

rehabINK Podcast

Connecting the Dots Mini-Series: Part II

SUMMARY KEYWORDS

injury, parents, research, youth, family, child, young adults, Johanna, adults, upper limb, brachial plexus, patient, experience, clinic, struggling, support, clinician, helping, involved, partners

SPEAKERS

Johanna Ponnuthurai, Dr. Emily Ho, Jennifer Ryan

[intro chime]

Jennifer Ryan 00:06

Hello and welcome back to the rehabINK podcast and our new mini-series: Connecting the Dots X Researcher and Community. In this mini-series we aim to bridge the gap between research and the community by hosting accessible and casual conversations between a leading researcher and a person with lived experience. A person with lived experience is someone who has first-hand experience with a health condition or injury. This mini-series provides an opportunity for researchers to share their research aims with the community, for people with lived experience to discuss their experiences with rehabilitation research, and for both parties to ask all of the questions they've never had the opportunity to ask before. In today's episode, we are joined by Johanna Ponnuthurai, a patient partner and person with a brachial plexus birth injury. And Dr. Emily Ho, who is an Assistant Professor in the Department of Occupational Science and Occupational Therapy at the University of Toronto, and the research director and clinician investigator in the Division of Plastic and Reconstructive surgery at the Hospital for Sick Children. My name is Jennifer Ryan, and I will be the host of today's episode. I'm a PhD candidate at the Rehabilitation Sciences Institute at the University of Toronto, and a physiotherapist at Holland Bloorview Kids Rehabilitation Hospital.

[intro chime]

Jennifer Ryan 01:37

Welcome Johanna and Emily! Before we begin with some questions that you've prepared, why don't we begin with some introductions? Emily, would you like to begin by telling us a little bit about yourself, your research, and how you know Johanna?

Dr. Emily Ho 02:03

Well, thank you, Jennifer, for this wonderful introduction and opportunity to talk to the rehabilitation community about my research, but also to have a dialogue with Johanna. Thank you Johanna, as well for being here. As Jennifer mentioned, I'm an Assistant Professor in the Occupational Science and

Occupational Therapy Program at the University of Toronto. But I've been a long-standing clinician at SickKids in the Division of Plastic and Reconstructive Surgery, and my clinical practice was in helping infants and kids born with congenital upper limb differences, that is children who have missing or underdeveloped or extra parts of their upper limb and hand, and also with those who may have injuries at birth, such as a brachial plexus injury, a condition that Johanna has, which affects the movement and sensation of the arm. So, I've been working as a clinician in this area, for a long time, and working with these children and family, I became really interested in how we evaluate and make decisions about surgery and rehabilitation interventions to improve upper limb function in these children and youth. And so I worked on developing tools to measure function and to research pre- and post-treatment. And through that, I found this important discovery and that was, you know, what matters most to our youth and families. And what impacts them isn't necessarily their physical condition. But it's their psychological well-being and their social interactions as well, and related to their upper limb difference. And so that's why my body of research now, which is housed in the Occupational Therapy and Occupational Science Program, as well as Rehabilitation Science Institute, really looks at the physical, as well as the psychological and social determinants on how youth with upper limb differences, participate in their daily occupations, or the activities that matter most to them. And so that's really what my body of research is about. So important to my research is the engagement of youth with upper limb musculoskeletal differences, as well as their parents to partner with me in my research. And really, I love their input to co-create my research questions and the materials that I use in my research because journeying with them really helps me to research what matters most. And it facilitates real world application and that's why I'm so grateful for Johanna and her involvement in my research and the support of her in my research activities.

Jennifer Ryan 04:33

Thank you, Emily. Johanna, would you be able to tell us a little bit about yourself, your experience with brachial plexus birth injury, and your role as a patient partner?

Johanna Ponnuthurai 04:44

Absolutely. Thanks, Jennifer. I have a brachial plexus birth injury in my left arm. So very simply put, that means I have nerve damage in my left arm, which limits a lot of my fine motor skills. And my left arm is also weaker than my right arm. So things that I have difficulties with are gripping objects, lifting items that have a weight to them, doing up buttons or zippers or putting earrings on, to name a few. These are things that I encounter every day of my life and have to find ways to adapt, work around, find ways to do the things that I want to do or ask for help. Through my whole life, I've interacted with SickKids and the team in the brachial plexus clinic, who has supported me all the way until my adulthood, and helped me find new ways to do things that I wanted to do and the things that I wanted to accomplish.

Jennifer Ryan 05:35

Thank you so much, to the both of you for sharing a little bit about yourselves. As you both know, the aim of today's discussion is to give the two of you a platform to discuss research from both of your perspectives. And I know that you've prepared some questions in advance for each other. So if it's okay with you both, perhaps we can get started with those questions. Johanna, would you like to start us off?

Johanna Ponnuthurai 06:02

Sure. So Emily, what made you start involving patient partners in your research?

Dr. Emily Ho 06:08

You know, it's, it's wonderful. And I think about the many years that we've had a chance to have discussions, and I think back. When did this happen? Why why did it all of a sudden, did I really long to have input from parents and from youth? Well, I, when I really think about it, it comes back to when I was a doctoral student, and I'm a proud alumni of the Rehabilitation Science Institute at U of T. And my project was focused on a clinical problem that I saw as an occupational therapist. When you have a brachial plexus birth injury, and you have a nerve injury, some individuals have a stiff elbow. So it's stiff in the sense that it's stiff in a bent position. As an occupational therapist, we would provide interventions such as stretching, casting, splinting, to help increase the range of motion, and flexibility of that joint. And I spent years with many different teens problem solving through this decision - do we stretch? Do we splint? Do we cast? How does this help with your function? How does this help to improve how you do things? And what I found was that over the years, this decision was difficult, difficult with from my perspective, because the youth would engage in, you know, have like casting, but then they would stop, they wouldn't adhere to the treatment, because it was just too frustrating for them. And they didn't like wearing the splints. And so I thought, you know, this decision is a very tough decision, because it's hard to adhere to this treatment. So my doctorate was on making a decision aid, a decision aid to help these youth and their families make these decisions. And I thought this was a big problem from a clinical perspective. And I wanted to get all the information possible, all the evidence about all the treatments possible, and give them to the families to make sure they had what they needed to make a decision. And so the first thing you do when you do a decision aid, is that you interview the stakeholders that are going to use the tool. And so I had to interview youth and family. And that's my first time doing qualitative research. And that was interviewing and getting a sense of what's the meaning behind what their experiences are. And that's what interpretive qualitative research is. It's about finding, you know, what are the lived experiences? And what do the people that have experienced that, what do they draw meaning out of? And wow, was I in a big, big surprise, because it wasn't about all the information that they needed, that came out of this. But it was, it was the relational processes in making that decision that made the difference. It was the relationship with their clinicians, with their surgeon, with their therapist, it was a relationship between the youth and the parent that mattered. And that small piece in regards to that information was very small, the information that they needed to make the decision, but the bigger piece was about the relationship that they had with those that were helping them through this. And so I realized how I kind of missed the mark when I started my research, because I wanted to focus on the information. And so that's when I realized, getting the input of youth and families and parents throughout the research process is so important to focus in on what matters most, to make sure my research question focuses on what matters most. And that's how it all began. And and that's how I really decided I need to make sure that within my research program, I'm involving youth and families throughout the process. So now I have a group of youth that I called my advisory group. And I meet with them either as a group and I hold meetings if there's a, you know, a new project that I need input on and I want multiple views. Or sometimes I might just call up a youth and say, "hey, you know, what is your thoughts about this?" and to dialogue with them. And other times I call upon parents. More recently, we had a mental health health professional survey that we wanted to send out to get a sense of their perspectives on the services that are needed for mental health to

support our youth. And I got one of our parent partners to look at the survey and she said, "You know what's missing on this? You know, most of us have to wait for services - you didn't ask them about wait times". And so that's just an example of why it's so important for us throughout the process, as researchers to ask youth and families and parents to be involved. Because sometimes we look at things one way that parents and youth look at another way. And together, we make it that much better. Johanna, you got involved in my research before my doctorate? How did you get involved in our research?

Johanna Ponnuthurai 10:30

Yeah, that's right, it was a little bit different, how I ended up getting involved. So I started learning about the world of research in university and I was curious about it, but I didn't really know how to get involved. And I was always interested in learning more about my injury. So I ended up reaching out to you and Dr. Howard Clarke, for direction and just asking how I can get involved in what I could do. And I ended up working for you as a research student. So that was my first introduction to research and engaging with you as a patient partner, especially when we had the opportunity to do a project that looked a little bit more at brachial plexus injuries. That's where our dialogue really started. So the way I got involved in research was not the typical way. But I think nowadays, we have more formalized ways of how patients can get involved in your research specifically - do you want to tell us more about those ways that patients can get involved in your research?

Dr. Emily Ho 11:30

I would love to thank you, Johanna. You know, I'm glad that you brought back memories of how you came on boards of research program. And that was before, I think there is a larger movement to have patient engagement in clinical research. At SickKids we're very fortunate, there's actually a formal program called Patient Engagement and Research. And it's a specific program in which our clinical research offices have created in a way to help patients and families that are interested in research to get trained. So there's actually virtual and formal in-person training, to help them understand what the research process is and how to get involved. And so that's one way people can get involved. And I also have a formal way in which, in terms of my lab, how I involved youth and families as well. And that is usually typically through our family education days. So in our clinical program, we have educational days and events where families come in, and they receive support through one another for mutual aid, as well as to get education from the interprofessional team. And during those days, we usually ask youth mentors to speak and shared about their lived experiences with having an upper limb difference, such as a congenital hand difference, or brachial plexus birth injury. And through those contacts, I often approach the youth to ask them if they'd be interested in participating as a Youth Partner in my research. And that's how I formally asked youth to get involved in my research. But I think it's also important, I realized, when I reflect on that, the other way that I find really important to engage youth and parents in research is very informal. I find it's really important that, you know, when I have families in clinic, and they're participating in one of my research projects, you know, I may have my graduate student, or my research coordinator in clinic and consenting and doing patient reported outcomes, because a lot of my research is questionnaires, which is called patient reported outcomes. And so when they're completing this, there's a lot of wait time. And sometimes I'm able to drop into clinic, and you know, after they're consented, and, you know, the parent might be waiting, and often it's the parent waiting for the youth to finish the survey, I may be able to chat with them aside and just ask them, you

know, what do you think? What did you think of the survey? Or what did you think of the research? And actually, what I find most interesting is just what they choose to say. And it just gives me a sense of what's important, what they pick up from the research and the research question, because I may be thinking something, but it's just asking that question of what did you think? How did it go? And what are your thoughts? And I love just actively listening to what they have to say, because it just helps steer where my research should go. How about you, in regards to your involvement, what kind of draws you to research and participating in research? I know I have discussions with patients and families and I enjoy those discussions and I know that we enjoy having dialogue - I'd be interested to know what draws you to continue participating and being a patient partner.

Johanna Ponnuthurai 14:33

I think what draws me in the most is being involved in my care a little bit in a way and also being involved in making things better for kids who will come behind me. If I can help support younger children with the same injury and make things a little bit easier for them, that really is just everything for me. The other thing is I guess I'm a little bit nerdy, in that I... in university, I just thought it was fun, I took the research courses and I was like well, let me research my own injury just just out of curiosity and just for fun because I'm curious about it. I want to know more. I want to know, like, does everybody experience the same thing that I do? I think I knew that, you know, an injury isn't, what isn't a one size fits all. But I was curious to know what other kids might be experiencing, or going through, and if they were experiencing the same thing as me. So engaging as a patient partner is, is a really cool way to meet other kids with the same injury or other young adults with the same injury and learn from their experiences, bond over, you know, having the same struggles or having someone understand what you're going through, and learning what someone else might struggle with providing tips or tricks. I've learned so much from other patient partners whenever we've had those group discussions. And it's, it's also been fun to be able to share with younger patient partners, what I might have experienced and what they might be facing ahead of them.

Dr. Emily Ho 16:13

Johanna, thanks for sharing it. You know, it's when I hear you speak, I realized that you're talking a lot about mutual aid. The fact that you're involved in my research allows you to have an opportunity to speak with other patient partners and other youth that have the same condition. Is that new to you, in regards to having the opportunity to talk to others about living with a brachial plexus birth injury?

Johanna Ponnuthurai 16:37

That is new to me. Most of my growing up years, I never got a chance to interact with others who had the same injury as me. I knew that I was going to SickKids to a brachial plexus clinic. So in my head, I knew there were other kids, surely there must be other kids who have the same injury as me, but I never encountered them. I certainly never encountered kids in my daily life. So in the last couple of years, as I've had the opportunity to engage as a patient partner in more of a group setting, and speak more with kids with the same injury, young adults with the same injury, it's been really refreshing and encouraging to know that, you know, I'm not alone, I'm not the only one struggling to tie my hair in a ponytail. There there's other girls who struggle with that as well. And it's, I'm also not the only one who's, you know, trying to beat the odds and do the thing that, you know, someone might say that, there's no way you can do that with that injury.

Dr. Emily Ho 17:40

I remember one time you were talking, some of the discussions you were having with some of the young adults about what it was like to live on your own. And after moving out of the house and, and being on your own and some of the struggles you had there, which really kind of was eye-opening for me as a researcher and as a clinician in regards to what is beyond the four walls of SickKids, in which most of our work is housed. What did you find different about after you left SickKids and your experiences then?

Johanna Ponnuthurai 18:11

Immediately after leaving SickKids after turning 18, I thought I was just fine. I stayed home for university. So my day to day was actually pretty, pretty much the same as when I was in my teens and still going to SickKids. I was just in university, maybe less so into sports as I was as a teenager or less so into more physical activities, as a teenager. And university is more about hitting the books, but it was after university that I actually moved out on my own. I moved away from home for work, I got a really great job. And that was my first kind of opportunity to live on my own. And I really thought it was going to be just fine. I mean, I was at home, living an independent life. Not really thinking twice about asking my family for help, whenever I needed help, because that was a part of my everyday. But it was when I moved out that I realized that I had to learn new ways to do a lot of things. Something as simple as cutting my own nails all the way up until I moved out. I didn't think twice about asking my mom for help because I really could not manipulate the scissors or clippers to cut the nails on my dominant hand. The other thing that I started experiencing when once I moved out was I started encountering pain and stiffness because I was sitting at a desk more. You know, in university, I wasn't at a desk eight hours a day, I was maybe going to class for a couple hours, had a long break, maybe a couple hours later, have another two hour class but once you're working every day, I was sitting at a desk and I was also taking transit a lot more and I experienced pain and stiffness. So at this point, I'm into my 20s I've definitely moved on from SickKids. I don't have that team that was always my go to as I was growing up. So, with my interest in research, I started looking towards the literature. I ended up taking a couple classes and learning about systematic reviews and literature searches. So I thought, why not look and see if there's literature about other young adults with brachial plexus birth injuries and see what they're experiencing. But I struggled a little bit to find something so specific, I didn't really find too much about that transition for children with brachial plexus injuries and that transition into adulthood. So, my question to you, Emily is what is being done to research the transition into adulthood?

Dr. Emily Ho 20:57

Johanna, you're absolutely correct. When we look at the literature, there is very little research in regards to what life is like for adults who have a brachial plexus birth injury, or adults who have an upper extremity musculoskeletal difference. And actually, there is no Canadian study specific to brachial plexus birth injury. And that's why, when my graduate students, Lexi Davidson came on board at September, and was working with the youth to take a look at their outcomes in participation. She looked at the literature and said, there isn't anything out there when it comes to being an adult. How are adults doing? How are you doing with your daily activities, and whether or not you're engaging in activities that are meaningful to you. And so she talked to the team and we've already had that interest in transitions in care but because of her strong interest and passion, we decided, hey, let's really dive in

and look into this. And so Lexi is basing her thesis through the Rehabilitation Science Institute, on specifically outcomes in regards to adults who have upper limb musculoskeletal differences. So the first thing we're going to do is we're going to look at the here and now, how are adults who have musculoskeletal upper limb differences participating in the activities that are most meaningful for them? So we're looking at variables such as you know, what is their physical outcomes, their psychological outcomes, and then we're looking at factors that may affect their participation, such as socio economic status, and education. That's the project that we're doing in the here now and that's going to be using patient reported outcomes, which are surveys. But we're also going to get a select number of adults to engage in qualitative research. Lexi is going to interview them and get them to reflect back on their childhood. And we're going to hone in specifically on two influences: parents and peers. We're going to ask them in terms of, you know, the sense of autonomy or the sense of choice that their parents gave them when they were kids. And then their peer group, how did their peer group influence them in regards to the activities that they felt that they could do when they were young? And then perhaps how it influences their choices later on in life in regards to their career choice, and the activities that they're choosing to engage in as adults? What do you think, Johanna, do you think that that's we're on the right track and looking at that in terms of looking at parents' influences and peers' influences, in regards to how you do things later on in adulthood?

Johanna Ponnuthurai 23:33

Absolutely, I think that's exactly it, which I don't think I quite realized until maybe as an adult, when I look back. As a child, you rely a lot on your parents, your parents are the ones teaching you, raising you, guiding you. So even as a child with a brachial plexus injury, the support you need from your parents is heightened even more. You're looking to them for help with a lot of things even all the way up into your teens that maybe another child might not need as much support with. So in clinic, as a child, you know, visiting the brachial plexus clinic when the question was asked, "What do you need?" I feel like as a child, I look to my parents a lot, because they're the ones who knew better than me. For me, my injury was normal. I didn't know any different. Having a left arm with a brachial plexus injury and a right arm that without injury was normal. I didn't know what it was like to have two arms that functions the exact same way. So when my parents were saying that, "Oh, she needs this, she needs that". I was more inclined to agree with them because they knew better what I was going to encounter ahead of me in life. They also could see what I was struggling with and could think ahead to "Oh, she might need this, to be able to accomplish that".

Dr. Emily Ho 25:01

What I hear is that you're sort of saying, you know, growing up, you felt like you were born with a difference in your arm. And that's all you knew, and that's how your arm should function and your body as a whole. But your parents kind of knew what the potential may be in your mind or what the possibilities may be in regards to potentially improving the physical function. And it sounds like you had a very healthy relationship that way, in which you had a trust in the sense that they kind of knew what was ahead for you, and potentially contributing to that decision making in regards to what could be offered to you in regards to physical treatment.

Johanna Ponnuthurai 25:41

Yes. From a young age, my parents always said, “Okay, you have this injury, but let's not let that limit you, you can do anything you want to do. It doesn't matter if you struggle, do whatever it is you want to do”. My mom was a big supporter in putting me in anything and everything, and just letting me do all of it. There was an acceptance that I had an injury, but she would not accept that it was going to limit me in any way of any aspect of my life. Even when my younger sister came along, my parents were very good about not showing us any difference. It was like, “Okay, your younger sister's gonna do this, you can do that, too, you're gonna do this, sure your younger sister is going to do that, too”. I would say the influence of my parents was very positive and very supportive in helping me become who I am today and how I view myself today. But I know that's not always the case, for a variety of reasons.

Jennifer Ryan 26:43

It sounds like your parents were very supportive and are very supportive, and that they gave you a lot of opportunities. But everybody sort of has a different perspective when they look at things. So when you look back at different things that you did, or that your parents motivated you to do, do you have any different perspectives on it now? And would you change anything if say, if you were in the role of the parent in that situation?

Johanna Ponnuthurai 27:15

I do give a lot of credit to my parents, and how they pushed me to do anything that I wanted to do. I think, if I was left to my own devices, I would have been more fearful to try new things, or do the things that were hard. I would have been more likely to give up if my parents hadn't pushed me to keep trying at a really young age. There are occasions where my mom and I will reflect back on moments of my life and she'll say, “Oh, maybe I pushed you too hard”. And I might tend to agree with that. But I do know, looking at where I am today, I needed that push. If both my parents hadn't pushed me, I think I would have leaned more on sitting on the sidelines, and not pushing against everything that was difficult, which is a characteristic that I think I've applied to all of my life, not just the physical challenges that I might encounter. It's a mindset that I think my parents instilled in me to apply in all areas of my life.

Dr. Emily Ho 28:19

Johanna, that's, it's so encouraging to hear that dance between your parents and you. You know, your mom pushes you a little bit more and you know, she knows what you need. And then you're able to succeed. That dance is sometimes challenging for some of the families that we research and actually see in clinic. And I'd love for you to tell me a little bit more about your parents. You know, how did they know what's best for you? How did like what how did that dance happen? Because I can tell you about the other side in terms of some of the struggles that some families have. And I think what you will share be very insightful to them.

Johanna Ponnuthurai 28:55

From talking with my parents, I don't think it was an automatic response for them. It was hard. They... I'm the oldest child, they were not expecting to have a child with a brachial plexus injury. They were not expecting to have to take their child for surgery right at 10 months old. My parents had to come to an acceptance of that this was the injury. They were going to work with the clinical team to do whatever could be done to help me function in life and do well in life. But I think my parents resolved that it was going to be on them because they were with me every day of my life. Visiting the hospital, seeing the

medical team, wasn't every single day, that might be every couple of months annually. But they resolved that they were going to be the ones to make sure I succeed in life. When I talk to my parents and ask them, what it was like for them when I was a baby, they do admit that it was hard. They there is no handbook, there is no step by step guide on how to help your child that has a physical injury, especially as a baby, when I, you can't tell your parents what's actually wrong, or if something hurts like, especially when it's your first child, you have no idea if this is what every baby, is how every baby is going to react, or if this is something that's more related to the injury. My parents took the card that they were dealt and decided that they, they also were not going to let anything, stop them from helping their child live to their fullest potential.

Dr. Emily Ho 30:45

You know, there was so much in what you just said, you know, in terms of there's no handbook. And you know, that your parents dealt with the cards that they were dealt. But also, one thing that struck me was the very beginning of what you said was that they accepted that you have a brachial plexus birth injury, you know, they wanted to improve your function as much as they can, but they also accepted it. And I actually see that as a researcher, in regards to that being one of the key things with our families is, there's a difference between a family that's accepts, you know, the, the child has a difference, a lifelong difference in an impairment in their limb, and ones that want to fix it, which would be different, you know, you want to improve it within this understanding that your subject, this is a condition that your child is going to be living with. And they can do any anything possible with it. And you're going to accept that. And then there's others who are still struggling to find, if we can make this "normal", or if we can make this and fix this situation. And, and so I see a difference in that and by the researcher, because we know there's, there's studies out there that actually show that in regards to, you know, parents who are still struggling emotionally, and having a hard time accepting or pushing their child's perhaps, to be more closer to being fixed, which has its consequences psychologically for the child. And and we've heard that in some of our qualitative interviews as well in terms of how that feels for some of the youth. Because like you said before it so if your arm is all you've known, and many of our youth have been saying that as well, is that their arm and their, the way they use their arm is all they've ever known. So please don't try to fix me, but help me along the way, in regards to understanding my experience. Actually, that makes me actually tell the story if that's okay, about that. Because one of our qualitative interviews, we were interviewing young adults. And what struck me and I think this personally struck me as well, because I'm a clinician and a researcher. And as a clinician, this young adult said, "My therapist helped me and taught me how to tie my shoelaces when I was a kid. And I remember that". And then they proceeded to say, "...but she didn't ask me how it felt that I had to ask for help". And it was so profound when I heard that in the interview, because as a therapist, and as a researcher we are we think of outcomes, right? "We think of, okay, can they tie their shoelaces? Have they got the skills to do that?" But what this young adult was saying is, "did you journey with me to know that the fact that you had to teach me, the fact that I had to do it differently - how does that feel?" And that's what makes the difference in my journey. It's those kind of experiences as a researcher, where I was like, oh, we need to hear the voice of our youth, we need to hear the voice of our parents. We need all the voices, even our clinicians, all to be heard, because they're different. And what does that mean, in real world to help all three? If we look at it, clinicians, parents, and youth to make decisions that are right for them in the healthcare context? So I guess I can throw that back at you in regards to how, how do you think we can best do that here? Get all the voices heard? To make sure especially as a young adult, and as a as

a youth, you know, that is growing up? How do we make sure your voice is heard and research and heard in the clinical realm?

Johanna Ponnuthurai 34:03

I think that's a great point. I definitely think everybody's voices need to be heard. Because especially with a brachial plexus injury, it's not just the patient, the parents are there too. And they have to work together. I think it's important that each parent and child voices are heard individually, but also collaboratively.

Dr. Emily Ho 34:25

Collaboratively is tricky. How do we do that? Because sometimes they talk over each other. I love the fact that you said it's important to be collaborative, when you hear their voices together. Why is that?

Johanna Ponnuthurai 34:38

I think because all the way up until 18, for the most part, they have to work together. The patient as much as we may want to be fully independent and do everything on our own. We need help and we have to know how to ask for help. And we're going to need the help from our parents. But we also need to receive that help and support in a way that actually allows us to flourish and eventually become independent too. I think sometimes at home, with any parent and child you're going to experience some friction. And that has nothing to do with your injury. I think, you know, that's something that every parent and child experiences. But sometimes we might need to learn how to work together a little bit to figure out how best to research it. Because every person is different. Every parent is different, every child is different. The dynamic of parent and child is going to be different across the board. But I think everybody's voice, everybody wants their voice to be heard. It's hard for a child, it's hard for a parent. But learning how to work together, I think that's where clinicians can also come into support, and research can come in to support how best to help the family. Because I really do think that a brachial plexus injury is very much a family, not a family injury, but it's it's the child's injury, but the whole family needs to be involved.

Jennifer Ryan 36:10

Based on my clinical experience, often when you have a parent and child together, there's a tendency, when the kids are younger, that when the clinician poses a question, whether it's directed towards the child, or whether it's directed towards the parent, they have there's sort of this relationship that's developed between the parent and child where the child learns to automatically defer to the, to the, to the parent to answer the questions. And I'm just wondering, at what age or stage of your development, did you feel like you could answer those questions or that you didn't need to defer to your parents or didn't want a clinician to defer to, to your parents for the answers?

Johanna Ponnuthurai 36:59

I think that's a tough question, because it really depends on the household you grew up in. My background is Sri Lankan. So there's a lot of cultural norms that come along with growing up in a Sri Lankan family. So growing up, I was definitely the child that deferred to my parents. For many, most of my years, a lot of my growing up years. Even as a teenager, I would have deferred to my parents a lot. I think I can only really speak on my personal experience, I don't think there's a one size fits all that this

is the age, where the child can speak independently of their parents. For me personally, it was all the way up until my teenage years that I was referring to, deferring to my parents to help me answer questions. I think at maybe 15, or 16, I was probably more comfortable with answering my own questions. And my parents were also comfortable with me being able to answer my own questions. But I don't think that's going to be the case in every single family, which is probably makes researching this a lot harder, because there's no, I don't think I can pinpoint an age at which that kind of separation can happen. Because I think it's tied to the family dynamic, the cultural norms, just a lot of the socioeconomic factors that don't necessarily see in clinic in that one hour appointment.

Dr. Emily Ho 38:38

No, and you got to get to the heart of the fact that we know that decision making, shared decision making and, you know, the health care is situational. And it's you know, it's not one thing fits all right, in regards to each family dynamic is different, each cultural preferences, but we need to ask, what you would like, we need to ask every family what they would like, how they would like to get involved, how do they make decisions? And who and what roles they will take in that decision making process? So you really hit on that in the sense that you're right, it's not easy to research and also, we shouldn't think that there's one answer, because that's not the right way to look at it. Because there's many ways and I think the best that we can do is educate all of us, in regards to the fact that there's many ways to make a decision and to make sure everyone is heard. I think that's really important. The other thing I realized is that we're talking so much about parents and, and youth. I think you mentioned that you're the oldest child, so you must have a sibling. How does she feel in regards to her involvement in your care or involvement in any research? Like, is there things that we should be looking at in regards to siblings in regards to research?

Johanna Ponnuthurai 39:48

I do think siblings should be considered as well. You are right, I do have a younger sister. She's four years younger than me. So as an older sibling, my younger sister is looking to me for... Well, she's looking up to me, not necessarily always for guidance, but you know, there's that sister relationship and the understanding that I've experienced things before she would. So she might come to me and look to me for help or advice, as sisters do. But there's an interesting dynamic, when you have an injury, in that there are things that I might need to ask my sister for help with, that she would never need to ask me for help with. To give you an example, as we get older, most people can, you know, do their clothes up on their own. Even at my age now, I still need a lot of help with zippers on dresses or shirts. But my sister who's younger than me, well, wouldn't need help with those same zippers or same outfits. So there's an interesting dynamic for siblings in that respect, in that she's my younger sister, but she is involved in supporting me and helping me. It's not just my parents, even things in daily life, just even at the dinner table, passing dishes around. Sometimes if my dad is asking me to pass a dish, I may not be able to pass that. And though I am the closest one to that particular dish, I might need to ask my sister to help that. And I think, sometimes, especially in your teenage years that can negatively affect you, in that, you look at yourself and wonder like, "Well, I really should be able to do this, this is something so simple". But here I'm struggling, but my younger sibling is able to do it just fine. And I think that can affect your self-esteem sometimes, that can sometimes affect that dynamic with your sibling. If you harbor some resentment, or end up harboring any anger towards your, your sibling, whether that sibling be younger or older. Fortunately for me, my sister and I have a great relationship. And she's very

supportive and very helpful anytime I need help. She's she's probably the first one to jump and help me anytime I need help and I'm really grateful for that. But I know that dynamic can be different across all families, especially in certain families where maybe it's the younger sibling who has the injury. And the older sibling, there's an even greater level of responsibility as an older sibling to look out for your younger sibling.

Dr. Emily Ho 42:37

That's wonderful and it really helps me to realize that we focus a lot on parents and peers, but siblings play a huge role, in terms of comparing yourself to your sibling, in terms of how you feel about, you know, the way you do things are your expectations for yourself, and how you do you things as well, but also her being a support to you. So it's important that we look at that as well. Is there any other peer group or social group that you think that influenced, aside from, you know, your sibling?

Johanna Ponnuthurai 43:07

The other social group that I realized, as an older adult, that influences me, would be my colleagues at work. Because... in the workplace, those that I work with, don't know my background. They don't know anything about my injury, I'm not really required to disclose that for the purposes of my job. But the closer you become with your team and the people that you work with, that's when you might need to disclose your injury for a variety of reasons, something as simple as carrying your laptop and holding a door, to open the door to go to a meeting. I remember the first time I was going to a meeting with one of the members of my team and we had to take our laptops with us to this meeting room. And I also had a notebook, I also had a pen, and I didn't have any issues carrying that. But as soon as we were going to elevators and opening doors, I happened to be the one walking in front, I had to pause and say, "Hey, could you get that door? Because I can't open it". So, there's a new challenge that you encounter as an adult in the workplace. Of... how do I tell people about my injury without any fear of being looked at differently, without any fear of that affecting my performance evaluations, or that affecting how my team perceives me? My injury may have nothing to do with my job but those things play on your mind because that's, that's a challenge that you have to grow up with your whole life of "What, what are they going to think? Or are they going to think of me differently?" I think personally, I find that I just get more stuck in my head. My team is great, I've never really encountered any sort of bullying or you know, negativity towards my injury in the workplace. I don't know if that's the same for everybody. I think that also could depend on the sorts of careers or work environments that a person might be in as an adult.

Dr. Emily Ho 45:19

Thank you for sharing that. Again, thinking beyond childhood, you know, as a researcher that's focused on childhood, we often don't think about what the work environment is going to be like in those decisions. And so I would love to ask, you know, what would you like to know from others who are adults who are in the workforce, and have an upper limb difference? What would you want to know about their experiences, collectively, that could be helpful? So if we had to research something about being in the workforce, what would be helpful to know in regards to helping support you? Even though you say your, your upper limb difference doesn't affect what you do in terms of your job, but it does affect in regards to how you feel about your job. So what would you want us to take a look at from a research perspective?

Johanna Ponnuthurai 46:05

I would be interested in knowing how others raise ergonomic issues? I mentioned earlier that as an adult after university, and when I was in the workplace, I started experiencing pain. That came from a variety of reasons: I was sitting at a desk for longer, so I was more stiff, taking the bus, and having to carry my bags was a little bit more challenging. But I ended up realizing that one of the issues was actually my desk setup and how my chair was set up at my desk, and how that was affecting the position of my arm and typing that I was actually experiencing a lot of tingling sensation in my arm. And I didn't know if it was okay, for me to ask for changes to my setup of my desk. I was unsure the best way to phrase it, I didn't want to be a person causing a bother, I didn't want to be a person who is fussing unnecessarily and I didn't know how it really the best way to ask. I have a good relationship with my boss. And I ended up telling her, but I waited until it was quite painful before I actually said, I think I need an adjustment, I don't know what I need but something is not right. I don't actually know what the issue is. So I would be curious to know what other people, other young adults with brachial plexus injuries, what they might encounter, and how they tackle those challenges.

Dr. Emily Ho 47:52

No, it sounds as though you know, there's a bit of advocacy there first and a sense knowing that this may happen to you, and how to advocate for your needs. But also, does this happen to others? You know, is ergonomic needs in terms of posture, in terms of workplace, how we use our limbs and our entire bodies, is that, you know, are these concerns more prevalent in those who have upper limb differences? I think you're saying two things and I think there are wonderful things to look into, because you're right, they haven't been answered in regards to are these concerns overuse syndromes? Or, you know, pains and aches caused by how we do things that our workplace is that that's one thing. And the second thing is how do we advocate? And when it comes to advocacy, you kind of remind me, you know, because we are also taking a look at youth who have upper limb differences and mental health concerns. And one of our youth most recently said, you know, I already have an upper limb difference. And you know, if I mentioned that I also have a mental health concern, I feel like I'm drawing a lot of attention to myself, because it's two things now, right? I already have one thing, and then people are gonna say, "Well, I'm saying there's two things about me". And we're like, "No, but you're who you are". And sometimes it's about us being able to research and understand that, yes, you have a physical difference but there's other things that you're going to experience, whether it be pain, or you know, concerns in regards to, you know, mental health symptoms, there's more than one thing, everybody is different. And the most important thing is that we know what's right for each individual, and what each individual is experiencing. And so when you mentioned that you weren't sure in terms of position, should I say something about this? And so I wonder, you know, is it because you have one thing? Should I be experiencing another thing and perhaps being able to research what individuals experience and know what their unique experiences are and be able to advocate for them? It would be important thing for us to do as researchers.

Johanna Ponnuthurai 49:44

Yeah, I think the other thing is that I wasn't expecting to experience any issues as an adult. Because I got to 18. I've been followed by the clinical team all this time and at 18, it's, I'm fine. I'm supposed to be fine. I'm not supposed to, or at least my interpretation was I'm supposed to be good to go for the rest of my life. So when I was encountering the pain and the issues, I wasn't sure if is this my injury? Or is this

something else? It's like, is this? Am I being unreasonable by saying that this is related to my injury? Am I trying to pull a sympathy card? There's all those things that kind of come into play in your mind. Because there isn't really information about... what am I supposed to experience or encounter? What could I potentially encounter as an adult with brachial plexus birth injury?

Dr. Emily Ho 50:43

And you raise a good point in regards to knowing whether or not this is within, you know, the expectation when you have a certain upper limb condition that is rare. And so you know, together with brachial plexus birth injury is quite rare. And congenital, upper limb differences are quite rare we've had many families say, it's not fair, you know, you go to TTC, you see all these different advertisements regards to you know, cancer or stroke, but no one knows what my condition is. And the more that we know about it, the more than we can understand what our experiences should be as we get older, and what takes back and that's why all the more we need to pull people together, find out, you know, how individuals are doing in adulthood, and pull people together to understand so that those questions can be answered, because you're not alone in what you're experiencing.

Jennifer Ryan 51:30

So Johanna, you have identified these issues in your your daily life and in that transition to adulthood. And Emily, you're interested in conducting that research and figuring out how you can better help families in that period? What does it take to then gather experiences from parents and adults, and children, and then actually make those changes to the clinical care that you receive when you're a child when you're making that transition to adulthood, and then once you become an adult?

Dr. Emily Ho 52:10

You know, we know that they're rare conditions so it's difficult to find individuals who are adults. And so that's actually the main purpose of why we're looking at the here and now. So as I described earlier, we're doing this questionnaire research project, to get a sense of how young adults and adults who have brachial plexus birth injuries or congenital limb differences, how they're actually functioning now. And what we're going to do is partner with different organizations that support individuals who have brachial plexus injuries and congenital limb differences. So we're going to tweet, we're going to use social media, to see if we can find these individuals. Because that's the first hurdle actually, is finding the individuals and so we're thankful that there is an organization called Lucky Fin project, which is targeting for children but there are also a huge social media presence in regards to those who have upper limb differences. There's also the CHAMPS program, which is part of War Amps in which you have individuals who have upper limb differences who are also connected as with as well. And for brachial plexus, we have a Canadian Obstetrical Brachial Plexus Working Group, which is all the clinics across Canada, so all the surgeons and therapists are tied in together and hopefully be able to reach out to our respective adults that have been seen their clinic and have graduated. And then as well as there's the United Brachial Plexus Birth Injury Group, which is mostly maintained in the U.S., but has a Canadian group as well on there as well. And we also know of different Facebook or Meta groups that are available as well. And that's how we need to find people, because that's the number one thing, is after they graduate from the pediatric institutions, it's hard to find individuals and because adult care is not as much continuity, in regards to frequency or follow ups, it's usually by need basis. And so it's more difficult to find these individuals. Once we start the study, we'll have a sense of a group that we

can begin with, to start to get understand what their lives are like, and then inform the planning of transitioning care. And that's our actual goal is to take a look at programming. How do we actually develop program looking at those final years, in terms of you know, 16 and 17, as you're just about to leave SickKids or just about to leave any pediatric institution - how do we best equip you? So how do we best equip us that, you know, when you're making choices about school and making choices about, you know, living on your own and your employment. What to expect? And a lot of it may be peer to peer mentorship? And we know that there's such value in hearing from other young adults that have gone through the experience, formed by research, but also, hearing those narratives are so important to know, you know, that someone else has lived through it. Someone else has been successful through it. Someone else has gone through struggles and can share how they problem solve through those struggles. And I think that's going to be key as part of our transition program. What do you think Joanna?

Johanna Ponnuthurai 55:00

Patient partners are also going to be quite important. I know that formally engaging patient partners in your research, has, is a more recent thing, but further down the line as you continue to reach out to those patient partners, as they get older, we, and they can continue to inform you of the things we encounter. And I think it would be interesting for you to see the similarities and differences in those partners in what they're experiencing as they continue on in life.

Dr. Emily Ho 55:38

You know, one thing that we are finding, and we're actually trying to also take a look at as well, is how to get our youth, that are just about to transition, to express what they need. And so, you know, it's one thing as you get older and speaking to some of our young adults, you're able to reflect back and tell us "Oh hey, this is what it's felt". But when you're in that moment, you know, you're leaving high school, do you really know what's next? It's really challenging. So that is a huge area that we're looking into. And one of the things that I've been chatting with, one of our clinical managers in our virtual care area, and that's Ashley Graham, and she is an occupational therapist by background, but she's actually looking at our virtual care at SickKids. And I said to her, you know, I want to, you know, when I look at our teens, and through COVID, we've had to actually do a lot of virtual visits with our teens, because we had to change our in-person appointments to virtual. But what I found is that because the parents are no longer on the screen, and the teens are on their own, all of a sudden, our teens in our clinic are telling us so much more about their lives. And it's almost like the the interface of being on Zoom helps them to be able to express themselves more. And so I was actually chatting with Ashley, I said, "Hey, is this the most appropriate care?" It's not just because we have to be online but is actual virtual care have an appropriate way to look at transition and care? Should we have the team on their own, on the computer, and then bring them in with their family to have an in-person visit with the interprofessional team. But that sense of being online with the teen on their own may be a way to actually get them to express, you know, what are their social relationship sites? What are their fears about leaving, and going to university or college or work after high school? They may not express that in-person but when they're online, they might be able to tell us a little bit more. And I'd love to be able to do a little bit more research to see if there's value added to be online. Is this the most appropriate care to do transition and care? And I think that's one thing our research team is going to look into as well. Johanna, what are your thoughts in regards to being online? Being a young adult yourself, how do you find using online

methods in regards to being able to share with you know, healthcare providers or others, in terms of communication?

Johanna Ponnuthurai 57:56

I do think there's definitely pros and cons. Some of the pros I think, are the young adult is in an environment that's comfortable to them. Not everybody loves hanging out at the hospital. I may be one of the few patients who found it fun to come for my appointments, but most people do not enjoy coming to the hospital. So when you can do a virtual an appointment, and a teen is in their own room, in their living room, somewhere that's comfortable to them, somewhere somewhere that they're used to, I feel like that they're more likely to open up, they're more likely to share what they're dealing with. When the teen is at home, it's easier to remember the things that you struggled with, because you can look around and say, "Oh, hey, at the dinner table, this was hard. Or I was in the backyard, and I was trying to shoot this basket and it didn't work". So I think, you're able to glean a lot more information and when a child or a young adult is in an environment that's comfortable to them. I do remember in... whenever I was in clinic for my appointments, whenever I was asked the question of "What's hard or like what are you struggling with?", in that moment, it was so hard to remember because I'm looking around and I'm like, trying to think hard at what I was struggling with, because I know that there are things that I have difficulty with every day. But when I'm taken out of my regular environment, it's a lot harder to remember those things. I also think that young adults, when you interview them with their parents in the home environment, everybody might be more comfortable and you might be able to gain even more information from parent and patient when they're somewhere that's comfortable to them.

Jennifer Ryan 59:55

In the future, if you have the opportunity to be able to share knowledge learned from research or from your own experience, how would you see going about doing that?

Johanna Ponnuthurai 1:00:06

So for my family, we we love to educate those around us about this injury. For myself, I love sharing with people what about my injury because I know it's not very well known. What my family has done in the past and something that my sister did is she wanted to create a fundraiser for the brachial plexus clinic at SickKids, because we recognize how much the clinic has supported me, supported my family. And we also wanted to use it as a way to share about the injury and the clinic with our friends and family. So my sister actually did a concert fundraiser, and we were able to share more widely about the injury, so that was one of, I think, the major ways that my family has shared about the injury and shared about the support from the brachial plexus clinic at SickKids.

Dr. Emily Ho 1:01:07

And I was just gonna mention how thankful we are for your family and its efforts and especially they were the way that you rally your community and there's been some events where you've shared your story with others, so they're aware of the differences and living with a brachial plexus birth injury, which has been helpful to other families in our clinic. And I think through sharing your experiences and especially rallying your community to educate them has been really inspiring and encouraging for us to see.

Jennifer Ryan 1:01:35

So I just wanted to thank you both so much for agreeing to be part of this mini-series, for sharing your experiences, for discussing the importance of patients and family and sibling partners, and for highlighting some of the unique aspects of research and health care that involves children and that transition to adulthood. I think it's important for listeners to hear about the research not only from the researcher's perspective, but also from the people who the research should be benefiting. This concludes this episode of the Connecting the Dots mini-series, I hope you've enjoyed hearing from Johanna and Emily, and learning about the importance of involving persons with lived experience in research, development, and design. To support our student run podcast, subscribe to us on Podbean, Spotify, Apple Podcasts or Google Play Music. You can also find us on our website at rehabinkmag.com/podcast. Thank you and bye for now!

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