisch, Bradley Klein, and Jason Anthony. Thanks also to our technical directors, Adam Keller and Nathan Marcus. Subscribe to the Proto Podcast on iTunes and Stitcher and follow us on Facebook, Twitter, and Instagram. Stay safe and see you next time.