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SPEAKERS Madge Kaplan, Paul Batalden, Charlotte Arvidsson, Serena Chow

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. In episode two, “The person will see you now”, Paul explores developing an understanding of the lived reality of the person we sometimes call a patient. Paul is joined by Serena Chow and Lotta Arvidsson. Here's Paul.

Paul Batalden 00:58
There are many ways to develop a deeper understanding of the person that we sometimes also know as patients. A simple way for a health professional to further develop their own capabilities is to work with a learning partner, a volunteer who's willing to share their stories, and in the process to allow the health professional to practice the inquiry and the questions that will help. To explore this further we invited Charlotte Arvidsson of Jönköping, Sweden. Welcome Lotta. With the help of a colleague, you found a volunteer learning partner to learn the process and benefits of a more deeply explored understanding of the lived reality of a person sometimes called “patient”. Will you tell us about that experience?

Charlotte Arvidsson 01:52
It was quite an interesting experience, actually. And it was really explorative. Because we didn't know what we were getting into. Neither of us were undergraduate learning students. But neither actually were our learning partners. What happened was that we were asked to find someone who would be willing to share their stories with us and to let us learn from their stories and from our exchange. And this was very generous of them, because what we could offer would be our interest and our curiosity in them, but really nothing else. But everyone who was asked was actually willing to volunteer. It took a little bit of courage to actually go and ask someone to be a learning partner. We all learn, obviously, from patients and people and colleagues and kind of everyone every day in our profession, but I rarely think that we actually ask someone as actively as we did this time.

When you think of it, it's very difficult to learn how to coproduce something together with a person unless you actually try it. And then there was a question of, okay, so I'm going to do this, who am I going to ask? And I think that all of us in our group of doctors decided to think first of a health condition of our interest. Because we thought that, I realized I was interested in heart failure. So, I thought if I have a learning partner with heart failure, I'm going to learn more about heart failure as a condition and the care of heart failure. I think all of us learned the lesson rather quickly, that what was the main health concern of our learning partner was very rarely their main medical diagnosis.

Paul Batalden 03:33
Fascinating. So you found a learning partner, and how did you decide to have the session and where you would hold it, and so on.

Charlotte Arvidsson 03:47
The first task for us was to get to know this person as a person first, and more as a patient later. At about this time, I was also interviewing people for a thesis I was doing. That had taught me very quickly that when I interviewed these other people in their homes, I got a totally different feeling for them than when they instead wanted to come to be interviewed in my clinic for the same subject. So it was kind of easy to actually say that if it's comfortable to you, Michael, whom we can call my learning partner, I will be very happy to come and see how you live, and I can bring some coffee and cake or something. And he very generously invited me to do so. I went to see him and he actually seemed happy to be a learning partner to volunteer for this to help me to become a better professional and I think to give something back to healthcare as well.

I went to his apartment and he immediately showed me around his apartment seeing all the pictures of his grandchildren and of someone who wasn't around anymore, his late wife. He was quite recently widowed a few years before. But her presence was there anyway, even though she'd never lived in this place. We came back to her quite a lot during our conversation. I think that having been in his environment and seeing the pictures and seeing his very smartly furnished apartment, which he acknowledged to the interest of his wife, we got into a conversation about his life, very, very quickly,

Paul Batalden 05:36
You now had a sort of a feeling for where this person lived, and who were the important people in this person's life. You also had a sense that his wife was no longer alive, but still very much a part of his life. How did that begin to open up this man's situation?

Charlotte Arvidsson 05:57
His life had changed quite a lot in these last few years: he had lost his life partner for quite some time, he had moved, he had had some operations on his knees and hips. So he had worked quite a lot with health care about all that. He also had this diagnosis of heart failure. But his main problem, according to himself, was that he was increasingly gaining weight and not the weight gain, as in heart failure with lots of excess fluid, but actually he was adding too many pounds around his stomach. He rather openly admitted that this wasn't particularly strange, because he knew that his diet wasn't particularly fitting for his situation. He didn't move enough, partly because of his knees and hip replacements, and the pain he had before that, but also because his heart failure gave him a worse starting point. So it was getting into a bad circle. But

also, he didn't really cook very nutritious food. I think this is one of the main clues that knowing his situation and knowing of his late wife came into play for me, because he said he had raised this many times with his doctor and different nurses and dietitians and other people who had given him a lot of information about what he should eat and shouldn't eat. But sitting there in his kitchen, and in his apartment, with the sense of his life around me, it was, I think, very easy for him, and very naturally, to say that he didn't know how to cook really, because he'd never done that–more accurately than for him to say "cooking was my wife's task."

So he had to learn that in his early 70s. Cooking wasn't really an interest to him, and he didn't know how. Also cooking and preparing meals which you have to eat all by yourself isn't very, very nice. One of the learnings for me to take away from this is that he knew this had we asked him basically what he volunteered without much questioning at all. He knew that the problem mainly was that he didn't know how to cook and that he didn't like to eat on his own. And the solution he wanted to have from healthcare was some help getting over that with practicalities. And maybe by meeting people in similar situations.

Paul Batalden 08:21
That might not have ever come up in the office visit and the normal exchange around his heart failure.

Charlotte Arvidsson 08:28
No, probably not. We know that it hadn't come up in four or five sessions with different people. But to him this exchange was actually better than what had happened in those sessions. He wasn't holding something back. But I don't think he had actually spoken voluntarily about this, either.

Paul Batalden 08:43
So in this experience of sort of practicing interviewing a learning partner, you thought about the questions before, you also had a worksheet that was distributed, and practicing the questions was helpful. Do I get that right?

Charlotte Arvidsson 09:06
Yes, I think so because I prepared by thinking about it in advance. It made it easier to pick up clues I think during the interview, and not only the verbal interview, but the kind of seeing his environment. For example, one of the things he showed was he had two small birds, which he actually looked after for a grandchild. And he was talking about these as his friends giving him company. Then he got a bit serious for a while. You could sense the difference of his voice, of his posture and things like that. And then he said that he had always been a dog person, and he had always had dogs for his entire life until his wife got very ill. Then he said, I've been thinking about getting a new dog. But I realized that even if I'm not really that old, with the diseases I have, I think my life expectancy isn't going to be that of a dog. So I don't want to get a dog that I have to pass on to someone else. And that was a very, very natural way into discussing what he actually thought about his life and the remainder of his life. And that even though just being briefly asked about what he thought about heart failure and other conditions, he didn't really

want to get into that. But this discussion about the absence of a new dog opened that area quite naturally. And totally from him. I didn't ask, but he volunteered this information. And that was about picking up the clues of his environment, I think.

Paul Batalden 10:47
This process took more time than the usual time in the clinic, so how have you applied these insights in your daily practice?

Charlotte Arvidsson 10:59
One thing is that you really don't know unless you actually ask, because it's very easy to make assumptions from what you hear or from what someone else has written. But unless you actually ask, you're not going to know or get closer to the situation. And the other thing is to ask about the person's own thoughts about the solution of the health problem, because we are taught quite extensively, at least in general practice, but I think, also modern day medical education, to inquire about the fears and the hopes and the expectations the patient has on the visit and on the problem. And then we can explore that. But very rarely, at least in my experience, is it done that “Okay, so we ended up with this problem, but what do you think for yourself might help solve it?” That gives us also a little bit of a clue about the resources of the person just from what they are going to offer as a possible solution. Some people have thought about this quite a lot, and sometimes have a very, very reasonable solution to try out. Other people claim they haven't thought about it, maybe they haven't. Sometimes they give me a call a week later and say, you know, I've been thinking about this, what do you think, could this be something? And then there are situations where the proposed solution maybe is not, from a medical view, really going to work out. But it tells me very much about the thinking of this person, the hopes of this person. And again, things like, “What's the situation at home?” So identify, maybe even know that this person is a widow, or widower, or has or hasn't children or someone else in the environment, but they might volunteer this information very easily when they come up with what they think is possible. And that is obviously very quick to do. It doesn't take any time at all. Because obviously, I can't go and spend two hours time at all my patients’ homes, even though I think it would be often well-spent-time at the beginning of relationships, which you think are going to last for a long time. I think in my daily practice at the moment, I do make home visits, but it's when someone is really, really ill, or often quite at the end of life. And then I might, you know, say to myself that, okay, I've known this person maybe for many years, this would have been really nice to be in their home before they got to this stage.

Paul Batalden 13:34
So this was a simple practice session with a learning partner. But it seems to have been a useful thing for you and your practice.

Charlotte Arvidsson 13:44
Absolutely. I got away with a lot after this visit. But it didn't end there. Because then we had other practice questions to work together with our learning partner. And I made another visit to his place when we discussed more of a patient journey from his point of view, and from my point of view, and when we compared these together, which was also kind of interesting, because it

opened my eyes to that his process started and ended much much further apart than what mine did. And then we actually also had some emails and phone calls. So we kept in touch for about a year.

Paul Batalden 14:25
Well, thank you very much for taking this time to be with us and for sharing this story.

Charlotte Arvidsson
You're welcome.

Paul Batalden
A deeper understanding of the persons and their situations is helpful when you're considering testing a change for improvement. A simple way to get that insight is to see the people involved in the settings where they're making the decisions that are relevant for the improvement that you want to design. Serena Chow of Cambridge, near Boston, Massachusetts, was interested in improving the use of the emergency room by patients with dementia. She decided to make a home visit to explore the situation the patient and family members were facing as they were deciding to seek help in the emergency room. We've invited her to help us see what she saw. Welcome, Serena. Will you tell us about that experience? What did you notice? And how did that influence what you decided to do to actually make a change?

Serena Chow 15:29
Back in 2017, I made a home visit to one of my colleague’s primary care patients after this patient returned home from the emergency room in a subsequent hospitalization. What I recall from that visit is that she was 95 years old, and she had moderate to severe stage dementia, and she had just been hospitalized after falling. She had other major chronic conditions on top of the dementia, including atrial fibrillation and chronic kidney disease. At the time of the hospitalization she had already lost her ability to walk independently and relied on others to do all of her basic activities of daily living such as bathing and dressing. I was struck that she and her family still wished for her to receive aggressive interventions like CPR and intubation with mechanical ventilation, even though she was in the last stages of dementia, which I do view as a terminal condition. I also wondered if the daughter that I met on this visit understood that hospitalization can be harmful to people with advanced dementia, potentially exposing them to increased risks of delirium, immobility and functional decline. We often say in geriatrics that hospitals can be dangerous places for older adults, and they're particularly dangerous for people with underlying dementia. I think that first visit really raised a lot of questions for me, in terms of, “are we doing enough as a care team to prepare our patients and their loved ones for what dementia is going to look like in the future?” And how perhaps we as a team, a homecare primary care team with a physician and nurse practitioner, could we do more to support family members to treat their loved ones in place, their loved ones with advanced dementia, where a hospitalization may, in fact, pose more harm than benefit.

Paul Batalden 17:25
So what was it like when you actually visited the home, Serena?

Serena Chow 17:30
So I saw the daughter in front of me–that was my first impression, who looked incredibly worried and looked overwhelmed. And she shared with me on that visit that she was also dealing with her own chronic medical conditions while also being the primary caregiver for her 95-year old mother. I 5 Transcribed by https://otter.airemember seeing the 95-year old lying in a hospital bed in her bedroom. And I also observed that the daughter appeared to be alone, she was the only one caring for this patient. I also observed in conversation with her that she didn't seem to have a lot of insight about her mother's underlying dementia, that she didn't realize how severe her mother's cognitive and functional status was. I also got an impression in speaking with her that she reflexively sent her mother to the emergency room at the first sign that there was an acute change in condition because she didn't know what else to do. And she frankly didn't have the resources or the energy to keep her mother at home.

Paul Batalden 18:36
So as you looked around in the house, were there things that might have made it easier for her to have a sense of what she might do or who she might call, or...

Serena Chow 18:52
On this visit, like every other home visit that I make, I always make a beeline to the kitchen to see what's on the refrigerator door. Because typically what you'll see is all sorts of cards and placards taped to the refrigerator door with important numbers, including the electrician's number or the cable service number. But in the case of our homebound patients that we serve in our house calls program there's also a yellow card, a placard, typically with the name of our practice, the doctor's name and the office number and a little sentence to say who you can call 24-hours a day, seven days a week. And I also look for other cards and placards of other community agencies that might be helping a patient and their family. The fridge with all the cards and the numbers that says to me that at least there's some indication to the patient, some reminder to the patient and family, that you can call someone if you have a challenging situation to get help. So I did see that yellow card in this patient's kitchen on the refrigerator. But then it dawned on me, it doesn't have much information on it. And I wondered from the start, did she know that she could call that number even when the office was closed, because there was an oncall doctor available on off hours and on weekends to discuss her mother's situation- if there was a change, and to hash out, what are some of the other options to take care of this patient situation, aside from going to the emergency room. None of that information is on that yellow card. And then I thought to myself, did this daughter after her 95-year old mother fell at home, did she think to call our office just to talk to the on-call doctor? I didn't know at the time of the visit if she had actually called the office prior to activating the emergency service to bring her mother to the emergency room.

Paul Batalden 20:52
So did the daughter seem to have an understanding of what you knew about the availability of services?

Serena Chow 21:00

She did not seem to know that she could have called. And it might have just been just how scared and nervous she was in the moment, which I totally understand, and get that her mother who was already so frail and bed bound, that she wasn't looking right. And it may not have occurred in that moment when the emotion of fear is hitting so strongly. That was one hypothesis I had.

Paul Batalden 21:27
It strikes me that it's a perfectly reasonable kind of intervention to create such a resource like a yellow card, but things like yellow cards don't implement themselves.

Serena Chow 21:40
That's exactly right. And I think that's one of the insights I took from that home visit. So right after that, a few months later, our housecalls program decided to begin a quality improvement project specifically focused on improving the care of people with dementia. And one of our main objectives was to try to improve the education and also the type of care we were giving in the home, in order to prevent avoidable transfers to the emergency room for those conditions that we felt as a team we could safely manage in the home, as long as we were alerted to those conditions happening,

Paul Batalden 22:23
Such a wonderful set of guidance for the design of a change. That's a wonderful story. If you had any kind of advice to anybody else, considering a similar kind of change, any advice you'd give them or any counsel that you'd like to suggest they consider? Serena Chow 22:46 Yes. One of them was the unanswered question that I had that the daughter call our practice, the oncall doctor first, before she called the ambulance to bring her mother to the emergency room. So one of the activities our quality improvement group did was to look at chart reviews of our house calls for patients with dementia who had recently gone to the emergency room, and perhaps were hospitalized. And to our surprise, even though we have physicians and nurse practitioners who are available during the day to talk to about clinical changes of condition, and also a 24/7 OnCall physician setup, there were up to 76% of ED visits of our patients with dementia that were not first preceded by a call to our office over a five week timespan. And so I was like, oh, that's curious, because everybody has those yellow cards.

So I think one piece of advice is to do the due diligence of gathering data, whether it be through chart reviews, or other methods to answer whether or not your question that you formulated when making that home visit: Is it true? (This reflection) may actually spur you to undertake interventions that you may not have previously thought about. I did not think I was going to need to create a flyer discussing our on-call services for our practice because we always give out yellow cards. So one of the interventions that came out of these insights was to create a “House Calls-Is-On-call flyer”, a one pager that just described who was available on call, and specific circumstances that we want our patients and our families to call us about at any time of the day so that we could discuss potential management in the home if it was safe.

And I think the other insight that I gained was the power of having a person on your quality improvement team who’s lived through the experience of the disease. And so in the case of someone who has dementia, they, by nature of the condition, really can't participate in a quality improvement group, but their spouse who's been the caregiver can. So we invited a woman who was a local resident in Cambridge, who was the primary caregiver for her husband who had early onset Alzheimer's disease. And she sat in on our monthly quality improvement meetings, and her voice was just so crucial to the shaping of our interventions.

Paul Batalden
What did she contribute?

Serena Chow
So I particularly remember one remark she made during one of these meetings, when we were talking about the House Calls-Is-On-Call-flyer, that she personally never ever felt like calling her husband's primary care doctor when there was something going on, because she didn't want to bother him if it was late at night or on a weekend. Which I thought was really interesting, because that thought never crossed my mind that people would be so considerate of their doctor in the moment of crisis like that. And I think that comment made me feel even more motivated to put together a flyer that would list the conditions that we do expect you to call (about) and give patients and families the permission to call. I didn't think I needed to give them permission, but Leslie's comment highlighted that.

The other really important contribution she made is sharing with us that she had found the local Alzheimer's Association chapter to be very helpful to her when she was dealing with a particularly challenging time period of her husband's disease. She called them often for advice. And then later on, as she became more experienced, she offered her volunteer services to that chapter and was very active in one of their committees and other activities they do to support other folks going through what she's gone through. And I think it was a few months into our project that we were discussing how caregivers still didn't seem to have deep understanding of what dementia means for their patients and what to expect, and Leslie piped up that maybe we should contact the local Alzheimer's Association and ask them for their materials to hand out to your house calls patients; “I'll connect you on email.” And so that action by Leslie then led to discussions where I found out that the local Alzheimer's Association had a free telephone consultation service where they would spend 90 minutes with the caregiver and address any questions that that caregiver had about the specific situation they were in.

Paul Batalden 27:37
Just a wonderful example of once you understand the resources that people who are working on the same problem actually have accessed, that may expose an entirely different sort of picture of what's available for the system that's trying to come to grips with this.

Serena Chow 27:57
Yes, I think that was one of the biggest takeaways I got from this project. When I originally conceived of the project, I really felt it was going to be our group coming up with the educational

materials for the patients and families and perhaps providing education to the local agencies, the personal care attendants, the visiting nurses, and I have to admit that I was completely wrong about that. I think our project was made so much better by us establishing a connection with the Alzheimer's Association, a non medical group that obviously has a lot of experience with dementia care, and for us to be able to connect our patients seamlessly to that resource was really tremendous.

Paul Batalden 28:45
What a wonderful story. I really appreciate your sharing this story with us, Serena, thank you very much.

Serena Chow 28:52
I have to say it's been such a pleasure to relive the events of that quality improvement project because it was one of the most rich professional experiences I've ever had. Thank you

Paul Batalden 29:08
Nearly 100 years ago, the Spanish philosopher Jose Ortega y' Gassett said, “I am me and my circumstances.” He suggested that the identity of someone arises from a consideration of the person and their setting, their resources, their challenges, and their supports. Our efforts to develop that understanding is one of the key streams of knowledge, skill and habit that help us coproduce healthcare service.

As we listened to Lotta and Serena discuss what they learned as they sought a deeper understanding of the person sometimes known as a patient, we heard them describe home visits where they witnessed things they wouldn't have gleaned just by reviewing an electronic health record. Photos of a recently past spouse, the frustration of a man struggling to learn to cook a good meal for himself as he deals with his congestive heart failure, and a daughter trying to care for her mother without the resources and information readily available that might help her.

Sometimes the motivation to develop a deeper understanding comes from the health professional, like Lotta, who wanted to learn and to add helpful methods of inquiry to her usual way of being a doctor. Sometimes it comes from the desire like Serena’s: to design a test of change for the improvement of service that would actually be likely to help. There are many more possibilities. One way to uncover them is to ask yourself the question: “Would a deeper knowledge of the person who is the patient open more options or more flexibility in addressing the situations we are facing in the coproduction of this healthcare service?” It is in this exploration that we are able to discover the real diversity of people as they work to be as healthy as possible. It is in this inquiry that we can discover the resources, the supports, and the assets that people have. We also can discover what truly matters to those whose health we are working to improve and exactly what they are trying to figure out as they work to create their own better health.

This is where the suggestions of the February 16, 2021 British Medical Journal editorial on “The Knowledge Building Needed for the Future of Coproduction” can be helpful– speaking directly to and about professionals. The editorial invites four things: first, get used to making the person's circumstances, as y’ Gassett would say, explicit; two, new levels of respect for the different expertise of the multiple stakeholders involved, despite the many power-influenced temptations to diminish those diverse voices; three, staying practical to build this knowledge to measure impact, and to create value for patients, families and communities; and four, building funding support for this coproduction knowledge creation that fosters long term collaboration across organizational disciplinary and national boundaries. Our thanks to Lotta and Serena for helping us delve into one of the key dimensions of coproducing health and health care, deepening our knowledge of the person or persons we're eager to help. We'll return to this theme again and again throughout the podcast series. Thank you. I'm Paul Batalden.

Madge Kaplan 32:57
Thank you for listening to episode two of the podcast series The Power of Coproduction with Paul Batalden. On Episode Three, “The way things are… let's get real”, Paul will be joined by Julie Johnson and Chandlee Bryan. They'll 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. 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.