Dr. Johanna Shapiro: Part 2

[00:00:00] **Christine Ko:** Welcome back to SEE HEAR FEEL. Today I have a part two with Dr. Johanna Shapiro. Just in case you didn't have a chance to hear her first episode last week, I will repeat her bio here. Dr. Johanna Shapiro has a PhD, and she was Director of the Program in Medical Humanities and Arts in the Department of Family Medicine at the University of California, Irvine School of Medicine. She's a Professor Emerita in Family Medicine and received her PhD from Stanford University. Her research interests have been focused on the patient narrative and the doctor patient relationship, communication skills, and literature and medicine. She has written extensively on teaching empathy and medical education, and I will put a link to one of her articles in the show notes, and she is also a poet, and I will put a link to one of her powerful poems in the show notes as well. Welcome to Dr. Shapiro.

[00:00:52] Can you talk about why patient stories are so important?

[00:00:56] **Johanna Shapiro:** Yes. I would love to, since I've devoted a lot of my life to this. The human animal has been called *homo narrans*, right? The storytelling human. That's what our species is. So, as I mentioned, I think stories make sense of who we are and what our lives mean.

[00:01:19] One of my favorite quotes is from the novelist and essayist Barry Lopez, he wrote something to the effect that sometimes it's only our stories that are holding us together.

[00:01:32] **Christine Ko:** I remember at a grand rounds, which is like a lecture setting where we're talking about patients and patient presentations as a group of faculty members in dermatology, that one of the residents once was giving kind of the standard presentation, meaning a story from the medical perspective of what the chief symptom was or symptoms. And then you present past medical history and family history and social history and like what we call review of systems. It is a narrative in a way, but it's very structured, and there's certain elements that are supposed to go in, and there's a certain order.

[00:02:09] When she was starting this presentation, early on, after the first three sentences or something, all of a sudden, unusually, she put in: this patient is dying, you know, of leukemia, is about to graduate from high school, and just wants to get to graduation and the parents want that to happen too.

[00:02:32] And it was very early on, it wasn't like down in like the social history part, where you talk about things like that. So it was raised in importance, in a way. This is actually the most important thing right now about the patient, and she put it front and center. That kind of thing shows how much importance the patient's story does have.

[00:02:54] **Johanna Shapiro:** That is such a beautiful story. What you've shown is that not every story is a novel, right? One of the most famous short stories in literature, which is attributed to Ernest Hemingway, it goes like this: for sale baby shoes never worn. In that book, *Being Mortal*, Atul Gawande's wonderful book, he talks about how life consists of a lot of rather routine, even boring stretches, punctuated by events that define us.

[00:03:33] And I would say that for that resident's patient dying of leukemia, her graduation helped define who she was. So hearing a patient's story is not necessarily about getting the whole nine yards from birth to where they are in their life now. It's about teasing out those life defining events.

[00:03:54] **Christine Ko:** It's so true. Stories don't have to be long. Even in a healthcare system right now where there isn't enough time, the story can actually be short and yet really meaningful. You say that some stories, some narratives, are more comfortable for physicians than others. Can you talk about that a little bit?

[00:04:13] **Johanna Shapiro:** Not just doctors or patients, but we all make assumptions about what a good story is, right? We like certain stories. We don't like certain other stories. So many years ago the Canadian medical sociologist, Arthur Frank, identified what he called the restitution story, okay? And restitution kinda gives away the punchline here. But basically, the way a restitution story looks is like this, the patient is healthy, the patient gets sick, patient goes to the doctor, diagnoses the patient, and prescribes this wonderfully efficacious treatment. The patient dutifully follows the doctor's advice and the patient recovers, right? So in the story, illness is this very discrete, temporary biographical disruption. The illness interrupts the patient's story, but the end result is that the patient returns happily and seamlessly to their pre illness life. It's all about: find the problem and fix the problem. Everybody loves that story, but the point is that it's not the only story out there. And when you try to impose the conventions of that story onto other more messy stories, it just doesn't always work. More complicated stories require not only medical listening, but narrative listening as well.

[00:05:48] **Christine Ko:** I remember being taught medical listening, how to get the facts that I need to create that medical story. I don't think I've ever been trained in narrative listening, and I don't know what it is.

[00:06:01] **Johanna Shapiro:** What you said is very telling about medical listening because it is very physician driven. That's not necessarily a bad thing, but it's something we have to recognize. We may think the patient is telling their story, but it's already shaped so much by these structured questions that the physician asks because it has this very specific goal, which is diagnosis and treatment, which again is a good goal. But its goal is to fix the problem. And so it's something that in a way is done to the patient, extracting those relevant pieces of information and discarding everything else. You're listening for certain things, fever or pain or this, and if they say, *well, my grandma told me this*, you're like, *no, that is just not to the point*. So it's easy to say what medical listening is. To be honest, it's a little more difficult to define narrative listening. But I'd say that it involves finding the story that matters to the patient. And I think the medical listening is finding the story that matters to the doctor.

[00:07:11] Now there's overlap there. You might be interested in whether my skin lesion is squamous cell cancer. I'm interested in that too, but I may also be interested in, if things don't go well, will I ever be able to play guitar, which is one of my passions.

[00:07:28] Narrative listening asks the physician to spend just a few minutes simply being present with the patient's story. Not saying, oh, you have this problem. Here's my thoughts about how you can fix that. But to say, *this is a hard story to live every day*.

[00:07:47] That they are present with the story of helplessness or the story of fear or the story of confusion, whatever the patient's story is that they can accept that. Not be frightened themselves by it, not start to run away from it because it's so overwhelming. And I think we all have those tendencies.

[00:08:09] Narrative listening also involves recognizing that patients have the right to tell their story in their own way. You want to be able to respect and honor the patient's story. In essence, it means being willing just for a few moments to become a meaningful part of the patient's story, rather than imposing a medical story on the patient.

[00:08:35] **Christine Ko:** I appreciate the way you've described that. What are some of the ways that physicians can listen narratively better?

[00:08:42] **Johanna Shapiro:** I think doctors are making choices all the time because they don't have enough time. We know that if we just pause and take a breath and settle down, then actually we don't lose much. We become, if anything, more efficient, more focused, less scattered. And I offer just a few very concrete sentences that if physicians can insert a couple of them, either explicitly through actual words, or just through their tone, their nonverbal behaviors, it reassures patients that their story is being heard rather than just their symptoms. So, things like, *I'm hearing your story*. I hear your story about wanting to graduate. *I'm grateful that you have chosen to entrust me with this story. I want us to work together as we think about your story*. And finally, *I stand with you in your story*. By that, I don't mean that you agree with everything the patient has told you but that you are saying, *I am on your side here and we will figure out a way to go forward in your story*.

[00:09:58] If we think about ways that we can give those messages to patients, then that is part of what narrative listening is about. And you can see that from a medical listening standpoint, all of those things are irrelevant: what's important is telling the patient, well, these are the real results of your test. This is your diagnosis. This is the plan going forward. Which also very important.

[00:10:22] **Christine Ko:** Do you have any final thoughts about narrative versus medical listening?

[00:10:27] **Johanna Shapiro:** I do just wanna say something about the possible benefits of narrative. When the physician is listening narratively, to the patient, the patient feels less alone. And we do know from empirical research that isolation and alienation are very common in people who are ill. That they just feel alone. Narrative listening can help counteract that. Narrative listening helps patients feel respected as far as their understanding of their problems and their own priorities about why it matters that they have this particular illness. Obviously, I think when you feel seen and heard, it makes you trust the other person more, in this case, the physician. Trust is foundational to the doctorpatient relationship. Narrative listening also gives patients the opportunity to collaborate, to be a collaborator with their doctor because it's saying I have certain expertise about medical stuff, and you have expertise about who you are and what your story is, and these are treated equally.

[00:11:37] I also think there are benefits to physicians for listening narratively. Narrative listening helps the physician understand their patient more deeply, sort of see them as a whole person rather than the diagnosis. I know a lot of the doctors that I've worked with for decades will say that some of the greatest rewards in the practice of medicine is in the connection that they have with their

patients. Narrative listening also makes doctors better advocates for their patients. If you don't really understand anything about your patient, it's hard to really advocate for them. And so finally, I think that all of these factors hopefully will result in decreased physician frustration and enhanced fulfillment of their clinical responsibilities.

[00:12:26] Ideally it's a win-win for the patient and the physician.

[00:12:30] Christine Ko: Absolutely. Thank you so much for talking with me.

[00:12:34] **Johanna Shapiro:** This was a great experience. I'm very grateful to you.

[00:12:37] **Christine Ko:** Thank you so much.