Personalized Medicine and the Statistics

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Andrew Schorr:
Okay. Let's talk about two things, personalized medicine and statistics and about trials.

I went in the clinical trial in 2000, 15 years ago. And it was by connecting with other patients online that helped me find out about the trials. When the trial was offered to me, I was able to connect with other patients from the trial. I went on the Internet on a certain listserv. I said, "Anybody in this trial?" And three people raised their hands. And then I said, "Can I call you on the phone?" That gave me encouragement to move ahead. Dr. Wong, as you hear on TV commercials and things, it says your results may vary. So help us understand how we don't judge what's right for us, even participating in the same trial, on what happened to somebody else.

Dr. Wong:
Right. So I want to just backtrack one second about what Dr. Patel said, which is, it's difficult to navigate through it. Even we have a hard time with that.

And that's one of the reasons why I'm here because I believe in patient power and the ability of hooking patients together. I'm a real believer in it. That's why I'm sitting here today. But that's very important. And the things you do to hook people together are vitally important. One of the reasons why it's difficult with trials is because they open and close. And I sit on the other side, which is on my own institution; I actually oversee some of these things. We have safety concerns. So if someone has a side effect, you can understand, you might close it until you understand what's going on.

Maybe sort of let things play out a bit as to what that side effect was. I mean, so I remind folks that people are alive and other things can happen to them on trial. So if someone has a heart attack, how do you know that heart attack wouldn't have happened? But the mere fact that they were on that trial caused that trial to close. So even I sometimes pick the phone up and call her directly and say, "Is your trial open?" Well, Tuesday it was, but now it isn't, kind of thing.

What about results varying? That's an important question. The thing is that, when you're in front of that physician, and they're looking at you for that trial, what trials are trying to do is to answer a question. A thumbs up or thumbs down on that drug, or that strategy could be surgery. So because of that, we are trying to make sure we pick the patients it benefits,

and we have a list of criteria, some which are scientific, some which are blood value, some which are so on and so forth. And others, which are pathologic and looking at the specimens. And, of course, we try to sort of exclude patients where we think we could do harm to them.

So that's why when you're talking to someone, it's hard to parse through those very fine details. When you're sitting in front of that physician, that's what we're trying to go through. Our mindset is, is this the right thing for that one person who is right there in front of me? That's why different people coming through on the same trial may be rejected.

As we discover new things with how these drugs are interacting with all the things going on in that person with the cancer, we may understand this subset may do better than those. The last thing I want to talk about is guinea pig. And Dr. Patel was talking about putting in when did you have the side effects and so forth. And I'm nodding my head because that's paperwork. And that's paperwork why? Because we're held to that standard in academic centers. We all know when someone has to sneeze, and it doesn't go right. Or they had a high blood pressure value.

So maybe it is a guinea pig, but you're probably the most looked-after, culled-over, prodded and paid-attention-to guinea pig that you've ever learned of. And it's all part of what we do. And built into that are regular assessments of whether the trial is hurting or helping. So all those things are important.

Andrew Schorr:
I'm just going to tell one brief story about me. Again, I've had two blood cancers. The second blood cancer was discovered when I was in the clinical trial for a blood thinner for a deep vein thrombosis, a clot in my leg. I entered the clinical trial. It had nothing to do with cancer, because I had success with the earlier cancer trial. I said, "Oh, I like the attention. They look at you stem to stern." And while they were assessing me and looking at me 25 ways from Sunday, that's when they picked up the second cancer. So if you like getting attention, that's another benefit of being in a clinical trial. They may pick up something.

It could be your heart. It could be something completely different that needs attention and was picked up in that cancer clinical trial or whatever it may be. So I'm a big proponent of it. Dr. Patel, I want to ask you one thing about statistics. So we're in this age of personalized medicine.

So what do you say to somebody when they say to you, "Doc, how long do I have?" Or they read it somewhere. Or it was in a textbook that thank God may be outdated now.

Dr. Patel:
Yeah. That's always a difficult question to answer. We don't have a crystal ball. As you say, results vary. We don't know that this recipe of treatments is going to give you a result. And we quote numbers like oh, "These immune therapies have a 30 percent chance of working if you failed a prior immune therapy." But Martha and T.J. are not 30 percent. You're 0 or 100. It either works, or it doesn't work for you. We can get lost in giving people those kinds of statistics.

What we tell patients is, if you are eligible to get some of these modern therapies, either FDA approved or on clinical trial, because even FDA approved, it may not be the right therapy for you. If you're able to get that, the chances are you're going to do better than classic statistics. Those classic statistics were really before the year 2011 before we had agents that could move the needle forward. So I tell patients we're going to do everything we can. And most likely, we're going to do better than what you're reading out there. We just need to see what's right for you.

Dr. Gimbel:
One thing I want to add is it's not uncommon that I'll see a patient with an early melanoma who will come in. And I'm looking at their pathology saying, "Oh, curative, no problem." And I walk in the room, and they're shaking in their boots, because they've read everything online. They've been told that they have a stage IV melanoma. And then they're kind of putting all the information together. They don't have a stage IV melanoma. They have a level IV melanoma when it's been misinterpreted by someone who has told them.

So there is a lot of misinformation that gets either told to a patient that they look up online. And it's trying to put all that together. So while doing literature searches and looking at the data out there is extremely useful and educational, you always need to be careful about what you're actually taking away from that.