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SPEAKERS Madge Kaplan, Paul Batalden, Morten Sodemann

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 Eight, “Am I allowed to cry here?”, Paul talks with Morton Sodemann about designing and creating effective services with an immigrant community in Denmark. Coproduction is key. Here's Paul,

Paul Batalden 00:54
Welcome. We continue our exploration of the way that scientific thinking informs the everyday practices of the coproduction of healthcare service. Dr. Morten Sodemann of Denmark specializes in infectious diseases, and leads a special clinic for immigrant persons and their families. You will help us explore how science informs the design and use of services for that special population of patient persons. Thank you for being with us, and welcome, Morten. Is there a story that helps us understand what you do and where you work?

Morten Sodemann 01:34
The other week we had a patient referred that was born in Thailand, but came to Denmark to visit her sister and found a Danish husband;he turned out to be an alcoholic and a wife beater. And when she was referred to us last week, she had signs of depression and pain sensation all over the body. And several neurologists and general practitioners, family practitioners had tried to figure out what was wrong with her, but they couldn't figure it out. They thought it was sort of a menopausal issue, but she was in her late 30s. So they finally referred her. What we usually do is to ask patients to tell us their life story, describe the family, and then give us a full problem list of all their problems -socio-economic, psychological, physical, mental. And she looked at me when I asked her and she said, “Am I allowed to cry here?”

I was a bit puzzled. So I asked her, yes, of course you are, but why do you ask that? But she had sort of gotten the impression that in Denmark, you don't cry when you go to see a doctor, you don't cry when you go to see your social worker. So she had stopped crying, but she also stopped sort of talking about what really mattered in her life. And that's probably part of the reason that they never really got around to what was the issue. She grew up in Thailand in a big family. And at some point, the family was so poor that one of her elder sisters sold her as a sex

worker at the age of 12 or 13, somewhere far away from home, and she was transported there and left there in a house.

She said she managed to escape and swim across a river and reach the house where a very old lady gave her money to go back to her village and her family. Her father was very angry when she got back because that will only create problems. But still, she managed to stay there. Her mother wanted her to go to school and had saved up for her. But her father said girls shouldn't go to school, but her mother insisted that she had some savings. So she could go to school with what her mother had saved up. Unfortunately, the house burned down and her mother died. And with that all the money, so she couldn't go to school anymore. So she was left with the cleaning and work in restaurants.

But when her sister went to Denmark, she came to visit her and she found one of her sister's friends very nice. And as I told you, he turned out to be an alcoholic and beat her, so she left him. Then she married another Danish guy who was very nice, but he died from cancer. And that really sort of got to her that she was sort of the most unfortunate person in the whole world. So that, trying to sort of re-describe her life and her life story, she sort of looked at me and said, how can you help me?

I said, I don't know how I can help you, but I can ask you, what would you have done if you had stayed in Thailand? What would have been the solution there? And she looked at the interpreter and she said, I would have gone to see a monk and talk to him about it because when you're in trouble and you don't know what to do, you go and see the monk. I said, Well, you have the money. Why don't you go back and see the monk and we can talk about it afterwards. And she did that. And she later came back and said I went there and I talked to this monk.

And this monk said well, you know in our religion if you commit suicide - she was actually suicidal, that was really her basic issue, that she wanted to take her own life because the world would be a better place without her. And he (the monk) told her well, you know, in our religion, if you kill yourself, you have to kill yourself every time you're reborn. And you're reborn 500 times, so you have to kill yourself 500 times. Are you really in that much trouble? You will kill yourself 500 times? I don't think so, he said and she thought about that and came back to Denmark and she wanted to try and restart her life and go back to work and maybe not get married again because she was not very good at that, she said, but she was good at working. And so, she did that. And she actually sort of somehow solved her own problems, but sort of with the (help of the process and) instruments that we had: her life story, the problem list and (an invitation to) describe her family.

Paul Batalden 05:10
That's an amazing story. So how did this place, this clinic come about? How did you do that? What did you do?

Morten Sodemann 05:18
I specialized in infectious diseases. And we see a lot of refugees and immigrants with suspicion of infectious diseases, but most of them also have other problems. And one HIV patient actually said to me, “Why should I take this medicine if it doesn't solve my problems?” And that was also the first time I thought patients have several problems. And he actually said,”You know, when you get HIV, you get two diseases: you get your disease with the pills and the blood tests and all the immunological issues. But the other disease, you don't have any medication for that. That's the problems with HIV, living with HIV, the life with a chronic disease, you can't solve that. You can't cure that with your pills. What are you going to do about that?” So he actually got me thinking, maybe we should have another try at finding out what are (our) patients’ secret, hidden burdens, and what do they really struggle with, especially immigrants and refugees (who) are a challenge in the Danish healthcare system?

I asked the hospital management, can we have an outpatient clinic where we try and look at some really, really difficult patients with language barriers? And they said, yes. I think they thought that this would be about really severe infectious contagious diseases or something. They didn't realize that this was about social and socio economic issues and issues related to being an immigrant. But they said, yes.

So we started, a nurse and me, and quickly found out that most of the patients actually looked at us and said, “How can you help me?” And we said, “We don't know. You tell us what, how can we help you?” And they said, “If you listen to me, maybe we can find out.” So, listening. How do you do that? You ask them: “Can you tell me about your life? Tell me your life story. What was your childhood like? School? How was your family? Describe your family.” And we started drawing (a picture diagram of) the family. And out of this, tons of problems came out of the fog. The stories that actually were the barriers in their lives, and they had repeated problems and repeated issues that weren't solved. And the more problems you have, the more unsolved problems you have, the more you create for yourself. So we ended up sort of creating, okay, you want a problem list, so you want to be seen, heard and understood. You want to be able to tell your life story, and you want to talk to somebody about all (of) your problems. And you maybe have an issue with your family. So let's put that into the pot as well. And that's actually how we basically developed, through the advice of patients. The problem list, the family tree, and (the) life story as clinical tools.

Paul Batalden 07:39
Those seem very practical. And the experience sounds like it's a very special experience in the lives of these patient persons. I wonder how they would describe the experience of being in this setting.

Morten Sodemann 07:55
One of the first patients, when we asked her after she finished treatment, what have we done for you-,because we couldn't really figure out what we had done for her - and she said, “Thank you for making a better version of me.” And in fact, that's probably most of what these patients would say: that they've been seen, heard and understood, and have been able to live on with

something (a life) that's probably unlivable. “I live an unlivable life,” she'd actually started by saying, “and now I live a life I can live. It's not a nice life. It's not a perfect life, but I can live it. I couldn't do that before. Thank you for doing (helping me do) that.”

And that's actually one of the leads into thinking about, what is clinical work actually about? I think it's about not curing patients, but enabling patients to find ways to live with whatever they're struggling with, in a way that they have invented themselves, and based on their own opinions and experiences and their life story. It's a solution to their problems, not my problems, problems with the pills that don't cure the second disease that you get with HIV, the problems with HIV.

Paul Batalden 08:57
That's such an amazing, focused approach to what seems to many to be almost insoluble. As you have tried to help new people who have come to help you or to work with you as a nurse or a doctor, how in the world do you teach them or orient them or help them get started in this work?

Morten Sodemann 09:21
It's funny you should ask, because as you and probably many other people around the world, we have been forced (because of COVID) to work from home. Most of us work shifts, so we only (have) a few people (in at) the same time for work. I was very afraid how we could communicate some of the spirit and the psychology and sense of team play and some of the hidden tricks that we developed through this clinic. I mean, very often you figure out patients by talking to my colleagues over coffee standing in the kitchen or meeting them and getting an idea just by looking at them or something.

But in fact, it turns out that the people who are attracted to this way of working, they're sensitive to an intuitive way of talking to patients. We just provide some tools that make it fairly predictable what happens and it makes it easier to do what they're best at, as professionals. Some of them are child psychiatry, or family medicine, or orthopedics or general medicine, whatever. But they actually manage quite quickly to grasp the idea, because we have the uniform tools that they are forced to use. And apparently, if you are sensitive to this way of working and like it, you like challenges, you like when it's difficult, you like the more problems there are, the better for you, as a professional.

It turns out that we actually invite people into something that's quite obvious and easy if you're sort of motivated to work like that. And apparently, we attract people that are motivated to work like that with patients and listening to the patients be the orchestrators. We're just sort of providing them ideas, and what music to play and how to play.

Paul Batalden 10:54
So the task of getting to know someone else involves them also getting to know you. And the opening that that one woman asked about, “ Am I allowed to cry here?” she was trying to gain some knowledge about you and your setting. And this process is a little vulnerable, because you

end up sort of putting your whole self right there, you and the person are both vulnerable in a little special way that allows you to tell the truth to each other and to address things that matter to people. Are people nervous about that other than this woman and her question?

Morten Sodemann 11:36
This particular patient group is heavily exposed to failure, and ignorance and rejections of the sort of entire person and their symptoms and their life and their language and culture, everything sort of ignored actively. So they're quite suspicious. Are you one of those people that are going to reject me and give me another sense of failure? Because that's the only experience they have. Most of them don't know what help is. Because in their home country help is something you buy or you owe a favor to something, somebody if you receive a favor.

So it's all a bit suspicious, this whole setup, but placing a box of handkerchiefs in front of them and having this sort of atmosphere of “I don't know what is going on here, but help me find out so I can help you.” And we will start on your side of the table. Talk to me about your family. “Describe your family” is an extremely good question because most of our first traumas arise from family stuff, and you are already there, you're deep into somebody's life and (their) deepest trauma and sorrow and loss. Things that didn't happen, fiascos, things like that. So having these simple questions like, “You come from a country tormented by war, a lot of people experience things that human beings shouldn't experience. Does it ring a bell? Have you seen or heard anything like that? Are there things that you can't even think about? Or talk to yourself about?”That kind of question actually, immediately creates a safe space. It's normal what you're feeling, it's normal to talk about things, it's normal to cry here, and we have an hour or more, we stop when you're tired, not when I'm tired. But when you're tired. I'll just take notes, and then we'll sort it out afterwards. Don't think about structure or chronology or anything, just talk. And then we can re-sort, rearrange the notes afterwards, and the events.

Paul Batalden 13:22
So as you've done this over the years, and you've had a chance to reflect on this in many different settings, and in many different ways, how would you respond to somebody who asked you, “So Morten, what gives you joy in this work?”

Morten Sodemann 13:38
You have several joys during such a conversation with the patient, I think. But the first one is to see a patient experiencing a safe space for the first time in their life. They relax, the gas sort of leaves the balloon, and they sink down into the chair. And they start thinking instead of being sort of tense, and I have these notes that they have these issues, they relax and they look at you and they're allowed to cry. So they relax because they're allowed to cry. I don't have to, but I can if comes to that, that sort of feeling of, is it called, a moment of zen? There's an immediate wavelength there that sort of connects. And the second one is when they realize that they are not boring people. They're not a nuisance. They're not a disruption. A lot of patients learn to see themselves as a nuisance. It’s my fault that my symptoms are not easy to clinically put a name on or anything. It's probably me, I'm stupid. I'm a bad patient. The medicine doesn't work. That's

probably also my fault. So they sort of end up in sort of an eternal dark corner where “I'm a bad person, I'm a disruption” and leave it there.

So they are doormats instead of warriors for themselves, most of them. So seeing somebody who should rise from a doormat position to sort of a warrior position fighting to explain the entire life history in an hour and all their problems is really a very “giving” experience. Feeling that the patient has the ball and I'm just an instrument is really the success criteria, I think to me. And if we can make them say thank you for making a better version of it, because some of them actually, they don't like themselves. They don't like the version that's been developed of themselves as sort of a hybrid version of the old self from their home country where they were nice and funny and helpful and had their own job and made their own money and then had their own family, to this sort of being totally dependent on social allowances, and medication, and doctors and stuff like that. That's really the final (sense of) joy of doing this as they regain some interest in themselves and self confidence also, as a patient or person with a symptom.

Paul Batalden 15:42
What an amazing biopsy of the creation of a service. That was such a gift that you gave us, Morten, thank you so much.

Paul Batalden
Science can inform our understanding of the potential ways in which healthcare service can help people from anywhere in the world. In the case of the migrant health clinic in the Odense University Hospital in Denmark, we heard how understanding the way humans experience and frame the problems they face allows us to design a meaningful, safe space to be present and helpful to one another.

Our insights into the biology of pathologic processes, such as infections or depression, allow us to understand the natural history and the manifestations of the disease processes. Our knowledge of the human experience of illness, as something that makes us all kin to one another, allows us to gain insight into the contributions we can make to another person's sense of agency when that person faces overwhelming or strange problems.

Our background knowledge of the need to minimize both the burdens of the illness and the treatment helps us focus on supporting and enabling patient persons to engage in self care. It is their health after all that's at stake. Our recognition of the need to address all these things I've mentioned at scale helps us see where, when and how to apply the lessons to whole populations of persons, like all the immigrants using the migrant clinic, and to the facilitating work, like creating the clinic policies and practices that are involved in working with a population of individuals.

When we think of these as networks for solving problems, it opens many possibilities for future development tools, such as the problem list. The life experience, history, and the family tree all help and we've seen their usage in action at the Odense migrant clinic. Thanks to Morten's

descriptions, using science to inform our work invites the development of application tools that are available on The Power of Coproduction website.

Morten's story of coproducing healthcare service with an immigrant person began with him trying to understand the patient person's experience of her illness. He had created a safe space and offered welcoming language through which he and the immigrant person could develop a shared understanding of the situation and problems she was dealing with.

Like other scientists, using their tools of measurement and of standardized approaches, he had developed a template for itemizing her problems, for understanding her life story in context, and for understanding her family. He knew that with that information, he could begin to understand the way that diseases were contributing to her challenges of the illness experiences that she was facing.

To prepare, he had studied the relevant diseases and the ways they produced limits in patient persons' lives. He had also studied the ways of intervening to limit the diseases and the burdens of illness they caused, as he was working to better understand the immigrant person's approach to life and her health related actions. He was also imagining the bridges that might be built to the previously documented and potentially relevant approaches that had been helpful for others. He was creating possible paths to limit the disease and the illness experience in her life. From this understanding, he was preparing to explore the support that he might offer and that she might need for taking any action.

Science was informing the ways he designed and made the interventions. Science contributed to the ways he assessed and improved their contribution to her health. He explored and documented who the service was for, what the circumstances were and what the effects were. In short, we see how integral science-informed practice is to the design, to conduct assessment and to the improvement of healthcare service. We're grateful for Morten Sodemann's stories and his willingness to share them with us. Thank you. I'm Paul Batalden.

Madge Kaplan 20:51
Thank you for listening to Episode Eight of the podcast series The Power of Coproduction with Paul Batalden. On Episode Nine, "Stories Clarify," Kathy Kirkland shares the way she uses stories and storytelling to integrate different ways of knowing. 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.