E01-final Coproduction-is-Everywhere

Mon, 5/30 8:02PM • 18:32

Wed, 6/22 8:30AM

SUMMARY KEYWORDS

coproduction, patients, surgery, health, cf, visit, healthcare, david, paul, kathy, surgeon, shared, story, cardiologist, team, trust, doctor, reception desk, jack, telehealth

SPEAKERS

Madge Kaplan, Paul Batalden, Kathy Sabadossa, David Leach

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 of 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 one, Coproduction is Everywhere, Paul helps us become better observers of coproduction when it happens in healthcare, especially its look and feel and benefits. Paul is joined by Kathy Sabadosa and David Leach. Here's Paul.

Paul Batalden 01:00
Welcome. Today we're discussing with Kathy Sabadosa and David Leach how the coproduction of healthcare happens. Kathy, can you tell us about a time when healthcare seemed to work well for someone that you know very well.

Kathy Sabadosa 01:15
Thanks, Paul. Thanks for inviting me today to share. I'm going to talk a little bit about my son Jack. Twenty-one years ago, he was diagnosed with Cystic Fibrosis(CF) at birth having meconium ileus CF. Life expectancy at the time was early to mid 20's with a lifetime of two hours of daily treatments and many patients having one to two hospitalizations a year for IV treatment.

Now fast forward to November 2019. A modulator that corrects the basic defect of the CFTR gene that causes CF in 90% of patients is approved by the FDA(Food & Drug Administration). As more and more patients start taking this modulator known as TRIKAFTA, it's having a dramatic impact on their health. There's no more coughing, lung functions are climbing. People headed to transplant are removed from waiting lists as they regain lung function. People with CF are having a level of health they've never thought possible.

March 2020 COVID-19 shut down and pivot to telehealth care. Jack is being seen by a care team where he's going to college. He had an in-person visit scheduled for the week of the shutdown which was canceled and he had to move back home to shelter in place with us. His care team here where we live reached out to him a few weeks upon his return to schedule a telehealth visit check-in. All I can say is, Jack loved it. This visit required no time off from school, no travel to a clinic, no waiting and no fear of picking up an infection from the clinic. It was the first visit he experienced without having it all being focused on the diagnostic testing and on screening surveys that he usually has to complete, no long list of symptoms or standardized questions. The team was not steeped in reviewing data and discussing results but instead leaned into really listening to him describe how he was feeling, asking more questions about his symptoms, sleep patterns, diet and exercise. He and the team focused on his well being and how he was coping with being home and having his life being disrupted. They also talked about the risks of COVID-19 to people with CF, they discussed his plans for classes and staying active. With the diagnostic data not distracting during the visit, it felt like a CF visit was more like a regular checkup for him that any other adult might experience. It gave him more time to cover who he was as a whole person and his well being and what's going on in his life.

It was the perfect storm for him: telehealth,TRIKAFTA, his life is stable, his health is stable. He's thinking about how is this new mode of care? And I'm sure his care team is thinking about the same thing. What's that gonna look like for him as an adult? Let's see,he's wondering: Can this be my future? How do I make it part of my everyday life?

Paul Batalden 04:07
Wow, what a story. That's just a phenomenal story. Kathy, as you reflect on that, what did the doctor or the health professionals have to do to sort of create this,

Kathy Sabadosa 04:20
The health team had to, first of all, adopt all the technology. And that was actually more of an uphill battle for them than it was for him, you know, being a young adult. He's very facile in online meetings and how that world works. His care team had to get used to interacting with him in a virtual environment. And they had to get used to sort of driving blind, right, all of their usual lung function tests and lab cultures weren't available to them in this new virtual space. They instead had to lean into him as the captain of his own ship to tell them how he was feeling and what his health was really like. He was able to, I think, be more descriptive and active. (It was) his visit, and the care team had to really listen to that, and to let go of some of their tools and staring at their EMR (electronic medical record) data and instead really look at him and who he was and how he was doing.

Paul Batalden 05:12
So as they were crafting the path forward together, what happened? What was the contribution that the professionals made? And what was the contribution that Jack made?

Kathy Sabadosa 05:22
You know, he's now living back home with us again, and really had to figure out how to live in this new environment of his. How he was going to exercise, take care of himself, and really begin to open up new conversations with his care team, maybe about how he was coping with the pandemic and the

isolation and being cut off from friends and just really digging deeper into his emotional health and being more open with that. And the care team on the other side, had to think about how often they should interact with Jack, right? How often do they need to really check in? There was such a rigid schedule of quarterly visits and, you know, lab function tests being done. And they had to start to unpack that and say, “Well, do we really need to check in that often?” And, “If we do check in, is it just a casual email to say how things are going…a text that doesn't need to be a full on visit. They have to learn this new dance together, both with him being so healthy and living in a virtual world. So it's been an adjustment for both sides, but a good one.

Paul Batalden 06:21
Thank you very much. So David, tell us about a time when healthcare worked well for you.

David Leach 06:27
Thank you, Paul. And thank you for doing this. I hope we all learn a lot about what happens when things go well.

My story is about aortic insufficiency, and valve replacement with a pig valve. I was diagnosed in 2000. My valve was replaced in 2016. And I'm now doing very well and take only a baby aspirin a day. It started when I was working in Chicago, and my murmur was detected on a routine exam. And then the next phase, because that was fairly routine, was when I retired and moved to Asheville, North Carolina, and I needed a new cardiologist and my Chicago cardiologist had trained with someone who worked there and thought highly of him. I did some research on public databases and he seemed to hold up under scrutiny. So I went to see him.

He had been trained at Duke. And at that time, Duke thought that surgery early for aortic insufficiency was the right approach. And so he told me, “I think it's good to do surgery early.” I was trying to crack my way through the guidelines and find a real person. And so I replied, Well, I'm sure it's good for you. But is it good for me? There was this pregnant pause when we looked at each other and then started to laugh. And out of that human interaction, we were able to develop a path forward that we both negotiated, that involved data, and that would determine when I would be operated on.

So I went like that for eight years. And the data showed my heart was doing fine and did not yet need surgery. And then I was on a virtual call with the finance committee for a board I was on and my heart rate suddenly jumped to 180. My mother taught me to never show anything but equanimity. So I didn't let the finance committee know that and we conducted the meeting to its end. I laid down and I tried a few maneuvers to break the rapid heart rate, but nothing worked. And so I eventually went and had to be converted with a chemical called adenosine. That happened again and again. And I came to trust the system. And the most dramatic example, I showed up in the ER at the reception desk and said, I have supraventricular tachycardia and I need to be converted, and I timed it: six minutes from the reception desk to successful cardioversion. So I developed trust in the system that also introduced me to an electrophysiologist, who did an ablation of a few aberrant pathways, and I've had no recurrence of the arrhythmia. But we also discovered my left ventricular volumes were increasing. And so it was time for surgery.

And thankfully, the Society for Thoracic Surgeons post outcome results for all the major practices that do aortic valve replacement. And although I could have gone anywhere in the country to have the surgery, it turned out my hospital in Asheville was very good. And so I saw a surgeon there, and I was candid with him. I told him I was grateful I had a disease that could be cured. I was grateful that he knew how to do it. And that I was terrified of what I had to go through to have it done. He paused. People didn't usually talk to him like that. And we again had a human interaction. He was spectacular. I had the surgery. I met the anesthesiologist and I told the anesthesiologist, you know, it's very rare for patients to die on the table when it's the surgeons fault. It's almost always the anesthetist's fault, and are you any good? And he laughed, and I laughed, and we again, touched the human in each other. I had spectacular anesthesia, spectacular surgery, and I went home on the third postoperative day. I should mention the ICU nurses were very good. It was helpful that my wife Jackie was involved in all these relationships, and that they came to trust her. And so when I said I wanted to leave the hospital early, they trusted that, and I got very good homecare. So that's a little nugget of my story.

Paul Batalden 10:40
So as you think about that, David, and that's just an amazing kind of example, it seems to me, what did the professionals who you saw have to do to make it work?

David Leach 10:51
I think they had to not only have wide experience with aortic insufficiency, but they had to reflect on their experience, so that they knew what the patterns were. And they could tell whether I was in bounds or out of bounds. But most importantly, they had to open themselves up as humans. And we could have a human to human interaction, rather than just totally data driven interactions. And that's what I think doctors in all circumstances offer, the computer isn't going to die, but the doctor is, and the patient is and there's a shared vulnerability that enables genuine trust and appreciation of each other that can develop.

Paul Batalden 11:31
What do you think helped create that relationship?

David Leach 11:34
I thought it was a sense of humor. I tried to crack the nut and find the human inside. So the comment I gave to the cardiologist, and if you could see the look on his face just sort of stunned him. And then he had no option but to sort of respond as a human being. And the same, but with a different approach with my surgeon and with the anesthesiologist. Another thing they bring is an ability to improvise. So during the surgery, they had anticipated I needed a certain sized valve, it turns out, I needed a bigger valve, they had that covered, they sort of had figured that out ahead of time. And so it was not a big deal. Having enough experience and willingness to improvise. That's an important trait. So willingness to be human, willingness to improvise, reflecting on experience, I think those are the things that I noticed that they brought.

Paul Batalden 12:24
Powerful insights. So as you heard Kathy's story, David, and Kathy, as you heard David's story, Did anything come to your mind that you'd like to comment on?

David Leach 12:35
Well, I was very moved by Kathy's story. And I'm very grateful that she brought it to a public arena, the amount of deep intelligence that's underneath the 1000s of improvisations she's had to make and her child and the doctors along the way, it is said that love is willing the good of the other. And there's a lot of “willing the good of the other” going on, which binds all this coproduction of healthcare together.

Kathy Sabadosa 13:05
I agree with that, David, and when you were talking about your story and your encounter with the surgeons and bringing humor to break into the humanity, I think that's so important, right? It's cracking that tension and finding that common spark of humanity that we share, right in healthcare, that I found so powerful, and then building a relationship of trust. You know, Jack and his CF team has the luxury of doing that over many visits in many years. And you David, you know, as you started to get to know your team and find comfort in them. building that relationship of trust, I think is key to good care.

Paul Batalden 13:44
You have a sense that at a base level we understand what coproduction is, when we describe what good care is. And this has been a wonderful opportunity for many, many people to learn from your experience and your noticing of coproduction. Thank you very much.

As we listened to Kathy and David respond to my questions, we saw that describing and noticing the coproduction of healthcare is sometimes easier when we're asked to describe an example of good healthcare service. Most of us already have an intuitive sense of the importance of coproduction in good health care services. Telling a story like they did offers the possibility of even more information transfer among us as patients and professionals. So the stories help us to learn more.

And as we heard from them, they were dealing with health as something that they or their loved one owned and were personally active in. It hadn't been outsourced to someone else like a professional. The work involved in creating or making a healthcare service involved a relationship and some activity. And these two were held together and enabled by knowledge and skill and habit, a sense of shared power and a willingness to be vulnerable. That included and enabled trust and respect, honesty, and even shared humor. Kathy and David were both able to describe active participation by both parties: themselves and the professionals who together were making the service. But sometimes this shared work involves times when it's harder to see the contribution of one of the two parties involved. For example, a patient may be present but unconscious, or the memory of a doctor's previous words not currently present, can become proxies, or the form that one of the parties takes in this shared work of coproduction.

Quality Improvement as we have known it commonly focuses on an activity, as if it's a product being made. And over the years, we have sometimes measured what was easier or more convenient to measure, incurring the risk of distorting the overall service. For example, when we measured minutes elapsed from door to balloon for a patient presenting to an emergency room with cardiogenic chest pain, we sometimes took that measure as a good general reflection of the service quality. Both Kathy and David shared the shifting contexts for the coproductive work, which in some ways highlights the

importance of relationship and shared agreements on the actions actually taken. These same ideas are at work when a group of people come together with another group of people and together they are coproducing services at scale. Our thanks to Kathy and David for sharing their stories of how coproduction happens. The series continues and as we move forward, in each of these podcasts, we will dig into many of the details and ideas that they introduced. Thank you. I'm Paul Batalden..

Madge Kaplan 17:43
Thank you for listening to Episode One of the podcast series The Power of Coproduction with Paul Batalden. In Episode Two, The Person Will See You Now, Paul will be joined by Serena Chow and Lotta Arvidsson to discuss developing an understanding of the lived reality of the person we sometimes call a patient. All podcasts in the series, including an overview of coproduction are available at ICoHN, that's 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.