# E09-pbbStories-clarify

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**SPEAKERS**

Madge Kaplan, Paul Batalden, Kathy Kirkland

**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 a 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. On Episode Nine, “Stories Clarify”, Kathy Kirkland shares the way she uses stories and storytelling to integrate different ways of knowing. Here's Paul.

**Paul Batalden** 00:53
Welcome, we continue our exploration of the various streams of knowledge, skill, and habit that come together and inform the coproduction of a healthcare service. Today, our focus is on how they come together, these various streams. Dr. Kathryn Kirkland of the United States is a physician who is specialized in caring for persons who are dealing with serious illness. She has helped persons who sometimes are in the role of patient, sometimes in the role of family member, sometimes in the role of professional and so on. She will help us explore some ways she deals with situations and people who are trying to make sense of what they are facing, integrating some of these different ways of knowing. Thank you for being with us, and welcome, Kathy.

**Kathryn Kirkland** 01:51
Thank you, Paul. It's wonderful to be here.

**Paul Batalden** 01:54
Is there a story from your work that comes to mind that would help us understand?

**Kathryn Kirkland** 02:00
Sure. There’s, I'd say, hundreds of stories, but let me tell you about a patient and a patient's family: I'll call him Peter. Peter was a hard driving executive who liked to work on his house on the weekends.

And Peter, unfortunately, was alone when he slipped on a ladder, where he was fixing his roof, fell and had a very bad brain injury. I met Peter's family after he'd been in the ICU (Intensive Care Unit) for probably a little more than a week. They were getting ready to make a decision about whether or not to place a feeding tube (in Peter). So I went into the room, and I met a wife and two adult children. I think the first thing they said to me was, “Welcome to our nightmare,” obviously having a family member who was at that time lying unconscious on the bed, still on a ventilator, not really responding to anything except maybe painful stimuli. So I asked them to tell me about what was going on. And they told me the story of how he had fallen. And I asked them what they were hearing from the doctors. The doctors said that it didn't look like he was waking up, that he wasn't responding to commands. But that there was some good news too:, that he was about to come off the ventilator and that it was time to put in a feeding tube to give him nutrition so that he could continue to heal. As they told me this story, the daughter became tearful, and said, you know, he's not waking up; if he's going to be a vegetable, we don't want to keep going with this. We promised him that we wouldn't do something like that. So I asked them what they were hearing from the neurologist and they said, all the neurologists say that it's going to be a long road ahead, but that he could do “okay.” So I responded, “Wow, it sounds like it's going to be pretty important to know what the neurologists mean, when they say he could do “okay,” so I can help you find out more about that. But in the meantime, tell me a little more about your dad and your husband's life.

So they started to paint this picture for me of this intense, fairly self reliant man, someone who has worked hard all his life, to some extent to the detriment of his family, spent long hours at work, tended to stay for meetings after work, come home late, and then take off on the weekends to a family farm where he kind of liked taking care of the place for himself. And then they started laughing about this addiction to *The Wall Street Journal*. They described that he escaped behind it every morning at the breakfast table. The son started to remind the sister of how they would poke at each other and sort of cause trouble and bicker and he was oblivious to it all, as he was behind this newspaper. So then I asked them, “What do you think it would be like for your dad, your husband, if he wasn't able to climb a ladder, again, if he couldn't do his own repairs on the house, you know, if he physically couldn't recover to that level from this injury?,” and they thought about it, and they said, they thought that would be hard for him. But they also saw him as a determined person who could probably take on a challenge, even a serious disability if it was physical. So then I moved on to a little harder question, you know, what would it be like if he couldn't regain his ability to think, to know people, to talk, to read? Do you think he could live without this daily dose of *The Wall Street Journal*? And at this point, I've seen his brain scan, and I've seen the look on the face of the neurologists, when they were visiting earlier, I know that this is a severe injury, and that likely that there's going to be significant impact on his ability to do these things. And so it was really important to me to push this as a “hypothetical” with this family, if he was physically disabled, but able to be physically present with you, but not able to communicate or to read, how would he respond to that? And his family said, as long as he's able to read the Wall Street Journal, everything else is negotiable. I think it was the daughter who said that, and I looked at her brother, and he was nodding his head. And then I looked at the wife, and she said, they know their father. And so armed with this information, I could then approach the neurologists and say, “This is what's the minimal acceptable outcome for this patient.” This is what “okay” means to this patient. And as expected, when the neurologist heard that the minimum acceptable outcome for the patient would be to be able to read *TheWall Street Journal,* they were able to clearly say that despite all of the uncertainty about exactly

what the recovery would look like, that there was no way he would recover to a point where he would be able to read again. So for them doing “okay” meant perhaps getting to a point where he could be conscious, where he could recognize his family, probably need a lot of help with feeding and toileting and things like that. But for the family, the “okay” bar (level of performance, recovery) was set at quite a different place. And once I was able to bring these two definitions of “okay” together and to dialogue with one another, it didn't make the experience of this devastating injury any easier for the patient, it didn't make the experience of grief any less for the family, but it showed a clear path forward, and what kind of care would be appropriate for him to receive. And so the family was able to say, “We don't want medically administered nutrition to support a recovery that will never get him to a point that's acceptable to him. We'd rather support his comfort and dignity, and allow him the rest of his life to be a natural process.” And so when he was ready to come off the ventilator, he was supported with comfort medications, the family was able to spend time around him, he never fully regained consciousness. He died about a week later, surrounded by his family.

So this idea that the neurology team wasn't saying anything that wasn't true, and yet the words that they were using meant something different to a family that was trying to make decisions. And once we were able to look at our language and understand each other's perspective on what that meant, it opened up a clear pathway forward. So this is the space, Paul, where I work, bringing narrative competence to the bedside, and trying to mix the stories of healthcare teams with the stories of patients and families in order to help them codesign the best care possible.

**Paul Batalden** 09:23
Wow, I can see where this focus on stories and narratives to help us create a shared language really is helpful. I also think that the job of connecting the generalizable, the particular and the imagined life in the shoes of another person are such good possibilities for a story. How do you know that a story has gotten where you think it needs to get?

**Kathryn Kirkland** 09:53
That's a great question, bringing people together and helping them share their stories, the story is going to take you where you need to get. So, I kind of think about this as medical professionals, we have learned clinical narratives, medical narratives, pathophysiological and scientific narratives that bring evidence from hundreds of 1000s of people, what have we learned about how disease happens, how treatments work, what works and what doesn't work. That's kind of the narrative of evidence, and patients and families bring together their experience of living and their experience of illness. And that's a certain kind of particular evidence that can only be understood on the individual level. And both of those types of evidence are valid and necessary, neither of them can take us where we need to get. And so the story is the story of weaving those two narratives together. To say, for this particular person at this particular time, given their particular experience of illness and their hopes and dreams, how do we bring the clinical evidence to bear on that and codesign a story that brings those two things together? Now, you might ask, so how do we help people learn how to do this? Or even that it needs to be done? And I think, you know, for patients and families, it's pretty easy. Tell me your story. They don't say, “Well, what do you mean? I don't know what you're talking about.” Clinicians, sometimes it can be a little harde;, they're farther away from the idea of the story. But when you bring patients and clinicians together, and you help them practice telling stories, and sometimes even trying to practice telling each

other's stories, I can tell you about a time when I've done that. But when you get people to help to step out of their own perspective and tell the story from the other's point of view, you can get incredibly rich, both self awareness and awareness of others, in ways that I think helps people to coproduce better health care.

**Paul Batalden** 12:09
So you mentioned that there was a time that came to mind that illustrates that powerful idea.

**Kathryn Kirkland** 12:15
Yeah, recently, I had a group of clinicians and people living with illness in the same room together talking about the coproduction of healthcare. And I was leading them through an exercise in writing as a way of discovering and as a way of expanding perspective. So I gave them the assignment of writing about a recent experience you've had in a recent clinical encounter that you've been a part of. So that was part one of the exercise. And I'd like to just read you what one of the people in the session shared with me, she wrote about an incredible experience. She's given me her permission to share that with you now. So let me just read the first piece that she wrote. And I should probably give a little trigger alert here that every time I read it, I feel my heart drop again. And so some of the people listening may feel that as well. She says, "I was speaking to my husband, by a phone hooked up to his IV, with my daughter. I saw his oxygen monitor drop to 60. I told him to push the alarm. He did but no one came. We called the switchboard - it was broken. We called each department in the hospital as we talked to my husband; we called the police. Fifteen minutes passed. He stopped talking. No one came. At 20 minutes, they came in and said, "Oh, we need a crash cart," and turned off his phone, our only lifeline in COVID. It was the last time we saw him conscious.

So wow, a five-minute writing exercise - write about a clinical encounter - this is what comes. It's really powerful. And I think many of us can imagine being in that helpless situation, especially during COVID, where families have been separated from one another. But I think even more striking is the next part of the assignment.

So I asked people after writing their first perspective, before reading it or sharing it with anyone, to do a second writing exercise. And that was to take the same encounter, and write about it from the perspective of someone else who was present. So Amy wrote from the perspective of an ICU nurse, and I'm gonna read what she wrote, because I think it's incredible that someone who had just written this piece was able to step into the shoes of another person. So from the perspective of the ICU nurse, she wrote, "I was so tired. I thought I heard an alarm in bed B but there were so many alarms and noises. It is strange we have had no codes today. Unsettling, as it is early afternoon and it does not seem normal that everyone is fine. Why am I unsettled by normal? I heard codes again in my sleep and I saw them along with the dead patients we stacked in the hall until they could be transported to the refrigerated trailers outside. They died alone, no matter what families did to try to be with them. I hope the patient in bed B lives. His family and I worked to string his phone on to the IV pole, as there are no iPads left or any of us left to help the families. Every day we bring him Starbucks (coffee) when we go for ours, his smile and his encouragement lights up our lives. She, the wife, asked me to touch him as if he was my own father, so he would feel safe and loved. Yesterday, he said, 'If I die, I want my wife to have my antibodies, we have been together for 50 years.' It is scary. And my face is raw from 12 hours

of wearing the same mask from patient to patient. They just cut our pensions yesterday and told us we need to work even if we have COVID. I remember my daughter asking me, “Mom, do you still love being a nurse?” I love people and I love medicine, but I feel betrayed by the system that did not care for our humanity.

So, wow. So these two narratives just, I think, say more than anything that I could say about the power of writing to discover what we need to know and say about our own experiences, and also our amazing human capacity to step into the shoes of another. And I honestly think that this work in the narrative space is key to a better world, much less better healthcare.

**Paul Batalden** 16:53
Wow, those are two very powerful stories and your discussion about them and how you elicited them. It suggests that the different people use different forms of knowledge to make sense for themselves. How do you know what might work for me?

**Kathryn Kirkland** 17:13
How do I know what might work for you?

**Paul Batalden** 17:15
Yeah, what might help me make sense of a situation like one of these kinds of situations?

**Kathryn Kirkland** 17:22
I think, Paul, we make sense of the world through the stories that we tell. And so I trust you to tell the story that you need to tell, in order to make sense of whatever you're trying to make sense of right now. I think that asking you to tell your story from someone else's perspective, helps you to explore meaning in a deeper way. You know, the ladder of inference, we can sometimes get off course and trying to make meaning out of what's going on. Similarly, for the neurologist who may make meaning that someone is going to do okay, without knowing what “okay” means to that other person. It's not that it's not true. It's just that it's not a broad enough perspective. And so for you, I would say, tell your story, and then tell it from another angle, and then maybe tell it again, and tell it again. They’re stories I've written a dozen times, same story from the same perspective. And the story is different. I trust in the power of that storytelling as a starting place.

**Paul Batalden** 18:35
So it seems to me that what you're talking about is a job that involves people in stuff that they might be variably comfortable with. Some might be very comfortable writing, some might be more comfortable listening, or reading, or telling. How do you give people permission to craft the story in a way that invites and attracts them?

**Kathryn Kirkland** 19:05
So I've learned some of my approach from Rita Charon, who's a narrative medicine founder and world expert. She invites people into the space by starting with something that they read together, or some form of a text, maybe it's a piece of art, or a photograph, maybe a film clip, or even a piece of music. And in the case of the piece Amy wrote, I think we started with looking at a painting together that just

depicted a waiting room. I think that helps people get into a space where they realize that they have powers of observation. They can see colors, they can see how the world is organized. And once they're into that space, then I try to create a writing prompt that doesn't require any expertise to respond to. All it requires is (kind of) writing and giving an exercise of five minutes of writing. Isn't it unbelievable that that writing came out of two five-minute segments, five minutes with a prompt that invites someone to go wherever they need to go with it. Write about an encounter, write about an interaction with a person, write about being in a waiting room, write about a time you waited, it could be anything. But then inviting them to write whatever comes to mind in whatever form it needs to come. It can be a list, it can be a haiku, it can be an essay or a short story. I think that helps to break down the barriers, and then the gift of being able to then share your writing with someone else if you choose. And having them give you the gift of being a reader. And to tell you I heard this; giving that back to someone as a reader is another way of encouraging them to go into that space to feel heard.

**Paul Batalden** 21:03
So you've developed what you now know and use over some time. What helps you get better at it?

**Kathryn Kirkland** 21:13
Practice. Both practice in exercises like I've just been describing: reading and writing. Lately, I've been doing a lot of writing from other people's perspective, because I feel like the world is full of people so entrenched in their perspective that I want to force myself to imagine what would it be like to be someone who was afraid to get a vaccine, for instance, but also I practice this in my work every day seeing patients and families. And it's almost routine to start by saying, “Tell me about yourself. Tell me about your family member.” I remember Ira Byock used to say, “I don't even know where you were born,” but (I’m?) inviting people to tell me what's important for me to know about you. And then it will become clear to me how I can help you achieve your goals. So I have the privilege of getting to do this every day. I trade in stories. I have the clinical narratives, the medical narratives, the scientific and evidence narratives that I carry with me, but I marry them every day, to the individual story of each patient.

**Paul Batalden** 22:29
So if I came to you as a student, and I said, “Can you help me learn how to do this?” what would you tell me?

**Kathryn Kirkland** 22:38
Practice practice practice. I would invite them to be familiar with stories, to read stories that have been written and published, to find out what their patients’ stories are, and to see for themselves, how those stories lead you where you need to go.

**Paul Batalden** 23:00
Wow, you are a master. Thank you for sharing this with us, Kathy.

**Kathryn Kirkland** 23:05
Thank you, Paul. It's my pleasure and not so much a master, but a “practicer.”

**Paul Batalden** 23:18
In this session, we see how Kathy uses stories, an art form to integrate and apply scientific ways of knowing. She builds on a deep understanding of the biology of the situation the patient person is facing. She seeks further insight into the experience of having the condition. She explores the ways that involved people are understanding and making meaning from and sense of the situation.

Building on her relationships, she invites those involved to codesign actions that help minimize the burdens arising from the condition and the treatments involved. She uses stories and builds on diverse ways of knowing. The common thread among those different ways of knowing is the commitment to build useful knowledge and a shared understanding for action from empirical observations and reflection.

Other ways to integrate the various forms of knowledge and coproducing healthcare service usually have in common that they begin with a specific situation that a patient person is facing. From our earlier episodes we know that diverse methods are used to build a good biologic understanding of a disease or condition, or a good understanding of the experience of living with it, or good services that help address the barriers to better health in the face of these challenges. The specific situation of the patient person invites the integration of these multiple ways of knowing. Each of these knowledge building methods has its own way of assessing the goodness and generalizability and quality of the information.

Often it doesn't exactly fit a particular person and situation. Closing the gap between what's known and what's needed involves deep respect and trust. This is part of the vulnerability involved in applying general knowledge to a particular situation. Social accountability for using good knowledge and faithfully working to apply it is part of what being a professional person involves today.

Forming and telling one's own story can take many directions. Hearing patient persons into speech involves careful listening by the professional person. Honoring the vulnerability of telling the truth requires the active participation of both parties, the patient person and the professional person. A context that is safe for telling the truth to each other is fundamental. Attention to adequacy of time and privacy are beginning attributes for creating such a safe setting.

Creativity in identifying and using the assets and resources available to the patient person helps form a truly coproduced service. Differences in levels of prior experience and relevant information access between the parties often requires the construction of a bridge that allows people to see one another at eye level. This usually requires the use of a shared language or at least language whose meaning is similarly understood by all parties. It may involve imagining from the framework of the other as Amy did in Kathy's tape.

We're grateful to Kathy for her example of the integrating work involved in bringing multiple threads of knowledge together in the coproduction of a healthcare service. I'm Paul Batalden.

**Madge Kaplan** 27:12
Thank you for listening to Episode Nine of the podcast series The Power of Coproduction with Paul Batalden. On Episode 10, “My Work Depends On the Setting,” John Brennan shares the way his work

settings influenced his medical practice. All podcasts in the series, including an overview of coproduction, are available at 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.