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SPEAKERS Madge Kaplan, Paul Batalden, Julie Johnson, Chandlee Bryan

Madge Kaplan 00:00

Welcome to the Power of Coproduction, a podcast series that explores the lived experiences of patients and professionals who are redesigning healthcare service to achieve better health through mutual respect, collaboration and science informed practices. Your host and guide is Paul Batalden, Professor Emeritus of the Dartmouth Institute for Health Policy and Clinical Practice and guest Professor Jönköping Academy. The Power of Coproduction is produced in partnership with the International Coproduction of Health Network (ICoHN), the Dartmouth Institute, Jönköping Academy and the Health Assessment Lab. In Episode Three, "Let's get real...the way things are", Paul is joined by Julie Johnson and Chandlee Bryan. They discuss navigating the as-is system of health care as patients. When the experience isn't what you expected or needed, taking the time to appreciate exactly what's wrong is a crucial step in coproduction. Here's Paul.

Paul Batalden 01:05

Today, we turn our attention to understanding the healthcare service system as it is actually experienced by those trying to use it. This knowledge is helpful if we're to make a bridge from current performance to better performance. To help in our consideration of the as-is system, we have Julie Johnson as a guest. Welcome, Julie, thank you for taking the time to be with us. You have a story of a time when the as-is health care system became clear, as something of a surprise. Tell us about it.

Julie Johnson 01:41

Thank you, Paul, it's really nice to be here with you. And I appreciate you taking the time to talk with me about this story. So my story is from several years ago, and it involves me as a caregiver to my husband. And this was just at the very beginning of our journey of his experience with colon cancer. So in August of 2016, he was diagnosed with stage three colon cancer. The story that I want to share with you is about the diagnosis and how that played out for us. During that summer, he had gone from being very healthy, very vibrant, to suddenly experiencing a lot of abdominal pain. And we were concerned about what was going on, we kept kind of waiting it out thinking it was just a stomach bug or... it continued. And so he started to become very concerned, as did I, and so he was scheduling appointments with his primary care doctor who kept trying some different approaches to dealing with it, thinking that he picked up a bug. Finally, we set time for him to have a colonoscopy. And so this was really after a month of trying to get in for a diagnosis of what we were starting to think was a serious problem. And we were concerned and aware enough at this point that this could be some bad news that we were going to get. But we didn't know yet for sure. So we went to the day of the colonoscopy. And as you know, the prep can be very difficult for people, more so than the

procedure often. And he had a particularly difficult time with the prep with drinking the liquid. And so he felt pretty miserable. That morning of the colonoscopy, we went to the appointment, and I helped him get checked in. And then I headed out to my office because I worked in the same facility where he's having the colonoscopy, I barely got to my desk and sat down when they called me and asked me to come back. And that was a red flag for me, definitely, because it's like that wasn't enough time for them to complete the procedure. So I was on alert for the potential of bad news.

I went back and they invited me to come back to where the recovery cubicles are. So all the patients are in their individual little recovery stations, and the curtains are drawn around each station so people can have some privacy. And they led me to my husband, and he's on the bed. And he's very groggy, as you would expect for someone who's just had a procedure, you know, but he's starting to drink some water and eat some crackers. You know, right after I got there. The nurse comes by and opens the curtain and peeks in and says, "Have you talked to the doctor yet?" And I said, "No, we're waiting to see the doctor, do you have an idea of when she'll be able to come talk with us?" She said, "Well, she's in a procedure. She will be here very shortly though." And then she turns, closes the curtain and walks away. Within a few minutes. She came back and said, "Have you talked to the doctor yet?" And I said, "No, I haven't talked to the doctor yet."

It's frustrating because it's like, well, I'm inside this little curtain cubicle. I can't see anything that's going on outside here. You know, surely you have a sense of where your colleagues are in the different procedures they're involved in... what's going on in the schedule during this day.

She comes back a third time, pulls back the curtain and says, "Have you talked to the doctor yet?" And I said, "No, not yet." And she said, Well, it's time for me to sign out. I need to leave and I need to give you these discharge instructions. They're the same for people with cancer as for people who don't have cancer," and she hands it to me, and she walks off. And I'm standing there, and I'm like, we're looking at these papers, and there were written summaries and also photos, you know, pointing out what they found and where the tumor was in his colon, and my husband saying, "What, what did she say? What did she say?" And it hit me at that point that I was going to be the one who told my husband that he had cancer.

And I turned and I walked over to him. And I say, "She gave me the discharge instructions, and you have cancer." I remember my hands shaking, as I told him this news, it wasn't the way I ever imagined receiving a diagnosis of cancer. And this was probably, if I think back about the news that we have received during our marriage, or even as individuals, this was one of the most significant pieces of information I had ever been given. And for her, this was just part of her tasks that she had to do before she signed out to leave her shift. We were standing there, we still hadn't talked to the doctor, we still didn't know what to do next. Even though we both work in healthcare, neither of us knew what the next steps were, what to do with this news and how to move forward. We just had been discharged, essentially, from his procedure without talking to the doctor. And without knowing what to do. The first thing I did was text a colleague of mine, who was in the hospital working as a physician, and he came to us immediately. He

came to us before we had a chance to talk to the physician who did the colonoscopy. And the first thing he did when he walked in, he said, "I'm so sorry to hear this." And he reached out and he hugged me, that was what I had been looking for. Because I had somebody to reach out to for support. That's what I was able to get. It wasn't the way the news was delivered to me. The physician eventually came, she opened the curtain and she said, "I am so sorry, that this happened in the way that it happened. It's not supposed to happen that way."

Paul Batalden 06:58

Wow. What a story. It's clear that the way that the as-is healthcare system that you were experiencing was very different than the way that the professionals who were involved thought the system had been designed to work. It was really an unfortunate occurrence. Thank you very much for sharing this story with us.

Julie Johnson 07:25

Thank you, Paul. One thing that I want to highlight and I think you raise an interesting point about this as-is system. You know, we talk a lot in health care about what the as-is process is. We've been talking about that from the perspective of the providers. It was clear to me that the nurses as-is system wasn't aligned with the physicians, even though they're working in the same clinic. But what was completely missing was the as-is experience of the patient. And I think that this experience highlighted those gaps.

Paul Batalden 07:56

It's just key to the coproduction of healthcare service. Thanks.

Improving healthcare service involves a deep understanding of the healthcare service system as it is actually experienced by those trying to navigate and use it. This knowledge is helpful if we're to make a bridge from current performance to better performance.

To help in our consideration of the as-is system we have Chandlee Bryan as a guest. Welcome Chandlee, thank you for taking the time to be with us. You have experience with the as-is healthcare system. Tell us about it.

Chandlee Bryan 08:45

So in 2013, I was diagnosed with multiple sclerosis. Multiple sclerosis is a disease of the brain and spine, and it's a neurological condition. And it's really hard to diagnose because you need an MRI ordered and you need, often, a spinal tap and MRIs of the brain and the spine. I found it really hard because MS has so many different symptoms, it affects people very differently. So for example, one of my MS friends has trouble with their hearing that's caused by her MS. She can walk a little bit faster than I can. She has no trouble hiking, but again, the hearing when I visit with her I have to speak up a little bit louder. Other persons with MS that are in my social circle have mobility issues, which I don't have, but there are a lot of symptoms that you can see but many of the symptoms with MS you cannot see.

And so one of the things that I have been struggling with is how to make the best use of my time when I meet with my health care providers and how to make sure that I feel like things are being documented so that I know how to follow up. And one of the challenges that I have sometimes going into my appointments with my providers is oftentimes I need to see specialists or to figure out who to talk to about different things. As my neurologist says a lot of times he gets pushback from primary care providers who say, well, you know, that symptom is probably related to the person with MS condition. And he will say, in turn, you know, we don't work with that in our clinic. So a classic example is 80% of people with MS have bladder and bowel symptoms. But when you go to see a neurologist, you're never asked for a urine culture. So there's some things that you can't necessarily see. And it's really important to gather that information.

And when I go to see one of my neurology practices, one of the things that has been a challenge for me has been figuring out how to have that conversation with my provider. I had some mis-assumptions that I think were probably in place for the first four years that I visited my local neurology clinic, and I'm going to tell you about sort of my experience with that, and the as-is healthcare system.

So when I have an appointment with my neurologist, every six months, I receive some pre-visit instructions. And those instructions are to complete an assessment called the MSIS 29, which asks you a series of questions of, in the past two weeks: How has MS limited your abilities? And how has it bothered you? And it's required before you start the appointment. So I either do that in advance of the clinic appointment, or I do it when I arrive at the neurologist's office for an in person appointment on an iPad. And I always assumed that when I was going into the clinic that that was going to form the basis of my conversation with my neurologist. So for example, if I mentioned higher scores on "my body's not doing what I want it to, I feel like I need to go to the toilet urgently at night", though it never asked me specific times, you know, "I've had problems sleeping or stiffness". I always assumed that my provider was seeing that before I came into my clinic appointment. I assumed that my responses to the questionnaire were really driving the conversation and allowing my neurologist to work with me to see like, how am I doing this time compared to our last visit? Are there areas of improvement? You know, in terms of my sleep? Is my score a little bit better than it was last time? Where am I falling behind? And what steps do I need to take? But recently, I was given the opportunity to talk to my neurologist about the assessment. And what I learned was that essentially, they just get one aggregate score from that overall visit. So that one score from those 29 questions is what's logged into my records. And they're not even seeing it before the appointment. So the assumption that I had of what was going to form the basis for that conversation was essentially a slip between cup and lip, you know. I went into the clinic appointment, saying, "Okay, I've already downloaded sort of what's been bothering me recently. So I'm ready to talk about this. They have that data, and they've been able to look over it. And so that's going to form the basis of our conversation."

Paul Batalden 13:48

So the assumption about the details and the care with which you've tried to document the substance of the conversation that you hope to have... that has now been truncated by the methods of analysis of the form, so that it actually loses the information that you've provided.

And so in essence, you haven't provided them that kind of detailed information, if the aggregate score is the only signal that the professional-person is looking at.

Chandlee Bryan 14:20

That's right. And it's been very frustrating for two reasons. One is that I really pride myself on trying to be the best person with MS or what's often referred to as a "patient" as I possibly can. So my father is actually a retired infectious disease specialist and when I first got diagnosed, he drew up what I now know is what's called an options grid for me to go over with my neurologist to look at medication options and really think about how to organize my information and I feel like when I started to get that questionnaire before I went into my appointments, it made me relax because I felt like okay, they know the questions to ask, you know, they're asking me questions about my symptoms and about signs and things that are invisible and things that are visible. And so we're going to have that as the basis for our conversation. So I don't need to spend as much time as I did initially preparing for those conversations with my neurologist because they're ready to address those issues.

Paul Batalden 15:25

Thank you so much for sharing this example of the difference between the system we assume and the system as it actually is.

Paul Batalden

With the help of Julie and Chandlee, we've been exploring the as-is systems. In their stories, each has helped us see that the healthcare system we assume is not always the same as the healthcare system as it actually is.

If our aim is a better system, we need to work from the realities of the current system, or our efforts at change and intervention will not amount to very much.

If we understand healthcare as involving a service-making logic, we know that both parties who are involved in making the service will do better if they share an understanding of the way the current system actually works and what happens when it doesn't work as assumed.

How might we improve our understanding of the as-is system? First, the people who are trying to navigate the journey in the actual system can offer us insights if we ask them. If we want them to share their observations and experience, we should create a safe space within which we can ask and in which we can listen carefully. Secondly, sometimes it helps others to share our understanding if we make a picture of the process, like we might do with a flow diagram. If we do that, we need to include all those involved in the real workflow, and to itemize what the various actors contribute to each of the steps in the process. If we annotate that picture, with the help of feedback, we can also see the portions of the process that may have emotional overtones because it's frustrating, or a source of fear, or a source of satisfaction and joy. Third, because boundaries of any process are arbitrary, it helps to decide and define the boundaries of our interest. Fourth, some elements in the process are common for all patients and professionals. Some elements are variably supportive of the journey in the system. Those that

are supportive, could be thought of as support processes, whereas those that are in common could be thought of as the core process. Fifth, John Ballatt and his colleagues in the UK have suggested that we should examine the journey as if we were wearing glasses that had two lenses, one that helped us see the task that was involved, and the other that helped us recognize our kinship as fellow humans 5 Transcribed by <https://otter.ai>involved in the shared work of healthcare service creation. Sixth, naming the journey, or the system, can help us clarify the aim of the steps and the relation of that aim to the context and situation in which we are engaging the system. We know that this as-is system is a system of this or that purpose. And lastly, when we discover differences between the assumed and the as-is systems, we're tempted to engage in a quick fix and try to install a remedy. That may be helpful, but integrating this insight with an understanding of the lived reality of the persons we sometimes know as patients and those we sometimes know as professionals, in addition to the science that can inform our work, will usually allow us to design an even better alternative to test.

So we're grateful for Julie's and Chandlee's stories, and thank them for sharing them with us. Thank you. I'm Paul Batalden

Madge Kaplan 19:47

Thank you for listening to episode three of the podcast series, the Power of Coproduction with Paul Batalden. On Episode Four, "Allow me to empower you: the wisdom of self care," Paul will be joined by Fiona Jones. They'll discuss how health professionals can improve their ability to support self care. All podcasts in the series, including an overview of coproduction are available at ICoHN that is ICoHN.org/podcasts. The website is where you'll find supplementary materials, guest bios and brief profiles of the production team. You can subscribe to the podcast series wherever you get your podcasts. Thanks for listening.