

rehabINK Podcast

Connecting the Dots Mini-Series: Episode 1

SUMMARY KEYWORDS

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SUMMARY KEYWORDS

Monika Szopinska, Dr. Kara Patterson, Lucas Crosby

[intro chime]

Lucas Crosby 00:15

Hello and welcome back to the rehabINK podcast. We present our new mini-series: Connecting the Dots - Researcher and Community. In this series of episodes, we aim to bridge the gap between research and the community by hosting accessible and casual conversations between a leading researcher and an individual with lived experience. In case you didn't know, a person with lived experience is someone who has personal firsthand experience with a health condition or injury and has insights to share about their recovery. Here, we provide an opportunity for researchers to communicate with the community their research aims and give an individual with lived experience the chance to ask their burning questions about research. In this episode, I'm pleased to welcome Dr. Kara Patterson, a University Health Network Senior Scientist and Associate Professor in the Department of Physical Therapy at the University of Toronto, and Monika Szopinska, a person who has lived with physical disability for 18 years as a result of stroke. Both individuals will get a chance to ask each other questions, and discuss real world applications of research to daily life.

[intro chime]

Lucas Crosby 01:33

My name is Lucas, and I'm a recent PhD from the Rehabilitation Sciences Institute at the University of Toronto, wherein I studied some of the factors associated with and ways to improve gait asymmetry in the stroke population. So we begin with introductions, I'll let you Dr. Patterson go first. So please tell us a bit about yourself and the research that you do, and how you know Monika.

Dr. Kara Patterson 01:56

So my name is Dr. Kara Patterson and I'm an Associate Professor in the Department of Physical Therapy at the University of Toronto, and a Senior Scientist at the Toronto Rehabilitation Institute. A little bit about my work - I'm interested as a initially as a physiotherapist and then becoming a scientist and trying to improve neuro rehabilitation practice in order to help people living with neurological conditions to increase recover and improve their mobility. So things like walking and their ability to balance and the ways that we do that, we're looking at things like the quality of the walking pattern. So gait symmetry, as you mentioned, in your introduction, Lucas, and then also looking to use some novel interventions, things like use of music and rhythm, as well as the use of dance to try and improve walking and balance. So Monika was introduced, we were introduced by another person working in our lab, Yashoda Sharma, who was the research coordinator for one of our studies. And I had initially asked, so I hadn't met Monika in person, but I had initially asked Yashoda if she had any ideas or suggestions of people that had worked with us in our research program before, who might be interested in being involved on some grant applications that we were putting in. And Yashoda thought of Monika, she said, "Actually, I do have somebody in mind."

Lucas Crosby 03:30

Excellent. And then you Monika, can you please tell us a bit about yourself, your experience and what a day in the life of Monika is like?

Monika Szopinska 03:39

Sure. My name is Monika Szopinska. I am, I guess, a stroke or a brain injury survivor. I have had, uh, I've been living with a physical disability for about 20 years, 18 years to be exact. In the meantime, I have managed to get a university degree, a college diploma and have worked full time, I live independently. Currently, my mother lives with me so that I can support her while she's recovering from some illnesses. I have traveled tremendously. And I have hemiplegia which means that my left side is weak. I can't move my wrist, my ankle, my fingers, my toes. But I am trying to live a very full life, enjoy as much as I can, and to be honest, I pretty much work to pay for physiotherapy. Maybe that's a bit of an exaggeration, but it sure feels like that sometimes.

Lucas Crosby 04:42

Thank you so much for sharing that. So now today, I want to really give the two of you this platform to discuss research from the standpoint of the researcher and the participant and allow each of you to ask one another some burning questions about research from those viewpoints. So you've prepared some questions. And I think we can probably dive right in, starting with Monika to kick us off. So go ahead, Monika.

Monika Szopinska 05:15

Hi, Kara, it's great to see you again. It's been a while. It's wonderful to see you here. And I remember when last we talked, you told me a little bit about your personal story, you told me a little bit about your research. Could you tell us about your research and the areas that you are focusing in?

Dr. Kara Patterson 05:34

Sure, it's good to see you to Monika, a little bit about my research? Yes. So I, as I mentioned in the introduction, I'm a physiotherapist. And so my interest is primarily in trying to, first of all understand the challenges that people who have neurological conditions face when they're trying to walk, and when they're trying to balance. So stroke is the primary population that I work in. But I've also done some work with people who have brain injury. And there's some work in my lab, working with people who've had multiple sclerosis, there's a student who's work, who's working on that as well. And primarily, there are two kind of themes or tracks to the work that I do. The first is, first of all, studying or trying to understand how walking and balance are affected, and most research focuses on when it's talking about walking, is looking at how do we increase speed? Or how do we increase endurance? How do we help people walk faster? And how do we help people walk longer. And those are important, of course, but I'm a little more interested in how people are walking. So when we walk, we tend to walk in a very symmetrical way, our steps are the same length, the time that we spend on each leg is the same. And oftentimes in different neurological conditions that gets disrupted. And we think there's probably a bunch of different consequences associated with that there could be issues further on down the road of recovery. So things like pain, and joint discomfort, and perhaps even things like bone density loss. And so we look to understand why that is. And then we're also interested in trying to help people recover that part of their walking as well. And then the other piece of our, the other track of our research looks at some interventions. So trying to understand how can we design interventions that people enjoy? How can we make them more effective? And the area of research that I think you've been involved in is our dance work. So we're looking at using an adaptive dance program to help people improve walking and balance, but also to have a little bit of fun to make it enjoyable.

Monika Szopinska 07:59

I can totally relate to the point you're talking about with the symmetry of walking and how crucial it is, having become disabled at 30 years old. I'm so worried about the hip damage, knee damage I'm causing. And already I have some strange foot deformities that are starting to happen, which are painful and uncomfortable. So definitely that kind of research, I can see being crucial. And that's for the fun. Yes, dancing is wonderful. I really miss dancing, and I really miss being able to move the same way I did. And if you can incorporate that I would love to participate in a dance physiotherapy class. But when you do your research, how does this research actually influence the therapy that will be developed?

Dr. Kara Patterson 08:49

Yeah, that's a great question. And that's a big issue that researchers struggle with and also on the other end clinicians struggle with as well. And it's something that's been gaining a lot of attention over the years. So for example, when I write a grant to get the money to do research, I have to put in a plan called the Knowledge Translation plan, which is essentially describing what you just asked. Knowledge translation means when we take the what we've learned from research, and we try to put it into clinical practice, and so you have to write a plan. But it turns out that it's such a huge task to do that, that now it's its own field of study. So they're actually scientists that like me, but they focus primarily on the concept of knowledge translation - what's the best way to try and facilitate research into practice? How do we support clinicians to help them use this information? That turns out it's a really complex issue. Specifically for my work, it's interesting because it really depends on what study it is. So for example, the work with dance I've been invited to give a few talks at different venues where there's clinicians in

the audience. And I usually very, it's very nice, I usually get quite a few people come up to me after the talk. And they ask, how could we do this? How could we create a dance class where I practice? And so that's a really direct way. And I've found that people, people are already trying to find ways to put it into practice. And I think partly, it's easy, because people are interested in it, there's a lot of physiotherapists, who enjoy dance themselves and also, you just need a space in music to do that intervention, so it's pretty easy for them to implement it. That some of our other work where we use equipment, or we have to have software that, you know, for example, we provide feedback to people walking about their, the symmetry of their walking, and we give them feedback as they're practicing to see if that influences how they walk and if we can improve it with practice. But that requires equipment, it requires a software program to create the feedback. And so those are, make it a little more difficult for clinicians to just take it and drop it into their practice. And it requires probably a little bit more work after the study is done. Not a little bit, a lot more work after the study is done. So it's, it's a big challenge trying to get research to move into therapy. [laughs] And we're working on trying to improve it. We have a website from my lab and we're we just hired a really smart research assistants, a work study student from the University of Toronto, who's making some short videos to put on our website, which are going to be describing the work that we do, but in language that everybody can understand. So removing all that research jargon. And so just trying to make it a little more accessible for people, so they can just come to our website and find out what we do right away, and just trying to get direct messaging to the public.

Monika Szopinska 11:59

I think that's great, because I know that I often look for exercise tips if I have an injury or if I'm sore, and I can't get to the physio right away to help that. That'd be wonderful.

Dr. Kara Patterson 12:12

You had mentioned about you are concerned about your walking in that you've developed some pain. It's really interesting to me, because right now, when, right now what we know about particularly people with stroke, a lot of research doesn't follow people much after, say two or three years after stroke. And as far as I'm aware, nobody has really described or looked at some of the musculoskeletal, like the aches and pains or their concerns about their joints. We're actually doing a survey right now where we're asking people about that. But I do think it's a huge area, that that is under researched, that people haven't looked at that very much. So it's interesting to hear you say that's important to you, because that's really good information to have that lets us know we're on the right track, when we're thinking about things like, "Oh, I think we should describe this", or "I think we should do a survey about this to find out if it's an issue or a problem.". So to hear you say that "Yeah, actually, it is.", that helps us. That's really good to hear in the sense that it helps us know we're on the right track, that we're doing something that might be useful.

Monika Szopinska 13:21

I think so, I think you are on the right track. I think that looking at sort of the residual damage of having an asymmetrical gait while you're moving is huge. And I think that it's also a great argument that then if anyone wants to advocate for proper care and rehabilitation for people with neurological disorders, through the government, because if you find that enough people are getting the secondary injuries and having to have a hip replacement quicker, or knee replacement quicker, or whatever it may be, or

they're immobilized, they need personal care, then it could save the government money by providing people with proper physiotherapy earlier on to try and mitigate that damage, right? So I'm glad you're looking into that.

Dr. Kara Patterson 14:09

Yeah, you raise a really good point about this idea of having to advocate or, or try to influence policy in a sense about what are you what should we be focusing on when we help people with therapy? Because oftentimes, in our work, and Lucas might even be able to talk about this a bit because he was interested in symmetry as well. I kind of find there's two camps. So I have some people who are like, "Yeah, I see where you're going with this, I think symmetries are also an important feature of walking. We should be focusing on on trying to help people recover that.", and then I have then there's another camp of people who are like, "You know what, that's the best like that, that represents the best that people can walk because they have hemiplegia and, you know, it's more important that they can walk at a certain speed or that they can walk far. So why are you even wasting time worrying about this? You should really be focusing on walking speed and endurance, because that's related to quote unquote, 'function'.". And but it's so it's very difficult to sometimes to make the argument that maybe in the short term, yes, and I'm not disputing that those are two important features we should be concerned about and people with stroke tell us that's important to them. But long term trying to make that pitch about, but we long term, this could be a bigger issue. But we don't know because nobody's described it yet. So yeah. And then and then you're right. If we can show that, then it makes it much easier in the short term to make the argument that "No, we should be caring about symmetry as well.". But you also I'm going to, I need to take notes after this conversation, get good ideas, we didn't ask about joint replacements. But that would be really interesting to ask people with stroke about whether or not they've had to get a joint replacement. And I think too partly because the age of onset of stroke is getting younger, so people are walking this way and walking for longer, longer. And so the longer you expose something to asymmetry, the more likely these secondary musculoskeletal issues could happen. So joint, that's a that's an excellent point, it'd be interesting to note.

Monika Szopinska 16:17

I had no idea that you're finding that unfortunately, stroke occurrence is happening in a younger population. That's very, very disturbing, isn't it? Not that we want seniors to get it, but it's very sad.

Dr. Kara Patterson 16:31

Yes, yeah. I've even noticed it over my career of doing research from the time I was a graduate student to the time now. Oh, my goodness, how long has that been? About 11 years? And when I look at the research groups that we, when we calculate things like what's the average age of the group? And what's the gender split? And those types of things? I've noticed over the years, my study, that average age of people in my study who've had a stroke is is decreasing. But yeah, it is, it is a trend, unfortunately.

Lucas Crosby 17:03

Kara, you mentioned that Monika did participate in some of the research that we are doing, I think you had some questions about what Monika's experience was like. So why don't we take the conversation in that direction?

Dr. Kara Patterson 17:17

Yeah, Monika, so I'd be interested to hear a little bit more about what your experience is like participating in research studies and I think you might have participated in others from other labs, so it doesn't have to necessarily be related to the studies that you've helped us out with. But yeah, I'm really interested in what your experience is, and maybe a little bit about maybe a significant experience in research that had an impact on you either negative or positive, something that stands out in your mind about having participated in a research study?

Monika Szopinska 17:52

Sure, sure. So I think it's very curious about what this research was all about, right? Because I, we live in Toronto, we have these great hospitals and centers all downtown, so whenever I go to hospital to visit someone, I see all kinds of posters about research, but usually couldn't participate. And then I happened to be at the rehab center and saw the posters for different studies, including yours. I thought, you know, I have the time I can do this. And I was so curious, what does it look like? And the idea of, of having an opportunity to witness a new method being tested and experiment, and science, really science, I mean, you read about science, but you don't really think you're going to participate in science. So for me, the experience in, in being in a study was very exciting, very novel, I found it was super friendly. I was surprised by how small the group I was in was because one study I was by myself, but that was just the nature of the study. But in your study, we were just a group. And I think there were six of us initially, and then maybe five or something. It was very small. And the detail, and some of the friendliness and just the human aspect of it was so interesting to me that it didn't seem like I was in a lab, like we were just doing certain things. We were told this is general this idea of this study, and there's a cohort that's going to be a control group and a cohort that's not a control group, and then it gives you sort of figure out which one you end because of what you're doing. But it was it was something that was very positive. It was very interesting, because I saw where the science is happening and what their notions are. I found, I found that I met other people, so it was incredibly motivating. Because I met people who have had stroke and have lives and are doing things, so we were able to bond a little bit, and talk a little bit, and joke a little bit. And that was very cool. And I just found that everybody was so supportive. And these young, really smart people are being the research assistants and are running their PhDs. And I mean, when you think about someone who has a PhD, you have a lot of respect for them, because you realize that they've spent so much time educating themselves, so much time working towards a goal, and then they're creating knowledge. And after all, I mean, as I said, I have been in physiotherapy for a while, at least, I guess, 25 years because of what happened to me. But these people are creating the methods that could potentially make me better potentially make the world better. It's very, very, very rewarding, really exciting. So I think for me, it was just a very rewarding, exciting experience that was fulfilled my curiosity about what is this research. I hope that answers your question?

Dr. Kara Patterson 20:44

Definitely. Yeah, that's so great to hear. We're trying to understand a little or I'm interested in understanding a little bit the experience of research from the perspective of the person who volunteers so that we can first of all recruitment, as you mentioned, the group was smaller than you expected, it was smaller than we expected too. Because trying to it takes a lot of time, particularly if you're doing a study where it's coming multiple times a week, over a prolonged period of time, if you're asking people

to give up a significant amount of time, we try to make sure that it doesn't cost them anything. So we, we if we have a grant, we're able to cost cover people's costs in terms of travel. But I'm interested in understanding it so that we can make it better or more rewarding or make it at least easier. And if there are any negative or positive experiences, it's helpful for us to know. So yeah, I was curious if there was anything that stood out in your mind that maybe had an impact on you or influence the way you thought about research.

Monika Szopinska 21:44

So I think, for me, personally, I realized that this kind of research is is is also painfully slow. I mean, you're watching people do something over weeks, and is there a change? Is there not a change? And and then you have so many people, you know, what do we do in our own time? How do we influence that on our own time, because you're not seeing what we do in our own time. But I think this is one of the significant aspects as a person participating in such a thing is, I met other people who had the same goal, right? Who had an interest in science, who had an interest in participating in something like this, had the time, and wanting to improve their physical ability, because we all want to improve our physical ability, nobody in a science group wants to be the way they are right now. Right? We're unhappy with the way their bodies are. And, and having that group, I feel like we wanted to kind of continue and stay together somehow. And, and kind of keep each other motivated in some kind of exercise. Of course, you know, COVID happened, and all this other stuff happened, and you got to let go of these things. But I think you're building a little community at that point, that can be very helpful. And it can be very motivating to everybody, because I think all of us with with with physical or cognitive deficit caused by illness or accident, you mourn that, you grieve that, and it comes in waves, right? Sometimes you're very positive about who you are and what you've accomplished. And sometimes you feel oh, you know, I wish it was better. This is kind of sucks and why. So it's nice to have that little support group that kind of pops up out of nowhere. Right?

Dr. Kara Patterson 23:25

I liked how you worded that encapsulates things this word, they're unhappy with the way their bodies are at the moment. That's really, I like that, that's the, the social aspect or the making the connection. It's interesting that you mentioned that, because when we first, so the study that you participated in, is the randomized control trial, which is kind of the gold standard, as I'm sure you're aware of having experience in research, you know, there's a control group and then the treatment group. And that's kind of the, we can do a lot of work up leading up to that, but that the results of that trial are what let clinicians know, okay, this, this, this intervention that they've come up with actually does work. And it's not just the placebo effect, because they had a control group, but we did some work leading up to that, to try and work out, "Okay, what should this dance program look like? You know, where, you know, how long should it be, though? Is it safe?". Those types of things, which was a feasibility study we did beforehand. And it was interesting, because the things that we observed kind of parallel what you just described to me, they created this really tight knit social bond or connection with each other, and that's not uncommon in research with people who've had stroke and I imagined in other areas as well. But when you've had a group experience or group intervention, you put some people in a room who have some sort of shared experience. And then of course, that's kind of a base for them to build a relationship with, but they were so connected with each other and I'd never witnessed that before. We're kind of doing a bit of research because I suspect the dancing actually helps facilitate that a bit.

But what they did was they started a Facebook group to keep in touch after the fact. And that really drove home for me how important this is, this idea that you need a space that you can connect with people and talk about your experiences. And now that I say that it sounds silly, because it kind of sounds obvious, but at the time it wasn't and so that's also started us off on some different research trying to find out, "Okay, well, what why is that important to people? And how can we create spaces and groups that can facilitate that for people?". So that's interesting. The other piece that you said about that it's interesting, because when I talk with other researchers, there's kind of this belief that, "Okay, well, what motivates people to participate in our research?", anyways, rehabilitation research, is that we were aware that there's this problem, I think you mentioned in the introduction, this idea that you work to pay for physio, which is a sad thing to say that, you know, because everybody should have access to the rehab that they need. But unfortunately, I think the rehab runs out before people have fully reached where they wanted to be in their recovery, so you're usually left to find your own. And if you can afford to buy private care, then then you can do that. But if not, then there's not many options for you. And so there's kind of this prevailing belief that in rehab research, part of what might motivate people is that they're getting treatment that they wouldn't be able to get otherwise, so the intervention in the study themselves, but I, I find it interesting that you had said, but what also motivated you, and it seems to be the more what was the one you name first anyways, was a curiosity about science and wanting to be involved in that. That's interesting to me, that's not necessarily something that scientists think from the conversations I have, I don't think that's the first thing that comes to mind when you start to say, "Well, why do people participate? And how can we try and motivate people to participate?". So it's really interesting - curiosity - which is also the reason why people go into science, is curiosity.

Monika Szopinska 26:57

It is interesting, right? Like I said, for me, around the same time, I was going a lot to Princess Margaret Hospital, I was going a lot to Toronto General Hospital. I was seeing a lot of research studies, I was always curious, what is this? What is this? What is this? And then finally, I had a chance to go quite frequently to the rehab hospital and saw and saw your stuff, poster, so it is interesting. Of course, in the back of my mind, I'm thinking, "Hey, maybe I'll get some cool therapy. This is awesome.". Right? And I mean, honestly, when I say you know, work to pay for physio, it's not quite so simple. But but if I had a dream come true, and someone said, "Here, Monika, have your life, live out the next five years, any possible way you wish.". Part of it would be, you know, snorkeling with the most beautiful tropical fish I cook every day and have a physio and a massage therapist with me all the time. Right. So these things, I think, depending who you are, and where you are at in your own kind of rehabilitation and what your goals are, I think those things motivate you. So yeah, definitely. I mean, always looking at proper exercise.

Lucas Crosby 28:06

Excellent. I think that's some really eye-opening parts of research participation from Monika's point of view. And, and, Kara, I think you both had some really good points on the research experience. Now, Monika, you've mentioned, you're from Toronto, and you have access to the hospitals and the research centers in this big city that we live in. But I think you had some questions about more rural settings, and how can somebody who isn't living in the city participate in research and and get the therapy that they need.

Monika Szopinska 28:39

Yeah, definitely. I mean, before I got sick, and I had the issue, you know, my dream was to live up someplace north in Alaska and the Yukon and do my own thing. And eventually, because of health complications, not only physical, but also other, realize, you know, better not better, hang back in the city and use the resources that I have available to me, but there are people elsewhere. So what do they do? How do they manage? First of all, how do they can they participate in research?

Dr. Kara Patterson 29:11

Yeah, that's a great question. That is something that's kind of again, another one of these areas that are receiving more and more attention. So it's, it's more, it's difficult. Research tends to happen or clustered around the universities, right? So kind of in that little radius around the universities, but what is opening up the possibility and what people are interested in a little bit more now particularly related to rehabilitation research is the concept of tele rehabilitation. So using like, Zoom, like conferencing, video conferencing or even just on the phone but trying to connect with people in their communities, so somebody from Toronto would call somebody say in Thunder Bay is the example that we're working with that. That's opening up some opportunities, but it's not the same experience. So we, well, before COVID, and the pandemic, as you already put in, mentioned there that's kind of put a wrench into things. But before the pandemic, I was talking with a clinician up in Thunder Bay, who was interested in trying to start a dance program up there. And so I was helping and consulting with them through video conferencing but also we've looked at trying to livestream dance classes so that people in their home can participate. And so it's kind of, it's a nice option to have I unfortunately, I don't think it really fully replicates the experience of being there in person, but at least it's an, it's an option for people living in rural areas is this idea of, of using the technology that we have, so people can either receive therapy and or participate in research.

Monika Szopinska 31:02

It's at least something right. It's not perfect, but it's something.

Dr. Kara Patterson 31:09

Yeah, yeah, exactly. It's not perfect. Something better than nothing.

Monika Szopinska 31:13

Yeah. So so yeah. One of the things I'm wondering about also, is there are different methods for physiotherapy, as far as I know, I only know one really well, but how do therapists who work or universities that teach, decide on what's the best method for people to apply to rehabilitation.

Dr. Kara Patterson 31:38

I teach in the physiotherapy program at the University of Toronto, and I'm I also am a physiotherapist. So I kind of can speak from both those perspectives. The approach that we take, both in our training as physios and then in education as people who train the future of our profession, is to graduate what we call a generalist. So somebody who has knowledge about a bunch of different things, approaches, techniques, different fields like neurological physiotherapy, orthopedic physical therapy, so that they can be put in a situation and then, and then pretty much take on whatever's presented to them. But the other emphasis is placed on this term of being a lifelong learner, so the idea that we're kind of setting

you up and giving you the tools to get you started as a physiotherapist. But that, that when you graduate, your journey doesn't end there, that once you've graduated, you're always expected to continue to learn and develop your skills, because the science is always changing, because we're doing new studies and coming up with new information. So physiotherapists will take what's called professional development or continuing education courses throughout their career. So where they go back into a classroom, or they go to a conference, and they take classes, or they go to research talks to learn the new information, but how they decide on a, which is the best approach, it's really physios focused on tailoring it to their patients. So it's actually probably links back to the concept that we had about how does research translate into clinical practice, which I can circle back to if I don't get too far down one path, but this idea that a clinician works with their patient, they ask the person what their goals are, and you know, "What's bothering you? What's your issue? What are your goals?". And then they work together to develop a plan, and then they select from their kind of toolbox, which techniques and which approaches do I think are going to help this particular person in front of me right now achieve those goals?

Monika Szopinska 33:46

I see. So it's really, really a question of professionalism within the clinic and professionalism of the individual, and being able to have access to further training so that they can become experts in whatever areas interest them or their clients, and then be able to pull that information together. I guess, If someone has a choice, they should really be interviewing the clinic, they're going to and saying, "So where have you gone for your professional development? What do you know about this?". Yeah, in order to buy the best possible service. That's the way it is. But are there are there therapies that are measured against each other? Or how do you know that this is no longer works? Like, let me just illustrate this for you. So I had a stroke when I was 24 and I became hemiplegic. And at that time, I went to an OHIP funded clinic. And the lady put on a bunch of electrodes on my thigh and a bunch of electrodes on my arm for two months and kept pumping electricity through me, and that was fine. And you know what? I recovered fully, and eventually someone told me "Yeah, but that was neuroplasticity. So don't you worry about that. That just happened because that's how it happened. That electrode didn't have anything to do with it.". And then I know I had another stroke. And, and the same thing happened. I was paraplegic. And I did all kinds of manipulative therapy. And I did all kinds of other therapy. And it happened very, very slowly. And I got some movement back. And things were coming back. And they said, "Oh, but that's the physiotherapy. But the electrodes would not help you, don't use the electrodes, there'll be really bad for you, right?". And then just recently, somebody else said to me, "Oh, no, you need to use the electrodes, that's going to be really great for you. Start using them, you're going to rebuild your muscles, you'll be repowering your brain, just keep using the electrodes. They're fantastic.". So how do I know? I mean, I can experience what I'm doing. But how do physiotherapist know where who guides them?

Dr. Kara Patterson 35:47

Yeah. That's a really interesting experience. And you just showed the whole kind of circle of how things come and go. That's really interesting. Monika. Yeah, how do you know [laughs] this is a thing we struggle with. So there's a couple of challenges that I see from my perspective as a, as a person who used to practice clinically as a physio and now does, does research. The, as I mentioned in the before, the gold standard, kind of the really the way that's been touted as the, this is the way we definitely

know what's better, is to do a research study where you compare these things head to head, and you take the same measurements in each group, whatever you're interested in. So I want to see if this intervention makes people walk faster, or makes people have better balance, and then you pick a measure and you measure it at the beginning and the end, and you see which group improves better. And then at the end of the day, the scientist kind of says, "Oh, now we know that this intervention A is better than intervention B, and everybody should receive this intervention." And so the way people thought it should work is that then clinicians will read these papers and then say, "Okay, I should use intervention A from now on." But that's never the way that it works because there are so many other factors. But in rehab, it's so multi dimensional. And there's so many factors that play into the interventions that people will receive in person, as a person with stroke, they go to rehab, they receive all different kinds of approaches and interventions. And it's a real mixed model, a mixed bag that's tailored specifically to them. But then in science, we say, "Okay, everybody's going to get this exact same intervention, rehab intervention." And then that's, that's what we test. But in reality, that intervention is not going to be the exact same way applied in clinically because you've just taken away the whole thing that makes rehab and physiotherapy unique, which is communicating with the patient, asking them what their goals are, and then coming up with an individualized treatment plan. So that, I think that's what complicates things of knowing which one's best, because in reality, we take a bunch of people have had a stroke and they have different lives, different backgrounds, different goals, they have different impairments, because no one, no stroke is the same across different people. And some of them get better, and some of them don't. And then we kind of take an average. And if the average got better than we say, "Oh, this is something we should use, this is great." But the reality is the clinician then has to decide, but you did that in a group, I'm dealing with a person one on one. How do I know that the person I'm dealing with is the one who gets better? Or the one who doesn't? So it's a huge problem for them to know, it's not really a good answer in terms of giving you the final answer of how do they know but I think clinicians really just focus on I'm going to measure the goals that my patient has, I'm going to ask them what they want to improve, we'll take measurements, and then I'm going to continually monitor them to see how they respond. And if they get better and if they move towards the goals they want to achieve, I keep doing what I'm doing, and if I see that they don't, then I'm going to change up my plan.

Monika Szopinska 38:59

No, it is it is very interesting how things can move forward, and how can they help? And I think the point that you said that really resonates with me is every brain injury is different. And you can't always say "Oh, just because this worked for Joe is going to work for you know, Mark." - no, not necessarily. Because every brain injury is different. And everybody has a different lifestyle, nutrition, stress, happiness, all these things, level of ability to practice. But I think using different methods and benefiting from that, that research can help a change a person's life. Right. And that's why it's so important.

Dr. Kara Patterson 39:49

Yeah. That's the goal anyways, sometimes it is very, maddeningly slow though, as you mentioned, it can be, the progress is not, uh, you'd like it to be faster, that's for sure.

Lucas Crosby 40:00

Monika, you've mentioned some things that were important to you and things that you think research could focus on. But yeah, Kara, you had some questions about where science can go next and where stroke rehab can go next.

Dr. Kara Patterson 40:15

Yeah. What do you feel research should be focusing on? Like, what are some of the questions that you have about recovery and stroke that you think, you know, people aren't paying attention to this, but you need to be looking into it? Is there anything that stands out in your mind?

Monika Szopinska 40:28

I do think that there's probably hundreds, if not thousands, of different questions scientists can ask themselves, and, and try and find answers. I think that, luckily, there's so many universities and so many departments, there's lots of people who are doing all kinds of research, so these questions are being answered. But I think almost, there's, for me, not being an expert in research, not having read rehabilitation research, there may be things like that are much more practical, in a sense, without development of new technology, or without anything else to seeing the effect of therapy on people. For example, I was struck...when I go to physiotherapy and I see people getting their therapy treatments up to all kinds of levels, and their movement and what they're trying to get. And then I'll go to a country like Poland, or Ecuador, or Peru and I noticed people who have physical disabilities who look, which looked like a stroke hemiplegia, and their movement and their stiffness and their hip hikes and their knee extensions. And I think, wow, you know, maybe in Canada is really great. But what does it mean not to have physio, and that differential of what does it mean to have physio, what does it mean not to have physio to just even something like that? Where, how much better, are you? And again, it's tricky. How do you research something that's so unique to every person, but, but seeing that the benefit of quality of life, seeing the cost benefit of being able to have a better life and work perhaps, or contribute or in some way, be more independent? So that's one aspect of research. I think it's the cost of not having rehab or the incorrect rehab. And then I personally am always hoping that scientists are going to be looking at interventions that include the brain and neuroscience and technology, and maybe stimulate the brain, stimulate the neurons to reconnect for neuroplasticity with actual stimulation directly to the brain. Maybe not necessarily through some kind of apparatus that goes in the brain, but on the outside of the brain. And I know that that kind of technology is being used for applications of this stage, probably more for military than for rehabilitative, but hopefully those will come because the brain as you know, I only think it's marvelous. And there is neuroplasticity, right? And you could retrain things. And you could really change pathways. But I think we have an opportunity to use functional MRIs and use other neuro stimulation technology to really help. I also think that just for the function, like the functional electrical stimulation therapy that you were talking about, they say that neuroplasticity occurs much earlier, right after the injury, not so much, you know, 30 years or 20 years later, like in my case - that needs to be propagated and given to people so they can have the right rehab immediately. So that intervention, when should intervention happen and most intervention should happen. I'm also curious about longevity of rehabilitation, understanding that there are, as you mentioned, more and more people who are younger, younger or becoming disabled.

Dr. Kara Patterson 44:21

I think it's, you know a lot. Just from hearing you talk, like have you sought out information yourself to educate yourself or is this did you gain your information through conversations with therapists or...?

Monika Szopinska 44:35

Well, I am very lucky that I do have a very knowledgeable therapist. He's a dancer actually [laughs] so up your alley, but he is, he reads a lot. He does a lot of professional development. And so he'll share some ideas with me about what works, what doesn't work. I keep asking him about, when is the implant coming? Where can I get my neuro implant? Yeah, he says you know, not yet. But so that's kind of interesting to have a guide, I think a physiotherapist becomes almost in part a life coach, where they not only do the physical aspect, but they also help you through the ups and downs and because you see them all the time. But I also am curious about science a little bit and about rehabilitation. So if I hear about something, then I pursue it and try and find out and see what I can do. I, before my, before my injury, I was very physically active and able, physically able. And I never thought about that. And then I think one time in a conversation with some other therapist, it occurred to me that my brain was wired for physical activity. Not that I was physically active, but my brain was wired for that. So I should be still wired. But of course, I have a, I have an injury. And so that kind of changed my mind frame and made me think, you know, what is this brain? And how do I motivate it? But it's not so easy. It's easier to think about it than to physically do it. But I, I think, for example, I love swimming. So swimming is fantastic. It gives me a lot of pleasure, this idea that you are pursuing as a scientist with dance and music, that's very pleasurable, that can be really fun. I think that's that's a nice thing to do for yourself. So to make therapy really, also enjoyable...will be easier. Yeah. Because I think it can be very difficult otherwise.

Dr. Kara Patterson 46:51

That piece about it being enjoyable is, is something that yeah, you're like, that's, it's interesting, because we've been doing some qualitative research so where we interview people, instead of just taking measurements, we actually speak to people and get data that way to find out their thoughts and their experience, things you can't measure, right? You can't, they're not tangible. And this, we found that with the adaptive dance program, people talked about it being enjoyable, like they felt they still got improvement, but they also enjoyed it. And then I think too you were kind of talking about the grieving process before and this idea of what we found was people talking about, "I entered this dance class, and I feel that I'm not, you know, quote, unquote, 'a patient'. So I'm not, I'm not a patient in a stroke floor. I'm a person, I'm learning how to dance." And that was really powerful for them, and really motivating. And then the fact that it was enjoyable and fun, at the same time, but they still had the motivation and the intent to improve, but they just made it enjoyable for them. And you mentioned swimming, too. And I think, I think we could probably do more about that is okay, how can we take the activities that people enjoy and make that therapeutic, but not to the point where you've taken all the joy out of it? [laughs] But you know, capitalize on what people enjoy and what makes them feel whole and human? And, yeah, that's interesting.

Lucas Crosby 48:21

Okay, so this has been great. And I think we're probably winding down towards the end of our conversation here. So I guess I just wanted to let you both have the opportunity to, for any final

thoughts or any final questions for each other? Monika, we can start with you. Do you have any final thoughts on the scientific process, your research experience or any questions for Kara?

Monika Szopinska 48:48

It's twofold. I guess the first question I'll ask is Kara about yourself. What made you decide to become a scientist? I mean, you were a physiotherapist, you were already doing this type of work. And then something changed for you.

Dr. Kara Patterson 49:04

Yeah, so Physiotherapy is a program that's a little bit challenging to get into. There's lots of interest and not as many spots, and even more so now than when I applied. So I had applied and was, and didn't get in at my first try. And so I was looking at other options. And the other thing that I was interested in when I was an undergraduate was, was neuroscience and cellular signaling was what I was interested in. And so I was looking at the option of doing a Masters back then, like, "Oh, if I can't get into physio, maybe I'll do some graduate work in that area.". But then I did get in on the second try. And so I went into physiotherapy, the program at Queen's University, but then while I was there, and I enjoyed it, and I kind of at the time thought, "Oh, this is good.". And right away, I knew I enjoyed neuro rehabilitation. Those were the courses that I gravitated towards. But then we had the option when we go on clinical placements, so you have to do classroom theory work, but then you also have to go in on placements, so you get practice under the supervision of a therapist doing the clinical skills. And one of the options was to do a research project, instead of going out on placements, I did some placements, but then I also did a research project. And that experience was really enjoyable for me the combining the clinical aspect with the research and science part, which I had already been interested in. And I had a mentor who encouraged me actually and said, "You know, listen, you should think about doing a PhD. I think that could be a good path for you.". And so I had sort of like kind of graduated with that thought that I probably go back to it. What I did at the time think well, I've spent all this time in school, I've learned all these skills I want to get out there, I want to apply what I, what I know. So that's what I did. I worked clinically for a couple of years, but I kind of always knew I'd make my way back. And so I think what finally did it for me is, as I was practicing, I realized I have more questions than I have answers. You know, like, I've learned what I, what I did in school. But kind of as I was working with people realizing like there, there are a lot more questions than there are answers and some of the things that you brought up in the beginning, like how do I know which is better? And is this really working? And so I kind of in the end thought, you know, I I would like to go back into research to try and help the profession in advance a profession from that, from that angle of trying to answer the questions that need to be answered.

Monika Szopinska 51:35

I see, so it was always a little bit of curiosity and wanting to know more and really measuring an impact and seeing a direction that makes sense. It sounds very interesting. I'm curious Kara, you, you obviously are a scientist, you have a community of scientists in rehabilitation - Where do you see the field going?

Dr. Kara Patterson 51:57

So I think some of the things that you hit on earlier about using brain stimulation. So there is some research that's being done with that looking at combining brain stimulation with, with physical rehabilitation. So I definitely think that's a piece that's going to be gaining more traction in the future, this idea of how do we boost? Or how do we take advantage of the brain's natural ability for neuroplastic change? How do we give that a bit of a boost? And then and take advantage of that with physical rehab to improve recovery? And then I also think, really, I know, as I mentioned earlier, one of the challenges with rehabilitation research is that you do all this work, and then at the end of the day, the studies come out and say both of these interventions were fine. One's not better than the other. So we have a lot of studies that kind of come out with those kind of lukewarm results, right? Like, well, well, both of them are pretty good. And we're not really sure which one's better so and then at the end of the day, you're kind of like what did it what did I do all that work for? But so I think that we have research needs to get better at figuring out how do we test that tailoring? Like how do we, how do we adapt our research so that we get it more how physiotherapy is actually practiced. So this idea of I need to still maintain scientific rigor, I need to maintain the, the the control on the intervention, but I also need to somehow identify what are the characteristics of the people that respond? And what are the characteristics of the people who don't? So that when I now do my research, I only select the people who will benefit. And for the people who I don't think will benefit, okay, what intervention works for them? So I think that's where it needs to go. I think we need to do better on the research side of being a little bit closer to how the physios actually do it.

Monika Szopinska 53:51

That makes sense that that makes it must be a very difficult process. I would imagine, though, to try and find those characteristics and say, what is it about it? Yeah, that would be very hard, because that would be a bit of science and a bit of sort of human guessing, I guess?

Dr. Kara Patterson 54:05

Yeah, it's a little bit of guesswork, we have some suspicion so that you kind of have to do it a bit retrospectively, too. So for example, with, with our studies, what we'll do is we'll, we take a bunch of measurements at the beginning that characterize people, but you're right, that's where the guessing comes in. Because you're like, what's important to measure? I don't know. So I'm going to measure a bunch of different things I think might be important. And then after the fact, I'll look at, okay, who got better and who kind of plateaued, and then we'll compare those two groups on all these characteristics that we measured. And yeah, so it's a little bit of guesswork, and then hopefully, we get a, like a little kernel of knowledge from that and then we can move that forward and start asking more questions. And yeah, I think too more conversations about this. I think the, like this is talking with people who actually live, live that, have that experience or have lived with I know from my own perspective on my own journey of a person who had a medical condition and went through rehab, it's very frustrating to be on the other end and recognize there's so much that there aren't answers. And there's so much that people don't know. And then you feel like you're the expert because you know what you've lived, but you don't see it reflected or you don't see it being understood. So I think the other way that rehab research needs to go is to have more conversations with people who we are supposedly trying to help, because they have a lot of information that we can learn from as well.

Lucas Crosby 55:38

Excellent. So now I guess I'll give you Kara the opportunity for any final thoughts that you might have. And any final questions you have for Monika, about her experiences or her participation in research?

Dr. Kara Patterson 55:52

Yeah. Monika, what you, what the next steps are for you or what your plan is? Either with participating in research, or what you've mentioned, you had a goal to live up in the, I think he said, Alaska or the Yukon, but you've changed you know, your goals. And your, and your plan is changed. So I guess I'm interested in what you what you see in the future for yourself and what your, what your plans are.

Monika Szopinska 56:18

Yeah. So the easier question research, I would love to participate in research but because I work full time, it's pretty much impossible. And that's actually something I wanted, I'm happy to have an opportunity to share with you that unfortunately, it's an interesting cohort, right, that you would grab for people for research, yeah, who are not working. Because it already means something. And, and of course, it's harder to run research after hours, because you have staff that you have to pay. So it makes it a little bit different. Are you or is anyone else researching mood and rehabilitation? So if someone is in a depressed mood, or someone is in a great mood, and they're doing rehabilitation, and how that exercise would then work out for them? Because I'm sure there's ways to help with mood during rehabilitation, through different activities, or else not by any way that was me was thinking about?

Dr. Kara Patterson 57:20

Absolutely, Monika, you, you've touched on a thing that we've ourselves have stumbled on, is this idea, and when I say we are ourselves, I mean for me, that's not to mean that there's probably not some other scientists who's already way ahead of me on this. But within our group, we recognize that that dance can improve mood. And that's not nothing new, people knew that. So we've been measuring it ourselves to see how mood can improve. And then also, this concept of social isolation has been identified by people with stroke as being an issue for them, when they go home after the hospital stay or inpatient rehab, they go home and they feel socially isolated, which itself is connected to a bunch of different things, including mood. And what we found was that with the dance group, people really had this powerful sense of connection with both the dance assistants and the dance instructors as well as other people in the group. And then that in turn, helped their mood and also, in turn, helped their motivation to find other ways to stay active. So yeah, it is something we're kind of just at the beginning of that journey of looking at how can we improve mood? And then also does that help improve other things like being motivated and wanting to be more physically active? So yeah, we're kind of, we just kind of found that and we're at the beginning of that journey to investigate.

Monika Szopinska 58:39

Sounds like an interesting journey, for sure. Now, you had asked me about my plans, that's a little bit difficult to say things often change. But I am still working full time and plan to work for quite a while. So while I'm doing this, I hope to continue with a lot of rehabilitation and personal exercise and wellness, both for my physical and mental health. And I am hoping that I will be able to learn more about different rehabilitation, and music and therapy and how it can benefit me and hopefully also have an opportunity

to participate in some capacity in future studies, to perhaps help to shape what research will look like and make a even very, very small impact on rehabilitation for others.

Lucas Crosby 59:37

Well, that's great. Thank you, Monika, for sharing your experience and your story, that's really inspiring. And Kara coming on to talk about your research, and I really thank both of you for coming on and having this discussion. I think it's going to be really great for our listeners and put it out there for both people with lived experience and, and researchers that can really dive into some, some of the issues and some of the questions that maybe don't always get discussed and hopefully this will be a great avenue for that. And that concludes our very first episode of the Connecting the Dots mini-series. I really hope you enjoyed learning from both Kara and Monika, about the application of clinical research to participants daily lives in ways that scientists have been able to engage participants in research design and objectives. To support our student run podcasts, subscribe to us on Podbean, Spotify, Apple podcasts or Google Play Music. If you'd like to read more about Rehabilitation Research or rehabbing, you can visit our website at www.rehabINKmag.com/podcast. Thanks for listening and tune in next time.

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